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OLDER PARENT CARERS' STORIES ABOUT THEIR ADULT CHILDREN WITH INTELLECTUAL DISABILITIES LEAVING HOME

Section A: Attitudes of parent carers of people with intellectual disabilities towards transition from the family home, and potential differences for parent carers of different ages: a narrative synthesis of the literature.

Word Count: 7999 words

Section B: What do older parent carers say about the experience of their adult children with intellectual disabilities moving out of their family home?

Word Count: 8000 words (plus 600 additional words)

Overall Word Count: 15999 words (plus 600 additional words)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
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2024

SALOMONS INSTITUTE
CANTERBURY CHRIST CHURCH UNIVERSITY

Acknowledgements

Thank you to all the parents who took part in my project, for sharing your stories and for trusting me to share them here. Thank you to Carmel, Paul, and Sheila for your help throughout this process, not to mention your reassurance, thoughtfulness, and patience. Thank you to my family for all your love and support, and for helping me to keep going. Thank you also to my friends, for your support and for the fun times we had together that helped me to stay sane.

Summary of the Major Research Project

Section A is a systematic literature review of research regarding parent carers of people with intellectual disabilities (ID) and their experiences of their children moving out of the family home. Eleven studies were reviewed, including qualitative, quantitative, and mixed methods research. The studies were assessed for quality and synthesised, with four themes emerging from the synthesis. Themes included anxiety related to transition, different reasons for starting transition, difficulties with moving out, and older carers' particular concerns. The results were discussed in relation to other literature regarding parent carers' attitudes regarding transition, and the limitations and implications of the review are also discussed.

Section B is an empirical, qualitative study exploring older parent carers' experiences of their adult children with ID moving out of the family home. Thematic narrative analysis was used to analyse interviews with eight participants, and six themes were developed. Themes included making decisions about transition, fighting for their children, feelings of responsibility, feeling uninformed, hopes for the future, and valuing collaboration. The themes are discussed with consideration of previous research involving parent carers and older parents, as are the limitations of the study and the implications for clinicians and researchers.

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Section A: Literature review

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Abstract

Background: People with intellectual disabilities (ID) often receive care from family members, particularly parents. Family carers report positive and negative effects of caring for their relatives with ID. People with ID sometimes move out of their family home, and this transition can be anxiety-provoking and challenging. Older parent carers face difficulties with their health that make it hard to continue caring.

Method: A systematic review of the literature was carried out using two databases. Eleven studies with varied designs (qualitative, mixed methods, and quantitative) were selected for review. The Mixed Methods Appraisal Tool (MMAT) was used to assess quality, and a narrative synthesis was conducted.

Results: Findings indicated that parent carers are anxious and worried about their children with ID moving out of the family home, and often have negative experiences of the moving process. Older parent carers reported issues with their ability to care for their children but wanted to continue doing so.

Discussion: It is recommended that services working with parent carers consider their concerns about care provision and accommodation when helping people with ID to move out. Recommendations for future research are also made.

Keywords: Intellectual disability (ID), learning disability (LD), parent carer, transition, moving out

Introduction

Family carers for people with intellectual disabilities

An intellectual disability (or ID) is defined by three core criteria: significant impairments in intellectual ability and social/adaptive functioning, and for those impairments to have been present since childhood (BPS, 2015). ID is also referred to as learning disability (or LD), including by the National Health Service (NHS) and the National Institute of Health and Care Excellence (NICE) (NICE, 2015). There are approximately 1.5 million people with ID in the United Kingdom (UK) (Mencap, 2024). People with intellectual disabilities frequently experience poor physical and mental health, and often receive care and support from others due to being disadvantaged in society compared to people without disabilities (Tracy & McDonald, 2015; Foundation for People with Learning Disabilities, 2024). A large proportion of that support comes from family carers; parents typically act as carers for their children with ID, though siblings also take on caring responsibilities (Heller & Arnold, 2010). Many people with ID also receive care from professional carers, who provide care within peoples' homes or in other settings (Leyshon et al., 2004).

Studies have explored experiences of parents looking after relatives with ID. Yoong and Koritsas (2012) interviewed parents who were full-time carers for adult children with ID: parents reported some positive benefits of caring, including developing relationships and personal satisfaction, but there were also negative effects. Parents reported that caring restricted other relationships and prevented them from pursuing employment and leisure opportunities: they were also frustrated with professional support, and worried about their relatives' future (Yoong & Koritsas, 2012). One parent said that they were so concerned by what might happen to their daughter after they passed away that “the only way I could see surety of a reasonable future for my daughter…is for her to die before me" (Yoong & Koritsas, 2012, p. 614). Fernández-Ávalos et al. (2020) also interviewed parent carers, and participants reported that their physical, emotional, and social wellbeing had decreased since their adult offspring had been diagnosed with ID. Parents also said they were worried about the future, particularly about what would happen to their children when they passed away: one mother said she was "very afraid that in the future my son will not have friends…that he'll be alone when we're not here anymore" (Fernández-Ávalos et al., 2020, p. 11).

Transition to living outside the family home

At least half of people with ID live in their family home (Foundation for People with Learning Disabilities, 2024). However, people with ID often move away from their families to live in alternative accommodation. Whereas people without disabilities typically move away from their family as part of a transition between life stages and towards independence, people with ID (and their families) often experience life stages differently and are frequently less independent (Janus, 2009). Codd and Hewitt (2020) interviewed parent carers about the transition to adulthood for their adult children with ID: parents reported it was hard to know how to support their children to be independent, and they felt they had little knowledge of what services were available to support their adult children.

Research suggests that people with ID are more likely to have insecure attachment styles, due to communication barriers and parental stress during their early development (Howe, 2006; Hamadi & Fletcher, 2019). Insecure attachment is likely to negatively affect people with ID when they transition from their family homes, as they will be required to form new relationships with their carers and might be wary and avoidant of new people and/or distressed by the separation from their parents (Seiffge-Krenke, 2006; Janssen et al., 2002). If people with ID and their parents receive professional support before, during, and after the transition process, they might have a greater sense of relational safety and be more likely to have successful transitions (Lambruschi et al., 2022).

When people with ID move away from their family homes, the transition process can be challenging. Unwin et al. (2008) interviewed a focus group of parent carers about their children with ID transitioning to adult services, and parents reported a range of concerns and issues. Participants felt that services were not responsive and that they were powerless to influence their children's transitions (Unwin et al., 2008). Jahoda et al. (1990) interviewed adults with ID, their parents, and professional carers about what it was like when the people with ID moved into residential care from their family home or from long-stay hospitals. Participants who had moved from home talked about how they had felt socially restricted and had been able to do more since moving out, but they had become isolated from people without ID (Jahoda et al., 1990).

Age-related factors in caring

Many parent carers continue to look after their adult children with ID at home, caring for them into their own older life stages, perhaps because of the challenges that can be involved in supporting people with ID to move out of the family home. Although there are health inequalities in terms of life expectancies, people with ID in the UK are living longer just as people without disabilities are also living longer (Emerson & Hatton, 2008). Approximately 29,000 adults with ID live with parents who are aged 70 years or older (Foundation for People with Learning Disabilities, 2024). Mahon et al. (2019) conducted a review of six studies to look at the needs of older family carers of people with ID: carers reported not having sufficient information about available services, neglecting their own needs, and being ignored by professionals outside of crises. Forrester-Jones (2021) interviewed older family carers about their experiences of caring for relatives with ID, who reported that it was difficult to get an assessment of need from local authorities and that they did not get all the support that had been promised. Participants also said that they had been “battling” with social workers to get the support they needed, with some carers reporting that they “never see them [social workers]” and others that the social workers were “patronising” and unhelpful (Forrester-Jones, 2021, pp. 108-110).

According to Erikson’s life stage theory of development (Erikson, 1950), people experiencing older age seek to establish whether they are content with how they have lived their life, and whether they have made achievements that will outlive them. As parent carers of people with ID often report concerns about what will happen to their children after they pass away (Yoong & Koritsas, 2012; Fernández-Ávalos et al., 2020), older parents could naturally be more prone to these worries. From a life stage perspective, older parent carers have less time remaining to establish satisfactory care arrangements for their children, and failing to do so could lead older parents to feeling more stressed and unhappy compared to younger parents or parents who feel comfortable with their children’s care situation (Grant, 2000; Osborne, 2009). Understanding more about older parent carers’ attitudes towards transition could help professionals to support them to make suitable arrangements that address their concerns, improving their wellbeing and life satisfaction (Grant, 2000) as well as ensuring that people with ID have appropriate care provided for them.

Rationale for review

Parent carers of people with ID face significant challenges when caring for their relatives, and there are particular challenges associated with their children moving out from their family homes. Older parent carers might face unique challenges related to age and caring, as they have to manage their own health needs alongside their caring responsibilities and are more likely to be concerned with their children's future care, based on their life stage. Understanding more about how parent carers think about and experience transition could help professionals involved with transition to support parent carers with the challenges involved with transition. Preliminary literature searches indicated that there were too few studies focused on parent carers' experiences of transition or on the role of parent carers' age in their experiences of transition for a review to focus solely on those areas. It was decided that the review would look at studies investigating parent carers' attitudes towards transition more widely, with particular attention towards the role of age within those studies.

The review asks the following questions:

What does the existing literature tell us about the attitudes of parent carers of people with ID towards transitions from the family home?

Does age have a role in parent carers' attitudes towards transitions from the family home?

Methods

Literature search strategy

A search was conducted on 22nd October 2023 on the following databases: Web of Science and the Applied Social Sciences Index and Abstracts (ASSIA). The search terms used are in Table 1 below.

Table 1

Search terms

	Search terms
Disability	"Intellectual AND disability" or "intellectual AND disab*" or "learning AND disability" or "learning AND disab*" or "ID" or "LD"
Parent carer	"parent" or "mother" or "father" or "mum" or "dad" or "guardian" or "family AND carer"
Transition	"moving AND out" or "move AND out" or "mov*" or "leaving AND home" or "leave AND home" or "leav*" or "transition"
Age	"Adult" AND "age"

The search terms were determined by exploring the literature using a range of potential terms, which they were grouped together to define the relevant areas of the search.

Key terms

"Disability" was operationalised as people having diagnosed intellectual disabilities or learning disabilities: other developmental disabilities such as autism and cerebral palsy were not included, though studies about carers for people with those disabilities who also had ID/LD would not be excluded on that basis.

“Parent carer” was operationalised as participants being parents or guardians of people with ID. The decision was made to focus on parent carers rather than family carers, as the experiences and attitudes of parents and other family members such as siblings are likely to be different, so studies that referred only to “family carers” rather than parent carers were excluded.

“Transition” was operationalised as moving out of the family home, regardless of whether the people with ID were moving to residential care homes, nursing homes, supported living, or other housing situations.

“Age” was included to screen out studies looking at parent carers' attitudes towards transition for children and young people with ID. It was decided to focus on the transitions of adults with ID, i.e. people aged 18 years or older, rather than including children and young people with ID, as children and young people are more likely to move out temporarily for school or college, whereas adults are more likely to move out permanently.

Inclusion and exclusion criteria

Table 2 lists the inclusion and exclusion criteria below. The definitions of the key terms above influenced these criteria. Studies were included if they reported data on parent carers of adults with ID and their attitudes towards their relatives moving from the family home. Studies were included regardless of whether carers' relatives had actually gone through a move, so long as they reported on parent carers' attitudes towards moves/potential moves.

Studies were included if they included data from other kinds of family carer, such as siblings, so long as data from parent carers was included and identifiable. It was not required for studies to focus solely on transition from the family home, so long as they included some data on parent carers' attitudes towards it. Studies were not excluded on the basis of location or date.

Studies were excluded if they were not available as full texts or if they were not available in English. Studies were also excluded if they were unpublished, if they were reviews rather than original studies, and if they only included data on parent carers for people with other kinds of disability. Studies that reported on transitions for people with ID other than moving out of the family home, such as focusing solely on the transition from adolescence to adulthood or educational transitions, were excluded from this review.

Table 2

Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Reported on parent carers of people with ID	Not available in English
The people with ID were aged 18 or over	Not available as full texts
Reported attitudes towards relatives' with ID moving out of the family home	Unpublished
Any country	Reviews

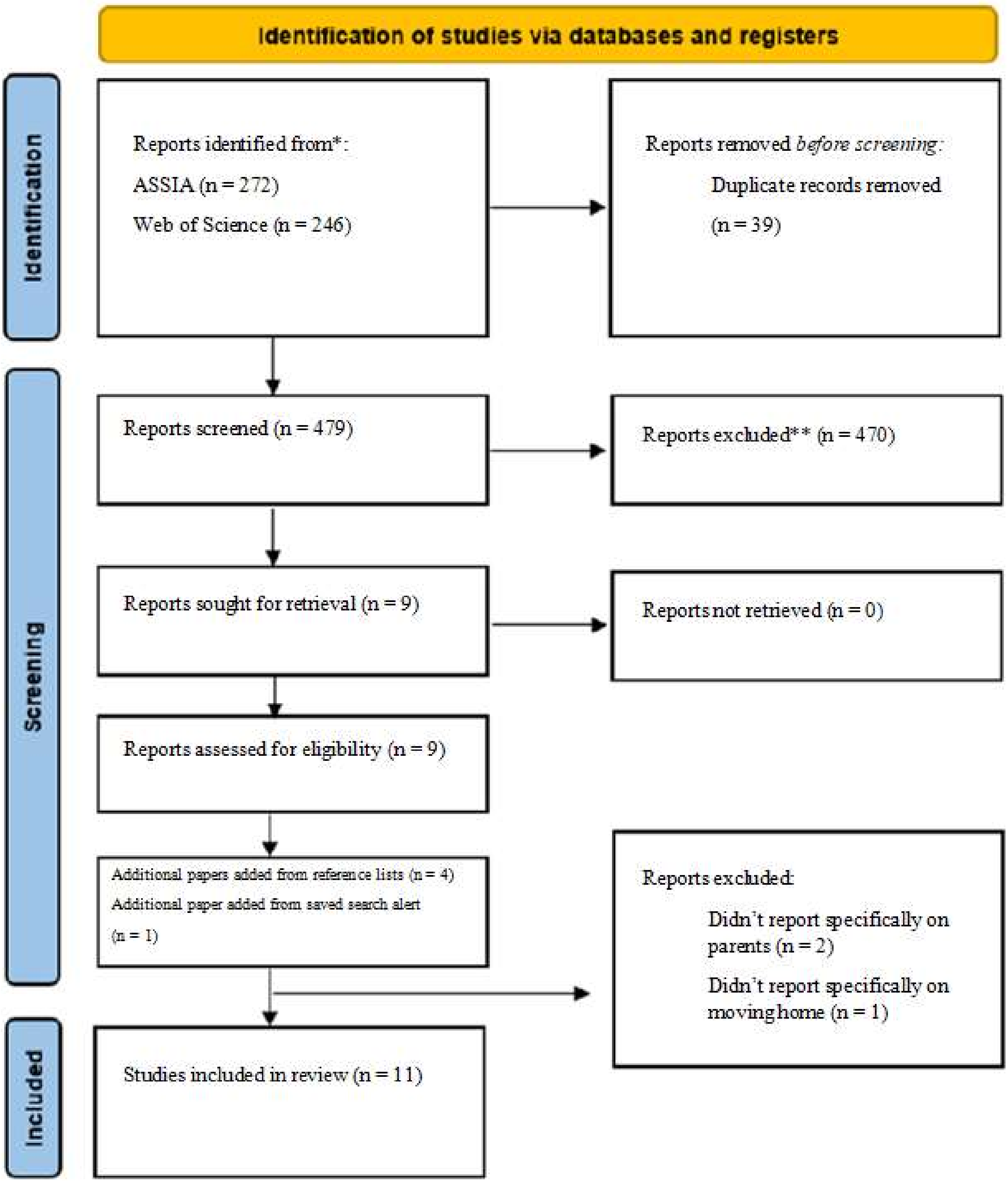
Any date	Reported on parent carers for people without ID
	Reported family carers' attitudes without explicitly reporting about parent carers
	Reported solely on transitions other than moving from the family home

Selection of studies

The initial search returned a total of 518 studies. These results were screened for duplicates, which removed 39 studies. The remaining 479 studies were screened using the inclusion and exclusion criteria. Three studies were excluded because they were not available in English. 470 studies were excluded, leaving nine studies that were retrieved from the search. The references sections of each study were checked, resulting in four studies being added. Another study was discovered through a saved search alert and was added to the review. Three studies were excluded after being examined: two because they reported on carers' attitudes towards moving out without reporting specifically on parents' views, and one because it reported on transitions from child to adult services rather than moving from the family home. A total of 11 studies were included in this review. See Figure 1 below for a flow chart detailing this process.

Figure 1

Flow chart illustrating the selection of studies from the search



Approach to synthesis

A narrative synthesis approach was used to assess the studies included in the review. Narrative synthesis was used to develop a preliminary synthesis of the findings of the different studies, so that the findings could be summarised and presented with themes that addressed the review questions (Popay et al., 2006). The studies included in the review were heterogenous and varied, and narrative synthesis allows researchers to synthesise stories from varied data (Popay et al., 2006). The narrative synthesis approach also helps to capture unique features of different studies and include them in the "story" of the review, rather than focusing only on commonalities (Barnett-Page & Roberts, 2009). Study findings were analysed for data that addressed the review questions. Parent carers' reported attitudes towards past transitions as well as expected or imagined future moves, including the reasons given for possible or actual moves and any reported role of parent age in those considerations, were the focus of the review.

Quality appraisal tool

The quality of each study was assessed using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018). The 11 studies included qualitative, mixed methods, and quantitative designs, so the MMAT was selected to allow for the comparison of quality across the different studies. The MMAT and the scores for each study can be found in Appendix 1. The MMAT scores for each study were used to highlight methodological issues in different areas, in order to support the appraisal of each study and the value of its findings.

Results

A summary of each of the 11 studies is presented in Table 3 below. The summary of each study includes information about the design, participants, and main findings of the study.

Table 3

Summary for each reviewed study

Study	**Country**	**Design**	**Description**	**n=**	**Participants**	**Age**	**Degree of ID**	**Ethnicity**	**Main findings**
Alborz (2003)	United Kingdom	Qualitative	Families of people with intellectual disabilities who had moved out of the family home were interviewed as part of a follow-up study. Content analysis was used with the interview data.	18	Eighteen families were interviewed. All interviews included mothers, with five fathers and one grandmother as well.	Mothers' ages at the time of the move ranged between 44 and 63 years old (mean age of 51).	4 were 'good', 6 'fair', 5 'poor', and 3 'low' (ratings of intellectual ability)	17 White families, 1 Asian family.	The majority of transitions took place because of family stress. Three transition routes were described: forensic (police involvement), family (breakdown of family relationships), and service (deficits in local provision).
Brennan et al. (2018)	Ireland	Qualitative	Family carers of older people with learning disabilities were recruited through an existing pool whose details were recorded in a longitudinal study of ageing in people with intellectual	17	Participants consisted of seven sisters, six parents, three brothers, and one sister-in-law.	Ages ranged between 46 and 85 years (no mean	10 moderate, 1 severe, 6 mild	Not reported.	Family carers reported thinking frequently about their relatives' future care, with some parents hoping that siblings would continue their care. The majority said that

			disabilities. Five focus groups and six individual interviews were held, and thematic analysis was used.			reported).			their ability to provide care was diminishing over time, and many felt that residential care was inevitable but hadn't planned for it.
Grey et al. (2015)	United Kingdom	Qualitative	Parents seeking placements for their adult children with intellectual disabilities were interviewed about their experiences. Thematic analysis was used to analyse interview data.	10	Parents from 9 families were interviewed: one father and 9 mothers.	Age ranged between 52 and 70 years (mean 57.2 years).	2 mild, 2 profound, 1 moderate, 2 not specific	White British	Parents felt decreasingly able to care for their relatives and desired a life outside their caregiving role. Parents reported their difficult experiences in seeking placements for their relatives.
Roos & Søndenaa (2020)	Norway	Qualitative	Parents and health care professionals were interviewed about working together during the moving process for young adults with ID after they turned 18.	18	9 participants were parents, 9 were professionals.	Not reported.	All profound	Not reported.	Parent participants reported a high burden of care whilst waiting for the transition to happen, and did not feel confident about the provision given to their children.

Vereijken et al. (2023)	The Netherlands	Qualitative	Parents of people with ID who had moved into residential care in the last 5 years were interviewed about the process and their experiences of it. Content analysis and thematic analysis were used with different sections of the interview data.	11	Parents: 5 fathers and 6 mothers	Age ranged between 45 and 60 years (mean of 53.5 years)	5 mild, 2 moderate, 4 severe	Not reported	Parents started looking for residential care when their children reached the age of 18. Parents reported a lack of information about the transition process and a lack of support from professionals, and talked about the emotional 'journey' of their children's transitions
Walker & Hutchinson (2019)	Australia	Qualitative	Older parent carers of people with ID were recruited through disability providers and interviewed about their attitudes towards the future care of their adult children. IPA analysis was used.	17	Parents aged 55+ of people with ID who were living at home or in supported living.	Age ranged between 55 and 86 years (mean of 70 years.	Not reported	Not reported	Participants continued to care for their children who had moved out of the family home and felt the need to be 'perpetual parents'. Participants talked about the costs associated with continuing to care.
Grey et al. (2020)	United Kingdom	Quantitative	In a follow-up study, family carers were sent questionnaires regarding placement decisions for	75	60 mothers, 10 fathers, 3 sisters, 1	Age ranged between 36 and	24.3% had difficulty communicating, 15.6%	Not reported	30 participants indicated that they were moving closer to supporting their

			relatives with learning disabilities at the start and end of a 12-month period. Participants' scores on a range of measures were described statistically.		partner, and 1 other relative.	86 years (mean of 61.36).	had hearing impairment, 9.5% had a visual impairment		relative to move out, and 14 had moved their relative to out of home care. Proactive coping strategies were associated with continuing to care for relatives with ID at home.
Bowey & McGlaughlin (2007)	United Kingdom	Mixed methods	Older carers (aged 70+) of people with ID were interviewed or given questionnaires about their views on the future of their family members' care. A thematic analysis was completed with the interview data.	62	89% of participants were parents: the rest were other relatives.	All were 70 years or older: 26 (42%) were over 80 years old.	Not reported	White	Participants talked about their fears for the future of their relatives' cares and the barriers to thinking about future residential plans.
Mansell & Wilson (2010)	United Kingdom	Mixed methods	Members of a parent/carer federation were sent questionnaires about issues and concerns, and some were then interviewed in focus groups. Descriptive statistics and an analysis of themes using NVivo (unspecified) were used.	151 (15 interviewed)	Members of a federation for parents and carers of people with ID.	Age ranged between 25 and 75 years.	52% severe or profound, 44% mild or moderate, 4% no data	Not reported	The key concerns of parents/carers included help accessing service provision/professional support. The focus groups reported concerns about 'anxiety about the future' and finding the

									right provision for people with ID.
Prosser (1997)	United Kingdom	Mixed methods	Parents/other relatives were interviewed about plans for their relative's residential and care arrangements. Descriptive statistics and content analysis were used.	32	Parents and other relatives of people with ID who were aged 40 or over. 22 were parents, 9 were siblings, and 1 was an aunt.	Age ranged between 41-89 years (mean of 67.2 years).	Not reported	Not reported	Only 28% of participants had made any plans for the future residential care of their relative. The majority of parent carers acknowledged that alternative provision would be needed. 95% of parents said they would continue caring for their relative at home until it was necessary for them to move.
Taggart et al. (2012)	United Kingdom	Mixed methods	A structured questionnaire was given to older family carers about their health, caregiving, and future plans. Interviews were held with a sub-set about their attitudes towards future care. Statistical significance testing and thematic analysis were used.	112 (19 interviewed)	Relatives aged 60 or more who were caring for people with ID aged 40 or over. 78.6% were parents.	48.2% were aged between 60 and 70; 51.8% were over 70	Not reported	Not reported	The majority of participants (82.6%) wanted their relative to continue living with them rather than moving into a residential or nursing home. Participants reported avoiding thinking about the future and not feeling

						years old.			that they had enough knowledge about options for provision, or that there was enough suitable provision available.

Summary and quality assessment

The overall quality ratings from the researcher, using the MMAT, for the reviewed studies can be seen in Table 4 below. The full scores can be seen in Appendix 1. Summaries of the 11 studies and their methodologies are presented following the quality ratings.

Table 4

Quality ratings for each study

Rating	Studies			
High	Alborz (2003)	Brennan et al. (2018)	Grey et al. (2015)	Roos & Søndenaa, 2020
	Vereijken et al. (2023)	Walker & Hutchinson (2019)	Mansell & Wilson (2010)	Taggart et al. (2012)
Middle	Grey et al. (2020)	Bowey & McGlaughlin (2007)	Prosser (1997)	
Low				

High: 100% MMAT quality criteria met
Middle: 80%-40% of criteria met
Low: 20%-0% of MMAT criteria met

Aims

Six of the studies aimed specifically to assess carers' attitudes towards their relatives with ID moving out of the family home (Grey et al., 2020; Grey et al., 2015; Alborz, 2003; Roos & Søndenaa, 2020; Prosser, 1997; Vereijken et al., 2023). Four of those studies had a focus on parent carers (Grey et al., 2015; Alborz, 2003; Roos & Søndenaa, 2020; Vereijken et al., 2023): Grey et al. (2020) and Prosser (1997) were interested in family carers' views, including siblings. The other five studies had various aims, including learning about older family carers' views about the future (Walker & Hutchinson, 2019; Taggart et al., 2012; Bowey & McGlaughlin, 2007). Brennan et al. (2018) aimed to learn more about older family carers' experiences of caring for relatives with ID as part of a wider longitudinal study on ageing for people with ID. All of the studies reported on the views of parent carers specifically, despite some having mixed groups of siblings and other relatives. Roos and Søndenaa (2020) reported on the views of professional carers as well, which have not been included in this review.

Study design

The most common study design was qualitative, as six of the studies were qualitative (Alborz, 2003; Brennan et al., 2018; Grey et al., 2015; Roos & Søndenaa, 2020; Vereijken et al. 2023; Walker & Hutchinson, 2019). There were four mixed methods designs (Bowey & McGlaughlin, 2007; Mansell & Wilson, 2010; Prosser, 1997; Taggart et al., 2012) and one purely quantitative study (Grey et al., 2020). The qualitative studies were of the highest quality compared to the other designs, as they were all rated as “high” overall according to MMAT criteria.

Sample

Studies were mostly conducted in Europe, particularly the United Kingdom (Grey et al., 2020; Grey et al., 2015; Alborz, 2003; Taggart et al., 2012; Bowey & McGlaughlin, 2007; Mansell & Wilson, 2010; Prosser, 1997) but also in Ireland (Brennan et al., 2018), Norway (Roos & Søndenaa, 2020), and the Netherlands (Vereijken et al., 2023). One study was conducted in Australia (Walker & Hutchinson, 2019). All of the studies were conducted in

Western societies, and there appeared to be a lack of cultural diversity across samples. Only three studies reported ethnicity at all (Bowey & McGlaughlin, 2007; Alborz, 2003; Grey et al., 2015): two of those only had White participants, and Alborz (2003) only had one non-White family included (who were Asian). Study samples were predominantly female, with mothers and other female relatives being represented more than male family members. Sample sizes ranged from 10 to 151. Ten studies reported data on participants' ages, but Roos and Søndenaa (2020) gave no information on age. There was a wide range of ages across studies, though most reported that participants' average age was over 50 years old. Prosser (1997) provided information on participants' ages but did not report ethnicity and reported little information about gender, so it was difficult to assess how representative the sample was of the target population.

The sole quantitative study, Grey et al. (2020), gave information about their sample that included gender, relationship to person with ID, and income status, but as it did not report on ethnicity it is hard to know whether the sample was representative of the target population. Grey et al. (2020) also did not account for the risk of non-response bias: family carers who responded at the 12-month follow-up point might have been more interested in moving their relative out of the family home, and carers who did not respond might have found it too difficult to think about or not had time to respond. Bowey and McGlaughlin (2007) gave limited information about the study sample, reporting ethnicity and two age categories - over 70 years old and over 80 years old - but not gender, so it was difficult to know if the sample was representative.

The studies took a range of approaches to reporting the degrees of ID experienced by the people with ID that participants cared for. Four studies did not report on this at all (Prosser, 1997; Bowey & McGlaughlin, 2007; Taggart et al., 2012; Walker & Hutchinson, 2019), and five studies used the “mild”, “moderate”, “severe”, and “profound” diagnostic categories often used by professional services (BPS, 2015) (Mansell & Wilson, 2010; Vereijken et al., 2023; Roos & Søndenaa, 2020; Grey et al., 2015; Brennan et al., 2018). Alborz (2003) categorised people with ID as having “low”, “poor”, “fair”, or “good” intellectual ability: these categories were derived from staff observations and were considered analogous to the diagnostic categories referenced above. Finally, Grey et al. (2020) reported on different kinds of impairment, including communication difficulties and hearing and/or visual impairments. Studies that reported on participants’ disability, or on participants’ family members’ disabilities, indicated a range of disability in each study except for Roos and Søndenaa (2020), where participants’ family members all had profound ID.

Data collection

Different methods of data collection were used across the 11 studies. Nine studies collected information by interviewing participants individually or in focus groups (Alborz, 2003; Bowey & McGlaughlin, 2007; Brennan et al., 2018; Grey et al., 2015; Mansell & Wilson, 2010; Roos & Søndenaa, 2020; Taggart et al., 2012; Vereijken et al., 2023; Walker & Hutchinson, 2019). Four studies collected information using questionnaires (Grey et al., 2020; Bowey & McGlaughlin, 2007; Taggart et al., 2012; Mansell & Wilson, 2010). Prosser's (1997) mixed methods study collected quantitative and qualitative data through interviews conducted for a previous study into informal support networks for people with ID. Grey et al.'s (2020) quantitative study gave participants a series of questionnaire measures at two time points 12 months apart to measure how participants' attitude towards placement on the

Placement Tendency Index (PTI) changed over time. Two of the other mixed methods studies (Taggart et al., 2012; Mansell & Wilson, 2010) gave participants questionnaires and then interviewed a sub-set of those participants: Bowey and McGlaughlin (2007) gave participants the option to complete a questionnaire independently or to complete it within a semi-structured interview.

Participation

One of the studies (Bowey & McGlaughlin, 2007) used a questionnaire that had been developed by older parent carers in collaboration with health professionals to gather information about issues and concerns regarding future care planning. The other studies did not appear to have included parent carers or people with ID in their research at any stage: service user participation does not appear to be widely considered in this area.

Data analysis

The qualitative and mixed methods studies used a variety of statistical analysis methods with their qualitative data: thematic analysis was the most common method, but content analysis and interpretative phenomenological analysis (IPA) were also used. Quantitative data from the quantitative and mixed methods studies were typically presented descriptively, though Taggart et al. (2012) used statistical significance testing with the data from the structured questionnaire it used. The analyses used by the 11 studies seemed to be appropriate for the studies' aims.

Synthesis of findings

The following section summarises themes from the reviewed studies that aim to address how parent carers of people with ID view transition from the family home, and whether the age of parent carers affects their views on transition. The emotional response of parent carers to transition is explored, as well as the reasons parent carers gave for moving (or planning to move) their adult children, and their experiences of that process. The factor of age is also explored in relation to parent carers' attitudes, exploring older parent carers' views on transition.

Anxieties around moving

Most of the studies with qualitative elements reported that parent carers expressed a range of negative emotions associated with their offspring moving from the family home, predominantly anxiety. Grey et al. (2020) did not report on parent carers' emotions and focused instead on the different stages carers were at with considering transition. Findings related to parents' anxieties around moving have been organised into three themes: concern about alternative care provision, avoidance, and uncertainty about the unknown.

Concern about alternative care

Many parent carers reported that they were worried about the care that their children would receive if they moved out. Seven studies reported on these concerns: Roos and Søndenaa (2020) interviewed parents who spoke about their concern that their young adult children would not be offered enough support in residential care homes, and they worried about their child being socially isolated if they lived in homes with mixed ages and levels of need. Similarly, Mansell and Wilson (2010) reported on carers who were worried their relatives would be moved into nursing homes where they would not have anyone their age to socialise with. In Grey et al. (2015), parent carers who were looking for somewhere for their children to live reported that many placements were “substandard, it was terrible” and unsuitable for their relative (Grey et al., 2015, p. 52). Parents reported that they were losing hope of finding somewhere that could meet their child's needs. In Vereijken et al. (2023), parents worried that their children might be unhappy with their new homes when they moved, particularly parents of children who were less able to express how they felt. Walker and Hutchinson (2019) spoke to parents whose adult children were living in residential or supported living accommodation, and those parents reported that they continued to fulfil many of the same caring responsibilities because they felt carers would not provide the same level of care.

In Bowey and McGlaughlin (2007), carers of relatives with ID living at home reported they had negative perceptions of the quality of residential placements, and some had previous experiences with institutional care settings that made them reluctant to consider alternative care. Parent carers in the Prosser (1997) study reported that no form of care could be as good as the care they provided at home: “My husband and I always said that whilst we can look after him at home because there’s nothing better than a home environment and not only that, of course, he gets much more personal attention.” (Prosser, 1997, p. 26). Some parents felt that sibling carers in their families should take on their responsibilities when they could no longer care for their children themselves, to avoid them going into care.

Avoidance

Three studies reported on parents who had avoided thinking about moving their adult children with ID out of the family home. Prosser (1997) reported that 82% of parent carers had not made any concrete plans for their children to move out in future, with 95% of parents reporting that they would keep their children at home for as long as possible. Several parents had refused to talk about the idea of their children moving out, despite social workers encouraging them, because they did not want to think about the future or felt it was unnecessary. Bowey and McGlaughlin (2007) reported that carers found it very difficult to think about the future of their relatives' care, with one mother reporting that she sometimes wished that her child would die before her so that she would not have to think about someone else caring for them when she passed away. Additionally, 55% of carers were not ready or willing to make plans for future care. Taggart et al. (2012) reported on an interview theme of "unremitting apprehension" (Taggart et al., 2012, p. 225): most parent carers expressed that they had been worrying about their children moving out for most of their lives, and they found it very difficult to even talk about.

> Well from the day he was born until the day I die, I have that worry on my head when I put my head on the pillow until I rise in the morning. If I die what is going to happen to X or will anybody be good to him? (Taggert et al., 2012, p. 226).

Uncertainty about the unknown

Some parent carers reported that they did not have enough information about alternative care provisions to have confidence in the support they could provide. Some of the carers interviewed by Taggart et al. (2012) said that they did not know enough about where they could get accessible information about care options. Grey et al. (2015) found parent carers saw the housing system as a “maze” that they did not have the knowledge to navigate, as well as feeling that professionals were keeping important information from them (Grey et al., 2015, p. 51).

Reasons for moving out

In studies where parent carers were asked about reasons for planning and/or carrying out a move for their children, participants reported a range of reasons for doing so. Parents' reasons for seeking a move for their offspring have been divided into three themes: being unable to continue to provide care, avoiding crisis, and moving for independence.

Unable to continue caring

Several studies reported that parent carers often looked for alternative care and accommodation because they were struggling to care for their children with ID. Parent carers interviewed in Brennan et al. (2018) spoke about how caring for their children depended on the family having the resources to do so, including time and stability: “I mean, he takes a lot of looking after” (Brennan et al., 2018, p. 230). In Grey et al. (2015), all the parents reported that it was becoming more and more difficult to care for their children as they became adults and grew stronger and heavier, and said that their caregiving role was taking up more time and energy. Roos and Søndenaa (2020) found that parent carers were frustrated and exhausted with caring for their adult children as they waited for alternative provisions to become available: participants felt that their care was unsustainable without professional support, which was lacking. Alborz (2003) reported that the most common reason for parents seeking a move was family stress: 78% of families said that life at home was very difficult, and parental distress and family dysfunction formed one of the study's three categories of reasons given for moving. Grey et al. (2020) found that participants' scores on a measure of coping strategies were significantly associated with carers' relatives remaining at home, indicating that carers who had more coping strategies to draw on were more likely to keep their relatives with ID at home.

Avoiding 'crisis'

Two of the studies reported that adults with ID often moved out because of urgent changes in circumstances that caused crises to develop. In Alborz (2003), one of the three categories of reasons for moving was “forensic”: parents said that the police had become involved, often due to their children engaging in aggressive or otherwise challenging behaviour, and they had moved their children to manage risk (Alborz, 2003, p. 81). Bowey & McGlaughlin (2007) reported that those parent and sibling carers who had made plans for their relatives to move had done so in order to prevent a sudden crisis from occurring if the move had to happen in an emergency, i.e. if the carers stopped being able to care for their relatives. Additionally, in Grey et al. (2020), three of the families who had moved their relatives by the end of the 12-month study period still had PTI scores that indicated they were in the early stages of contemplating a move: although carers were not asked why the moves had taken place, the authors speculated that sudden events might have forced those families to make urgent decisions to move their relatives out.

Moving for independence

Finally, four studies reported on carer concerns that their relatives with ID should move for their own independence. In Grey et al. (2015), parents talked about how their children wanted more independence from them, particularly when they had positive experiences of college placements. One parent said that her daughter had seen her non-disabled sister move into her own house and wanted the same kind of independence for herself.: "So she was comparing notes with her sister really. Having seen her sister in her house…it just became something that she could relate to…and I think she does imagine herself living by herself. (Grey et al., 2015, p. 52).

Alborz (2003) reported that parent carers wanted their children to move so they could have a "near 'normal' lifestyle for their age" (Alborz, 2003, p. 79), living separately from them whilst being close enough to continue the family relationships. Some parent carers indicated that their children were ready to move and frustrated with living with their parents (Alborz, 2003). Parents interviewed in Vereijken et al. (2023) gave a range of reasons for deciding to seek new homes for their children, and the most common reason was that "moving seems better for offspring" (Vereijken et al., 2023, p. 6). Mansell and Wilson (2010) reported questionnaire data from carers about their main concerns: 16% said that "independence/quality of life" was the most important issue for them, and a further 23% said that this was the second highest priority for them (Mansell & Wilson, 2010, p. 26).

Negative experiences of moving out

Four of the studies also reported on parent carers' actual experiences of supporting their adult children to move out. Those parents reported universally negative experiences of the transition process, having dealt with a range of issues. Grey et al. (2015) reported from parent carers who were frustrated with an "ongoing cycle of placement offers", where they had to wait a long time for alternative housing to be offered only to find out that it was inappropriate for their child, which meant further long periods of waiting (Grey et al., 2015, p. 52). All of the parents spoke about their frustration with social services, who they felt did not share information and did not consider their children's needs. In Walker and Hutchinson (2019), parent carers whose children with ID had moved out were continuing to provide care, as they felt that the care staff did not have the funds or time to provide appropriate support. Roos and Søndenaa (2020) reported similar views from parents who were continuing to care for their children, as they were dissatisfied with the level of care given: in this case, the study involved parents with young adult children, who were comparing care services with the support their offspring had received when they were under children's services. Roos and Søndenaa (2020) also reported that parents felt professionals did not communicate with them, and parents did not trust professionals to choose appropriate housing for their children due to inappropriate offers being made. Finally, Vereijken et al. (2023) spoke to parents who found the transition process unstructured and overwhelming, with little support from professionals. Participants spoke about having to rely on their own resources and worrying for parents who were less familiar with the care system or less able to seek help.

Older parent carers' views

Four of the studies focused particularly on older carers and their views regarding their children moving out (Brennan et al., 2018; Walker & Hutchinson, 2019; Taggart et al., 2012; Bowey & McGlaughlin, 2007). Older carers' views appeared to be similar to those of other carers, but there were two considerations that stood out: the role of older carers' declining capacity for care, and the interdependence of parents and their adult children.

Declining capacity for care

Taggart et al. (2012) gave older carers questionnaires about their physical and mental health: although there was no younger age group to compare results to, 40% of carers reported experiencing anxiety and 31% experienced depression. Carers aged over 70 years old had significantly more sleep issues, back problems, and heart conditions than carers aged 61-70, and 92% of the carers felt that they were having to slow down as they got older. In Walker and Hutchinson (2019), parents reported that they were continuing to care for their children who had moved out but had to reduce their responsibilities to look after their own health.

> Normally, [I look after his hair-cuts]. I haven’t been able to see him for about three weeks because I had an angiogram, two stents put in and I was in hospital for a week. When I came out I was a bit [nervous] about doing things so I just took it easy for the next couple of weeks. (Walker & Hutchinson, 2019, p. 1520).

In Brennan et al. (2018), parent carers felt that their capacity to care for their children was diminishing over time, but the majority had still not planned for their children to have alternative care provision: indeed, some sibling carers interviewed in that study said that they had taken over their siblings' care because their parents had died without having made any future care decisions. Bowey and McGlaughlin (2007) found that, of the carers aged 80 years and over in the study, 11 out of 15 were unwilling to plan for their children to receive care elsewhere in future, despite experiencing deteriorating health and anxiety about the future of their relatives' care. Difficulties associated with older age appeared to be significantly impairing carers' capacity to care for their relative with ID, yet many of the older parents in these studies continued to act as carers.

Interdependence

Interdependence could explain why some older parent carers did not want their children to move out. Walker and Hutchinson (2019) reported that some parents felt they relied on their children for physical and emotional support: one parent said that she relied on her son so much that she could not see a future for herself without them living together. Some parents felt that they were co-dependent with their children and saw this negatively, but others talked about being happy that their lives revolved around their children and felt this gave them purpose. Bowey and McGlaughlin (2007) reported similar views from family carers who felt they "just couldn't be without" their relatives because they feared being isolated and alone without them (Bowey & McGlaughlin, 2007, p. 47).

Discussion

This review aimed to explore what the research literature said about parent carers' views about their adult children with ID moving out of the family home, and whether the age of parent carers affected their views on transition. Eleven studies were reviewed, including six qualitative studies, four that used mixed methods designs, and one quantitative study. Six of the reviewed studies aimed to understand family carers' attitudes towards transition, whilst four studies were particularly focused on older carers and their views on their children's future (one study spoke to professional carers as well as parent carers). Based on this review's synthesis, the studies' findings indicate that parent carers primarily viewed the transition of their children from the family home with anxiety and concern about their welfare, and that they avoided going through that process until they were no longer able to provide care themselves. Parents reported avoiding even thinking about the transition process and feeling uninformed and ill-prepared for dealing with it. When people with ID did move out, parents reported being dissatisfied and continued to care for their children in their new homes.

There were no studies that compared older and ‘younger’ carers, so direct comparison between them was not possible. There were similarities in findings between the older parent carer studies and the other, more general studies, with older parents reporting similar avoidance of and concerns about transition. The studies with older parent carers also reported that they found it increasingly difficult to care for their children with ID as they grew older, frequently related to worsening personal physical and mental health. Additionally, older parents spoke about being interdependent with their adult children, whilst parent carers in other studies spoke about wanting their children to move out for their own independence, suggesting that older parents might be more likely to rely on their children.

From an attachment perspective, parents’ anxieties about their children moving out could reflect their understanding that their children would struggle with being separated from them and with having to form new relationships, which could encourage them to avoid transition. However, parental anxiety could also reflect insecure attachment relationships with their children, which are more commonly experienced with parents of children with ID (Schuengel et al., 2012), sometimes related to ongoing issues such as ‘grief’ and anxiety about not being able to protect their children from their disability (Fletcher, 2016). Parents might have also been anxious about how they would feel following their separation from their adult children (Howe, 2006).

Older parents’ anxieties about transition could be particularly distressing given their developmental life stage, as the thought of moving their children into inappropriate care or leaving them without support when they pass away could be especially painful. However, concern about transition was reported across the reviewed studies, including those that did not specifically focus on older parents. The challenges associated with developmental stages can occur at different chronological ages for different people, but this might also reflect that parents experiencing Erikson’s penultimate life stage conflict – generativity versus stagnation (Erikson, 1950) – are also concerned with creating something lasting, perhaps in a more active way compared to older, more frail parents.

The review’s findings fit with other literature that looked at parents' views and experiences of their children moving out. Fernández-Ávalos et al. (2020) reported that parent carers had a range of fears about the idea of their adult children moving elsewhere and being cared for by others: “The future worries me because of the way the world is, they will still be vulnerable people, and as always, when there’s a problem, they don’t have the same defences as other people have, they can’t defend themselves” (Fernández-Ávalos et al., 2020, p. 11). In Unwin et al. (2008), parents of adolescents and young adults with ID felt that they were the best people to continue caring for their children because of their years of experience caring for them, and reported negative experiences of working with social services: “You know, they don’t give you information about direct payments, they don’t give you any information about person-centred planning…you have to find out for yourself" (Unwin et al., 2008, p. 24).

The findings related to older carers are generally consistent with other studies with older parents, which also indicate that older parent carers typically have similar concerns to younger parents. Mahon et al.'s (2019) review indicated that older parent carers reported that they had difficulties with their health, that they did not get enough information about alternative care options, and that they were afraid about the future of their children's care. Carers also reported low levels of trust in professionals: some participants spoke about historical negative experiences that meant they were less trusting, perhaps indicating a cultural, generational influence on how parents experienced social care professionals. "With me being one of the older ones, you've seen things from years ago, how it used to be and it sticks with you. The stigma is hard to forget." (Mahon et al., 2019, p. 170). Forrester-Jones (2021) found that older parent carers reported negative experiences of working with local authorities in relation to their adult children, with issues related to getting their children assessed by social services, insufficient communication from professionals, and a lack of continuity of social workers.

This review contributes to existing literature by showing how common the reviewed studies' findings were, such as parents' concerns about moving and older parents' decreasing capacity to continue care, as well as by highlighting how little research has been done specifically looking at older parent carers in relation to transition. In particular, this review found little existing literature regarding older parent carers' actual experiences of transition, indicating a potential area for future research.

Limitations

This review is limited by the scope of the studies reviewed, as they were carried out within Westernised countries and appeared to have mainly (or entirely) White samples. Although some of the studies looked at older parent carers' experiences, there were no studies that looked specifically at the experiences of younger parent carers that could provide a comparison. Information about the degree of disability was not consistent across the reviewed studies, so it was not possible to understand whether participants had different experiences based on their children’s needs. People with moderate or severe ID are likely to have different needs compared to people with mild ID, and people with disabilities that impair communication or mobility will also have particular needs that require different forms of care, which could affect the process of finding appropriate placements. Although the use of different “levels” of ID according to intelligence quotient (IQ) can be unhelpful (BPS, 2015), it would be helpful to understand more about the needs of participants’ children and whether this affects their experiences of transition.

This review was also limited by its search terms, as the term “mental retardation” was not included as an alternative to “intellectual disability” and “learning disability”. This term was excluded on the basis that it can be stigmatising and is no longer used by the BPS (BPS, 2015); however, mental retardation has been used historically, particularly in the United States (Walker & Johnson, 2006), so the review might have unintentionally excluded historical research and studies from the United States.

Some of the studies in the review included other family carers as well as parents in their samples: although parents' views were reported separately, including other carers could have affected the development of themes in the qualitative data presented. However, carers' views appeared similar across studies with parents and those with parents and other family carers.

Clinical implications

It would be helpful for services working with adults with ID and their parents to be aware of how parents are likely to be anxious and worried about their children's future. As parents' anxieties appear to be partly caused by a lack of information about available care, professionals should consider how to share knowledge about support services with parent carers, helping them to feel more confident. Parents also complained about being offered inappropriate services and were frustrated with having to wait for long periods between offers that they then had to decline. It might not be possible to be certain about whether a placement is appropriate before discussing it with parents, but it could be helpful to involve parents as much as possible in the process of assessing placements so that they feel more included and do not experience long waiting periods.

As the majority of parent carers who had experienced the transition process reported negative experiences, health and social care professionals should consider how they might improve the process for parents at each stage. It could be helpful to arrange regular, frequent calls with parents to improve communication between parents and professionals and help reassure parents during a difficult and distressing process. Developing educational resources to make the transition process more transparent, including searching for appropriate placements and funding arrangements, could support parents to understand what their social workers are doing and to make the process more predictable and less confusing.

Older parent carers living with their children with ID often struggle to continue caring for their children due to their health, but they frequently continue to do so anyway. It is important for professionals to understand that older parents do this because of their fears about their children receiving inappropriate care, and because they are sometimes reliant on their relationships with their children. Professionals should consider how to help older parent carers with their anxiety and other needs when it becomes necessary for their children to move out. Additionally, as older parent carers often continue to care for their children despite struggling to do so, the quality of care they are able to give their children may worsen, and social services might be required to get involved. It would be helpful for social care professionals to be sensitive to parents' reasons for wanting to keep their adult children at home, and to be flexible enough to help them to care for their children at home if that is in their children's best interests.

Future research

The studies in this review generally appeared to be of good quality, particularly the qualitative studies. Parent carers from minoritised ethnic backgrounds do not appear to have been included: ethnicity was not reported for most studies, so it is not possible to know if parents from non-White ethnic backgrounds had different views regarding moving out. It would be helpful for future research to talk to parent carers from other ethnicities and from other, non-Western cultures to see if there are differences in their views and experiences of transition.

Parent carers generally reported wanting to continue to care for their children with ID for as long as possible, even when parents were getting older and struggling with their own physical and mental health. Some of the studies reviewed gave reasons why parent carers decided to look for alternative care provision, but only one of these (Bowey & McGlaughlin, 2007) specifically talked to older carers. Future research could investigate what older parent carers whose adult children with ID had moved out of the family home said about the transition process, which could help explore whether there were particular, unique factors involved for older parents that led to transition. Studies looking at how older parent carers whose adult children had moved out could also explore whether there were unique aspects of how they experienced the transition process compared to other, younger parents.

Conclusion

Existing literature indicates that parent carers found it difficult to think about moving their adult children with ID to live outside the family home, and that they avoided doing so as much as possible. Additionally, families found the actual process of their relatives moving out to be frustrating and difficult. Health and social care professionals working with families with people with ID should be aware of this and consider how to support people and their families when they are planning to move.

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Section B: Empirical study

Section B: What do older parent carers say about the experience of their adult children with intellectual disabilities moving out of their family home?

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Abstract

Background: People with intellectual disabilities (ID) often receive care from their parents. Caring can be stressful, but parent carers sometimes continue to care for their children into old age, when they are more likely to experience health problems. Transition from the family home can be particularly stressful for people with ID and their parents, and some older parents avoid thinking about transition because they are worried about what will happen.

Method: Eight older parent carers were interviewed about their experiences of what happened when their adult children with ID moved out of their family home. Interview transcripts were analysed using narrative analysis.

Results: Six themes were developed using thematic narrative analysis. Participants spoke about how the decision was made to start transition, having to fight for their children's care, feelings of responsibility, feeling uninformed about transition, hopes for the future, and how much they valued collaboration from carers.

Discussion: Overall, transition was a difficult and emotional process for participants, who frequently found professionals unhelpful. Professionals could provide more information and support to parent carers and their children during transition to make it easier for them and reduce stress.

Keywords: Intellectual disability (ID), learning disability (LD), parent carer, ageing, transition

Introduction

People with ID and their carers

There are roughly 1.1 million adults with intellectual disabilities (ID: also referred to as learning disabilities, or LD) in the United Kingdom (UK; Mencap, 2024). People with ID experience significant inequalities: they have shorter life expectancies (O'Leary et al., 2018), greater risk of physical and mental ill health (Cooper et al., 2015), and they are more likely to be abused and socially excluded (Hall & Bates, 2019). Abuse of people with ID has been documented in hospitals and residential care settings and has serious effects on people's health and wellbeing (Wiseman & Watson, 2022). It is important for professionals to ensure people with ID receive support and care that meets their needs.

In 2019/2020, 155,400 adults with ID accessed social care support (Wilson, 2020). Parents are often concerned about the quality of care that their children would receive from paid carers outside of the family (Bibby, 2013). Many adults with ID receive support from family members (particularly parents) instead of or in addition to paid support. Family carers of people with ID are more likely than the general population to experience physical health issues as well as mental health issues related to stress, particularly when they are increasingly struggling to manage their relatives' care (Miodrag & Hodapp, 2010; Thomas et al., 2023; Dillenburger & McKerr, 2009; Yoong & Koritsas, 2012). Research indicates people with ID face health inequalities because they are more likely to live in poverty and to have limited access to health services (Emerson, 2021); their parent carers are often impoverished and are frequently stressed by having to push against discrimination to get healthcare for their children (Emerson, 2003; Ali et al., 2013).

Older parent carers

As people with ID grow older, they are less likely than people in the general population to get married and start families of their own, so it is common for their parents to continue caring for them (Ryan et al., 2014). Older parent carers often have concerns about the quality of care that their child would receive outside of the family (Weeks et al., 2009), but another reason why some older parents continue to care for their children with ID could be that some older carers report having mutually supportive relationships with their children (Gant, 2010; Bowey & McGlaughlin, 2007).

Older parent carers experience additional stress compared to younger carers: they are increasingly likely to experience physical health problems, such as joint pain and visual impairment (Taggart et al., 2012), making it more difficult to care for their child's needs despite being skilled carers (Dillenburger & McKerr, 2009). Abramson (2015) wrote about how older parent carers of people with ID are caught between caring responsibilities and their own health needs, causing them stress and affecting their mental health. Older parent carers are less likely to be confident with seeking help from social services, and services generally do not support them to find help (Walker & Ward, 2013).

It is common for older parent carers to worry about what will happen to their children after they pass away (Bowey & McGlaughlin, 2007; Weeks et al., 2009). Parents often express concerns about their children being poorly looked-after, and about their other children feeling forced to care for their siblings (Brennan et al., 2018; Engwall, 2017). One parent reported that she was "kind of afraid to think five years ahead. I'm too old to think five years ahead." (Engwall, 2017, p. 163). Despite worrying about their children's future, older parents frequently continue to care for their children until they become unable to cope due to poor health and burnout (Prosser, 1997; Taggart et al., 2012). Parental stress appears to negatively affect the quality of life of people with ID as well as their parents (Staunton et al., 2020), so it is important for services working with people with ID to consider how to help parent carers to feel less stressed (Gant, 2010).

Older parent carers' distress can be understood in relation to attachment theory; people with ID are less likely to have secure attachment styles, and their parents are more likely to have insecure attachment relationships with them (Hamadi & Fletcher, 2019; Fletcher, 2016), so transition is more likely to be difficult for everyone involved. According to Erikson's life stages model, older parents are more likely to be concerned with whether they have established care provisions for their children that will outlive them (Grant, 2000; Osborne, 2009), and parents who continue to avoid thinking about transition might be more distressed by thinking about the future. Professional support for older parents could help them resolve anxieties related to separation and feel more comfortable with transition (Lambruschi et al., 2022; Grant, 2000).

Transition process

Moving out can look different for different people. Adults with ID might live in a care home and receive residential care, or they might live in their own accommodation with carers coming in to support them, also known as supported living. Housing might be privately owned, or provided by local authorities, housing associations, or charitable organisations: similarly, carers might be employed directly or contracted by the local authority (Mencap, 2012). Placements are usually funded by social care, but people who are eligible for Continuing Healthcare (CHC) funding because of ongoing complex needs that involve mental and/or physical health issues are funded by integrated care boards (ICBs: replacing care commissioning groups (CCGs)) under the National Health Service (NHS) instead. This can mean that NHS workers take responsibility for sourcing and funding accommodation and care rather than social workers (Foundation for People with Learning Disabilities, 2024).

People with ID and their carers have to navigate different options and frequently report negative experiences, with people feeling that they had little choice in where they moved to and who they lived with (Blood et al., 2024) and parents reporting that they felt unsupported by social care professionals (Vereijken et al., 2023). Health and social care professionals are often involved in supporting transition for people with ID alongside their parents, particularly when mental health issues and/or aggressive behaviour is involved (Hudson, 2006; Perry et al., 2007). The process of finding appropriate care is complex, and parents report not having enough information and not knowing what was available (Tarleton & Ward, 2005; Grey et al., 2015). When people with ID move to placements that do not meet their needs, it is distressing for them and their parents, and they have to start the transition process again (Vereijken et al., 2023).

Rationale for research

Older parent carers of people with ID often continue to care for their children, despite increasing carer stress, mental and physical health problems, and a decreasing ability to meet their children's needs. Parent carers frequently report negative experiences of the transition process, and older parents are reluctant to start the process when they feel unsupported and fearful about what might happen to their children. Although there are studies exploring older parents' attitudes towards transition (Walker & Hutchinson, 2019; Bowey & McGlaughlin, 2007), there has been relatively little research with older parent carers whose adult children have moved out, so this area remains open for exploration. Understanding more about older parent carers’ experiences of transition could help professionals to improve the quality of life for this group.

This research study aimed to learn more about older parent carers’ experiences of transition, to support health and social care professionals to help improve transition for people with ID with older parent carers. This aim was in line with the NHS values of seeking to improve lives and committing to quality of care. This study aimed to explicitly explore how health and social care professionals featured in participants’ narratives. Professionals are frequently involved in transitions, but previous research has indicated that parent carers report being frustrated and disappointed with professionals’ support (Grey et al., 2015; Forrester-Jones, 2021), so it was hoped that asking participants about this would help to explore ways in which professionals could improve future parent carers’ experiences. The study asked the following research questions:

What stories do older parent carers of people with ID tell about their adult children moving out of the family home?

How do health and social care professionals feature in these stories of moving out?

Method

Design

For this study, a critical realist position was used. Critical realism takes a realist view of knowledge, arguing that participants’ experiences reflect objective reality, whilst also arguing for a relativist position: that participants’ experiences and views will be affected by various influences, including personal, societal, and cultural contexts (Stutchbury, 2022). As the researchers were concerned with improving the experiences of parent carers and their children, it felt important to understand how participants' accounts reflected the reality of the processes they had experienced, as well as considering how context affected their stories.

The study used a qualitative interview design, following a narrative analysis approach. Narrative interviews were used with older parents of people with ID to explore their experiences of their children's transition via the stories they told. Narrative analysis is well-suited to interpreting meaning from small groups, including how and why participants have constructed their stories in particular ways (Riessman, 1993; Riessman, 2008). Thematic narrative analysis (Riessman, 2008) was selected because it felt appropriate to focus primarily on the content of participants' stories rather than on the structure and dialogic elements, as the study aimed to identify guidance to improve parents' experiences of the transition process whilst still attending to how and why narratives emerge.

Participants

The aim was to recruit between eight and twelve participants, based on sample sizes in similar narrative studies (Engwall, 2017; Grey et al., 2015). Nine people expressed interest in participating in the study: only eight were interviewed, as one person later said they were too busy to participate. Participants were required to be parents of at least one adult child (age 18 or older) with a diagnosis of ID who moved away from living with their parents as an adult. To ensure that participants would be able to provide rich narratives, only parent carers whose children left home in the last 10 years were included: initially this period was set at five years, but it was extended to support recruitment of sufficient participants. Parents whose adult children moved out and then back home again could take part only if their children were no longer at home, as the study was focused on parents whose children had moved out permanently; the author and their supervisors wanted to avoid including parents whose children moved out with the intention of moving back home.

As people have different experiences of ageing, and as chronological age is not a straightforward measure of age-related impairment (Grenier et al., 2016; Diehl et al., 2020; Phoenix et al., 2010), participants were asked to self-define as “older” based on having experienced changes related to ageing. This criterion was discussed with consultants including parent carers and people with ID, and it was decided that it was a sufficiently open definition to allow people with different perspectives on ageing to feel that the project was open to them.

Demographic information about participants is shown in Table 1 below. Participants’ mean age was 59.6 years (range was 9 years). All participants were White, with the majority reporting their ethnicity as White British and one as ‘Other White ethnic background’. One participant was male, and the others were female. Two participants, Stephen and Elizabeth, were married and gave separate interviews about their son. One participant, Sarah, had two daughters with ID and spoke about them moving out together.

Table 1

Participants' demographic data

Pseudonym	**Pseudonym for child**	**Gender**	**Age range**	**Ethnicity**
Andrea	Thomas	Female	60-64	White British
Janet	Lucy	Female	60-64	White British
Emma	Jack	Female	55-59	White British
Samantha	Taylor	Female	65-69	White British
Stephen	David	Male	55-59	Other White background (Arabic descent)
Elizabeth	David	Female	55-59	White British
Abigail	James	Female	55-59	White British
Sarah	Jill and Mary	Female	55-59	White British

Procedure

Participants were recruited through carer networks, charities, and care organisations such as Mencap, who shared posters with parents. A range of organisations were contacted and were offered alternative language versions, to try to include parent carers from different backgrounds. Participants were invited to contact the author if they were interested in taking part and were sent information sheets and asked to complete demographic questionnaires and consent forms before being interviewed. Participants were compensated with a voucher. The poster, information sheet, consent form, and demographic questionnaire are included in the appendices (Appendices 2, 3, 4, 5).

Interview design

Interviews lasted between 45 and 88 minutes (mean length was 64.5 minutes). Participants could choose between being interviewed online using Microsoft Teams or meeting at a local NHS site or in their own home: two participants were interviewed face-to-face and six were interviewed online.

Interviews were largely unstructured; participants were asked to tell their stories about what happened when their child moved out, starting from whatever time they chose and moving forward. Additional prompts were used to explore participants' narratives in more depth. Consultants for the project, including parent carers and adults with ID, felt the interview questions were appropriate but advised the researcher to inform participants of the narrative nature of the interview in the information sheet. The interview schedule can be found in Appendix 6.

Ethical considerations

Ethical approval for the study was given by the Salomons Ethics Panel (see Appendix 7). Participants gave informed consent after being given time to decide. A warning was provided beforehand that interviews might be upsetting, and participants were debriefed by the author afterwards. Participants were told they could take their time and choose not to respond, as research shows this can support people recounting traumatic experiences (Newman et al., 2006). All confidential data was saved securely on the author's secure university drive and was accessed only by the researchers: all identifying information has been anonymised. Participants were told before their interviews that their information would be kept confidential unless they disclosed a safeguarding risk.

Data analysis

Interviews were transcribed verbatim, including pauses and notes on emotional tone. Thematic narrative analysis was used to analyse the transcripts (Riessman, 2008). Each transcript was read and re-read, with annotations made to comment on elements of the content, emotional tone, and possible function of the narratives. Narrative summaries were written for each transcript and checked with participants to ensure that they agreed with how their stories had been understood: four participants asked for amendments, which were made. Annotations were compared across transcripts. Emerging themes were developed by the author and discussed in reflective conversations with supervisors, who looked at the annotated transcripts to help them make suggestions about whether the author's themes related to participants' narratives. The author's interpretation of the narratives' emotional tone and function were also discussed to help the author decide whether their interpretations seemed appropriate. Quotes used in the report were "cleaned up" for clarity by removing repetition. There are copies of transcript annotations in appendix 8, and notes on developing themes in appendix 9.

The author kept a research diary to keep track of thoughts and emotional responses during the research process, which supported reflections on the tone and function of narratives during analysis and helped the author to consider their own role as an audience that influenced participants' stories. The author's reflections were discussed with supervisors to reduce the impact of bias on analysis. An excerpt from the research diary can be found in appendix 10. The author's position as a psychologist with experience of working in community ID services was considered: an expectation that participants would have had negative experiences with paid carers, based on the author's experiences of placements breaking down, was identified before data collection to try to reduce the impact of bias.

Results

Narrative summaries were produced for each participant and are displayed in Table 2 below.

Table 2

Narrative summaries

Participant pseudonym	**Narrative summary**
Andrea	Andrea said she had planned for her son Thomas to "*always*" be with her and her husband, and she was happy to have him living with them. Unfortunately, when Thomas was 23, he fell ill with flu and his behaviour permanently changed: he rarely slept and was active throughout the night. Andrea explained that people with Thomas' particular condition typically engage in increasingly challenging behaviour in their early 20s. Andrea said that it became clear then that she and her husband could not cope alone. The next chapter of Andrea's story was about finding the "*right place*" for her son. Andrea described how social care had been "*singularly unhelpful*" in finding somewhere, as they had suggested "*irrelevant*" options that included homes that were female-only. Through her own research, Andrea 'eventually' found a care provider that seemed appropriate and trustworthy, and after "*fighting*" with social care she managed to convince them to fund it.

	Two days before the move, the care provider called to postpone and potentially call it off: Andrea described how absolutely distraught she was when this happened. Andrea told me she had felt "*the lowest*" she had ever felt. Fortunately, after her husband talked to a solicitor for legal advice and spoke with the local authority, the move did go ahead. Following Thomas' move to his new home, Andrea said that she and her husband became much more relaxed, and they were able to have a happier relationship with Thomas. Andrea also described how happy her son was with his home. Andrea spoke about a "*horrible*" incident where some of Thomas' carers were found to be "*goading*" and abusing him: she was grateful that the care provider dealt with them quickly. Throughout her story, Andrea said she wanted to tell other parents of people with ID to consider their own children and whether they might benefit from moving out. Andrea explained that parents might want to keep their children at home, as she did, but felt that it was important for them to think about what would happen if they got too unwell to care for their children.
Janet	Janet told me about her daughter Lucy, who moved to residential college when she was 19 before she then moved out to supported living. Janet said that she had been thinking about Lucy moving to her own home from when Lucy was 14, because she wanted to make sure that Lucy had moved somewhere where she was happy before she and her husband became too old or unwell to look after her themselves. Janet also felt Lucy had been becoming more interactive and so it was a good time for her to move out and live with other people. Arranging Lucy's residential college placement involved "*conflict*" with the local authority: Janet said she had to prove why she believed Lucy should not go to a local college, and she spoke about feeling frustrated by how professionals ignored her until a clinical psychologist wrote a report that confirmed "*everything*" that Janet had already been saying. When Lucy did go to college, Janet said that the initial transition was difficult because Lucy did not like change, but with some time and staff adaptations, Lucy did really well at college. Janet spoke about looking for supported living arrangements for Lucy and how she learned from other parents about how parent-commissioned care worked. Janet said that parent-commissioned care helped her to have more control over Lucy's care, and to be sure that her daughter would get on with her housemates by coordinating with other parents and children that she knew. Lucy's move to her parent-commissioned supported living home went well, and Janet spoke about how happy Lucy was in her new home and with her carers. Janet said she

	felt lucky to have been able to find other parents to commission a home with and to have managed to get funding from the local authority, and she suggested that other parents might not be so fortunate. Janet said that she wanted to use her knowledge and experience to make things easier for other parents. Janet explained that the main challenge for parents was to know what they needed to do and how to find the information they needed, and she felt that parents needed to take responsibility because "*there isn't anyone else to do the work*".
Emma	Emma told me about her son, Jack, and explained that her story about Jack moving out had four stages. The first two stages were when Jack moved to two different residential colleges, and the third stage was when Jack left college at 23 and moved into supported living: the placement failed and then Jack moved into a funded placement in his own rented accommodation, supported by a team of carers. Emma found there were no residential options that "*felt right*" and that were close enough. Emma said she felt completely unsupported during this process by the local authority, who provided only a very short list of possible places. Emma was unsure about what options were available for Jack and did not know how to decide on what kind of care her son needed. It also became apparent later that she was not aware of all the types of care options available. After she found a care provider with a supported living placement which seemed right for Jack, Emma described having a "*nightmare*" with that care provider. Emma said that the provider assured her that they could look after Jack and manage his "*challenging*" behaviour, but the placement broke down shortly after Jack finally moved in because staff felt unable to manage him. Emma described how she was left "*sobbing*" when the placement broke down and Jack had to move home. Looking back, Emma said she had not realised how inappropriate the supported living placement was for her son, and that she wished she'd had somebody to give her more information about that type of placement. Emma said that finding Jack somewhere else to live was difficult with the "*baggage*" of a placement breakdown and, following the breakdown, she spoke about viewing "*shadowy*" emergency placements which made her feel uncomfortable. Fortunately, there was a helpful person in the local authority who found a provider who agreed to administer a package of funding. Emma found a suitable rented property for her son and personally funded two carers

	to work with him alongside her and her husband. Following a long fight with the local authority, a package was agreed and then transferred to the new local authority. Emma described Jack's new home and how grateful she is to the organization that administer the package of funding. She also spoke with pride about how the local authority that fund the programme want to set up new homes like Jack's. Emma said she wanted a "*guidebook*" to help other parents understand transition and funding processes and options.
Samantha	Samantha spoke about how she was diagnosed with a progressive, degenerative condition when her son Taylor was an infant, and how her husband later left them both because "*everything was just more*" than he could deal with. Samantha said this made her think about how Taylor would be looked after if she became too unwell to look after him, and she had then started thinking about him moving somewhere with his own professional carers. Taylor first moved away from home for a college with a focus on performing arts: Samantha said there were no local options that would allow him to study "*at a meaningful level*", so he moved to another town and really enjoyed getting involved with the local music scene. Samantha spoke about how this was a relatively "*gentle*" transition because Taylor came home during term holidays, but still found it "*a wrench*". Samantha said she worked with Taylor's college to find somewhere to live, and they found a residential placement, where Taylor lived for four years. The placement worked well at first, but Samantha said that Taylor became "*ill*" during Covid lockdowns because he was not able to visit her and spent a lot of time online. Samantha said that the carers did not stop Taylor from eating unhealthy food or spending all his time on his iPad, and that Taylor ended up running away. This was a "*really frightening time*" for both of them, and Taylor moved back home. It was difficult for Samantha to find a new placement for Taylor, who wanted to go back to the same town so he could stay connected with people he knew there. Samantha said there was little available locally that would suit Taylor's needs, but the local authority wanted to find something local and disputed who the "*placing authority*" was. After threatening legal action, Samantha persuaded the local authority to support her in getting Taylor a placement in the same town he had lived before. Samantha said Taylor was happy in his new placement, and she was happy that his carers kept her informed about what was going on. Samantha spoke about being worried every time there

	was a change in management or in personnel, as similar changes had preceded the breakdown of Taylor's first residential placement. Samantha also spoke about being her son's "*interpreter*" and "*ambassador*" and how she continued to fulfil those roles for Taylor after he moved out.
Stephen	Stephen told his story about his son David, who was born with serious health conditions and suffered brain damage as an infant. David had an applied behaviour analysis (ABA) consultant at his primary school and moved to an ABA school that Stephen and his wife Elizabeth found for him. David learned a lot at the ABA school, but David's behaviour at home became more challenging around the time he turned 8, and he spent a lot of time awake at night. Stephen explained that he used to work as a lawyer, initially cutting down on his work to spend more time with David and then giving up work completely to be David's main carer at home. The idea of David going to residential school came from his specialist psychopharmacology team: Stephen said they encouraged him and his wife to think about residential care for David because they were struggling to manage his behaviour. Stephen said that it took some time to decide, partly because there was a period where David's health got much worse. Stephen spoke about how difficult it was caring for David at home and how it was the right decision for David to go to a residential school, which had nurses to help look after him. David stayed with the school until Stephen and Elizabeth decided that it was no longer the best place for him. Stephen spoke about how challenging it was for the family when David turned 18 and transitioned from child to adult services. Stephen explained that the CCG team, who assigned a case worker to David, were healthcare workers with no social care expertise and little knowledge of places where David could live. Stephen said an independent auditor later found that David's case had been handled poorly and that the auditor helped them find a residential placement for David, with no help from the CCG "*in any way, shape or form*". In the end, David moved to a placement close to his family, and they have been able to visit him more than when he was living at his residential school. Stephen said that some things have changed, as he has had more time to do other things, but he felt that he and his other children have been able to maintain their relationships with David. Stephen told me how he had been politically active on behalf of other families because of how hard he knows people have to "*battle*" for their children and how poorly the CCG handled

	David's case. Stephen appreciated that the local authority funded his son's care, but he felt that all the work involved in finding a placement was down to him and his wife's hard work.
Elizabeth	Elizabeth told me her story about her son David after Stephen spoke to me in a separate interview. Elizabeth said that David's hospital consultants first brought up the idea of David moving into residential care when he was 8, because they had been struggling to manage David's behaviour around food at home. David's consultants continued to bring up this idea at his appointments: Elizabeth talked about an appointment where she had an "*awful*" time trying to get David back in their car, and she said that this had been a sign for her that they were not coping and should start researching residential care. However, "*everything was put on hold*" when David developed a life-threatening tumour in his brain. Elizabeth explained that this was a difficult time: fortunately, David had treatment which saved his life. Elizabeth said that it was hard to know what would have happened without that delay and whether David might have moved out when he was younger. Elizabeth talked about feeling guilty when David moved to a residential school, though she felt the transition went "*okay*". Elizabeth said that the school was not as good as she wanted it to be, as there were "*things that we were not terribly happy about*", but it was not so bad that she wanted to move David somewhere else: she reflected on whether she would be "*completely happy*" with any care setting. When David turned 18, Elizabeth described a "*rug being pulled*" from under her: David's respite care stopped and his case worker seemed to know very little that was helpful, which meant that Elizabeth and Stephen had to do a lot of work themselves. Elizabeth said they managed to find somewhere local for David so that they could see him regularly. Elizabeth described her life now and how things have been with David since he moved out. Elizabeth said that she was stressed with the pressure of her work as a GP and liaising with David's carers, who did not communicate well with her and her husband. Although she felt guilty for not pushing David's carers to do more with him, Elizabeth said she felt too stressed and busy to fight for things to change. Elizabeth said she felt that David was safe but was not "*100%*" happy with his care: she also felt unable to look after David at home.
Abigail	Abigail told the story of her son James, who went to a residential college to study hospitality. James wanted to stay in the same town when he finished college: Abigail described how the town was welcoming to people with ID and how James knew a lot of people there. Abigail

	said their initial plan for James to live with some other young people fell through, and James had to return to live with her while she found somewhere else for him to go. There were some difficulties in working with social care to find somewhere for James. Abigail said that the social workers for James seemed to "*rotate*" often, and she felt that they did not listen to her when she talked to them about her son's needs. Abigail also felt that social care wanted to "*offload*" responsibility for funding James' care to the town where he wanted to live. Fortunately, the housing provider from Abigail's previous plan managed to find somewhere else for James to live, and he moved in after social care agreed to fund it. Unfortunately, the person managing James' home left the company soon after James moved in, and Abigail spoke about her dissatisfaction with some aspects of James' care. Abigail said that some carers were bad at supporting James to make healthy food and drink choices, and that she had been trying to get them to do more with James with his 1:1 care hours. Abigail asked the care provider's managers to make some changes, and Abigail said she hoped that they would make improvements to James' care. In contrast, Abigail spoke about how James got a good job with a catering company, who had been very supportive of James and worked with a charity that trained their staff to know more about her son's disability. Abigail spoke about how she was still adjusting to having James live apart from her, though she felt that he was safe and happy with where he was living. Abigail said that James was more independent and confident now, whereas both she and James felt anxious for his safety when he lived with her in the city. James' move also affected his brother: Abigail said it meant she could spend more time with him, and that she was reassured that her other son would not have to feel responsible for caring for James if anything happened to her and her ex-husband. Abigail also spoke about her concerns with how difficult it was for parents to navigate social services when their children left education, as it was extremely hard for her to find the information she needed. As she felt social care had tried to "*ram-roll*" her into options that were less expensive, Abigail worried that parents who might not understand the transition process would be pressured into accepting whatever they were offered.
Sarah	Sarah told me about her daughters, Jill and Mary, who both have ID. Sarah started her story by talking about them going to a residential college: a staff member approached Sarah on their first day and encouraged her to start thinking about where they would live after college. Sarah said she had planned for Jill and Mary to live with her for longer, so it was helpful to have

someone prompting her to think more about it. There was also a friend who talked to Sarah about how she could separate her "*parent*" and "*carer*" roles if her daughters moved out, which Sarah found helpful.

Sarah said that finding a care provider for her daughters was difficult because it was so complicated, and because she went into it without knowing how it would work. After looking at a range of care providers and homes, Sarah decided to go with a small, hands-on care company with a team leader who seemed very knowledgeable about the people living in their homes. Jill and Mary had a proactive social worker, but there were still delays with getting funding agreed and renovating the home: Sarah said the delay was "*painful*" because she had to care for her daughters at home for longer than planned.

Fortunately, Jill and Mary's transition into their new home went smoothly, and Sarah said she was surprised by how well it went. There was a problem when there were some staff changes in the house, as Jill and Mary spent less time with people they knew well, and later there was an incident when they went to a family wedding and Jill was "*out of sorts*". Sarah said she hoped that Jill would feel better when she got home, but she remained low and spent a lot of time in bed and on her own. Sarah spoke about trying to understand what was wrong with Jill and seeking support; the care team leader spent more time with Jill, and the GP prescribed anti-depressants. Sarah said she wanted specialist support for her daughter, so she asked the GP to refer Jill to the community LD team: the community team took a holistic approach and had a lot of useful information about medication and therapy options, which Sarah appreciated. After some initial issues with her anti-depressants, Jill gradually seemed happier and spent more time with other people. Sarah spoke highly of her daughters' carers, as she felt they were "*open and transparent*" about everything going on there.

With Jill and Mary living in their new home, Sarah said her relationship with her other two children had changed, as she had more time and energy for them: Sarah said she had also had more time for her husband. Sarah said she was still trying to figure out how to separate being a parent from being a carer for her daughters, as she continued to do certain things for them and often visited to complete "*jobs*" rather than doing "*nice things*" together.

Emotional tone of narratives

Participants' stories contained a mixture of different emotions. Each of the narratives appeared to be highly emotive for participants to talk about, as well as being emotional for the author to listen to. Participants' warmth and love for their children was particularly evident, and it was common for participants to recount positive stories about their children.

So we went to see them – James was amazing. The guy who talked to him, who was the head honcho at [catering company], said, 'okay, well, James, tell me a bit about yourself'. So James goes off rabbiting off, and I said, 'actually, James, I think [employer] was just asking you this' and James goes, 'oh, yeah. Yeah. No, you're right. You're right, mum'. And then he just goes off, and I could see [employer]'s face just like, 'fuck me, this kid knows what he's on about', you know? (Abigail)

Some participants were positive about professionals they had worked with as part of the transition process, and they spoke warmly about carers who were taking good care of their children and social workers who had been helpful.

It's just beautiful and we're so grateful, you know, that we found that, and the [landowner] was good, and the people who maintain the property are good, and it's safe and he's got his own car, and the carers are lovely, and we all get on with each other. (Emma).

However, participants were also deeply frustrated as well, and they frequently spoke with anger about where the transition had been difficult and where professionals had been unhelpful. Some participants used humour when talking about their frustrations, possibly to defuse tension: "*When people just go 'oh no, we don't do that'. I just want to [laughs] slap them"* (Samantha). When recounting situations where other people made mistakes during their children's transition, participants expressed their anger strongly.

> *I would say they promised us the world, something like that. But it looked like they knew what they were doing. (Interviewer: Mhmm) Turns out we were completely wrong. So what happened was, um, oh God, it was a list of the most horrendous fuck-ups in, excuse my French, in the history of the universe.* (Emma)

Some participants expressed how desperate they had felt during their child's transition and appeared sad and tearful as they spoke about what had happened. It was possible that this was the first time that some participants had relived the events they were talking about, and telling their stories clearly had an emotional impact.

> *And we got a phone call out of the blue. From [care provider] saying, 'I'm afraid, uh, something's happened to the place and it's not happening now, certainly it's not happening or it's certainly not happening now'. And at that point, that's the lowest I've ever been in my entire life.* (Andrea)

There was also a sense of weariness and constant worry that came across from some of the participants. Parents talked about how they were unable to relax because they were always worrying about their children and their care: *"So, I don't think, in the last five years, I* *have ever breathed out. And gone 'oh yeah, sorted'. It just never feels like it"* (Samantha). Elizabeth talked about how she and her husband Stephen had "*got to the point where we, neither of us can quite cope with dealing with it*". A couple of participants spoke how uncertain they felt about the future.

> *Umm, that it's all so unknown, you know, that there is no way of going 'oh yeah, you know, that's, that's his life sorted.' You know, he's got somewhere lovely to live and that's going to work. You know, it really feels year on year that you don't know what's going to happen next. You know, will the local authority pull the plug?* (Samantha)

All of the participants appeared emotionally affected through telling their stories: although each of them had different experiences, it appears that each participant had powerfully touching stories about their child's transition.

Function of the narrative/s

Participants seemed to be telling their stories for different purposes: some stated what they wanted their stories to achieve, and for others the function of their narrative was interpreted by the author. A common function appeared to be education: some participants stated that they wanted to pass on information to other parents to help them with their own children's transition.

My advice to people is to start at 24 at the latest, to start thinking about it, and you're not doing it to get rid of the young person, you're doing it for that young person's benefit. But you need to stop being a martyr about it and thinking 'Thomas's my responsibility. I will look after him until the day I die'. That isn't the best thing for Thomas, actually. (Andrea)

Other participants talked instead about how much they wanted to make the transition process better for other parents, and the majority reflected on how they felt more fortunate than parents who were less well-equipped to manage their child's move.

And I just think if somebody hasn't got English as a first language, if somebody does not have a level of understanding. They are getting absolutely, umm, ram-rolled…And I just think that's really bad. Umm, and I think something has to change, just to make things a little bit easier and a little bit fairer. (Abigail)

It appeared that some participants might have used their stories to vent about how emotionally difficult their experiences had been, and that they told narratives that allowed them to express their feelings and to (hopefully) feel heard and validated during their interviews.

It's quite emotional. Even thinking about it. I actually [pause] contemplated doing away with myself. I, I couldn't cope anymore. I'd completely become unhinged for an afternoon. I, literally, that was it for me. I couldn't do anymore. (Andrea)

Finally, another possible function for some participants' narratives might have been to tell their children's stories and to help the author, as well as readers, understand their children. Samantha talked about acting as an "*ambassador*" for her son and spoke warmly about him and how other people related to him.

I sound like this sort of sad, over-proud parent. But when people meet Taylor (Interviewer: Mm) You're either so exhausted by him, you can't deal with him, or you just, sort of, come under his spell, and a number of social workers have absolutely, just come under his spell. (Samantha)

Themes

Themes and sub-themes were developed predominantly regarding the content of participants' narratives, separately from observations regarding possible functions and emotional tone. The six themes can be seen in Table 3 and are discussed in more detail below.

Table 3

Narrative themes

Themes	**Sub-themes**
"…*my inner emotional drama, or journey to get to the point of accepting that this was a good idea*" (Sarah) – how the decision was made to start transition	- Struggling to cope - Preparing for the future - Children wanted to move out - Wanting their children to be independent

"*We had to keep pushing and pushing and pushing...really put our tin helmets on and just kept on fighting*" (Andrea) – participants having to fight for their children's care	- Pushing back against social care and ICBs/CCGs - Concern for other parents
"*But there isn't anyone else to do the work. It is you, as a parent*" (Janet) - parents feeling responsible for their children's transitions	- Having to do the work themselves - Continuing to feel responsible
"*…there are so, so, so many things. There needs to be a guidebook or something about all of this*" (Emma) - parents feeling uninformed and searching for guidance	- Not knowing what was available - Professionals lacked knowledge (or did not share it)
"*I wanted him to have a life, to have an absolute life"* (Samantha) – parents' hopes for their children's future, before and after moving out	- Doing the things they love - Having a community - Keeping what they have
"*...that's great they did it. But then why didn't they tell us that 'we're going to do it' or they did do it, that would have been so nice to hear"* (Elizabeth) – parents valuing collaboration from their child's carers	- Celebrating openness and honesty - Frustration with poor involvement and communication

How the decision was made to start transition

Participants generally framed their narratives as a journey, from when they first started thinking about the idea of their child leaving home to the present day, frequently moving back and forth in time. All but one of the participants said their children went to residential college as adolescents before returning home and later moving out as adults.

Participants made the decision to start the transition process at different times, and each spoke about one or more factors involved.

Struggling to cope

Several participants said they decided to start the transition process because they felt unable to continue caring for their child. For Stephen and Elizabeth, the idea of their son David moving out came from a specialist health team, who encouraged them to think about transition when David was 8. Elizabeth said that she was "*not ready for that conversation*" until an incident where they had struggled to get David to come home from an appointment: "*I remember thinking, 'you almost did that on purpose, David'. Like, almost, you know, this huge decision to make, you're making this easier for us, actually, that acknowledgement that we're not coping*". Andrea said that she had intended for her son Thomas to stay at home with her, but after his behaviour became much more challenging, she and her husband were unable to cope: "*Um, and it got quite difficult, and I started thinking that [pause] I can't carry on like this. It was very, very stressful.*"

Preparing for the future

Some participants were worried about what would happen to their children if they continued to care for them at home as they got older. Samantha said she had worried about the progression of her degenerative condition since her son was an infant, so she had "*always worked towards*" finding him somewhere else to live. Janet talked about being an "*older parent*" and wanting to get her daughter "*settled*" somewhere: "*we are of an age where, you know, something could happen, one of us gets ill or whatever, and we didn't ever want to be in a position where we were unable to care for Lucy*". Andrea spoke about how she was finding it hard to make the decision to seek alternative accommodation for Thomas until a friend told them a story about "*an elderly gentleman*" who looked after his son with ID.

> *My friend was saying 'what will happen when, inevitably, that gentleman passes away, and that boy who's known nothing else, the young man with Down syndrome would suddenly have to have a whole new life. You've known nobody'. And it just brought us up short, it was like you could almost hear cartoon brakes going on, thinking, 'hang on a minute, this isn't right'.* (Andrea)

Children wanted to move out

Two participants spoke about how their child expressed their own preference for moving out. Samantha said that, although it was "*down to me*" to decide, she knew that Taylor wanted to live in the town where he had been at college because he "*became very involved with the music scene in [town]*", and that he wanted "*to be independent*". Similarly, Abigail spoke about how her son James "*was very interested*" in staying where he had been at college: "*And we were just like 'crikey, okay, here we go. We're going to have another battle with social services trying to get him down to [town].'*"

Wanting their children to be independent

Participants also spoke about wanting their children to maintain and develop their independence by moving out. Sarah spoke about how she had assumed that her daughters would stay at home with her "*quite a lot longer*" than they did, but college staff suggested that they would "*maintain*" their skills and independence better if they moved into their own home. Janet said that she felt her daughter Lucy had "*opened up and blossomed*" during school and college, and she wanted her to move out and get to know people whilst she was more active and open to doing so.

Participants having to fight for their children's care

Pushing back against social care and ICBs/CCGs

Language about "*battles*" and "*conflicts*" was frequently used by participants in relation to securing appropriate housing and care for their children. The majority of participants spoke about feeling exhausted by having to persuade social care and CCG professionals about what their children needed, and often felt professionals were trying to convince them to accept proposals that were "*demonstrably unsuitable*" (Stephen). Andrea reported that Thomas' social worker tried to "*push you down a supported living route*" to reduce financial costs rather than the residential placements she wanted for him, and she spoke about having to keep a "*log*" of unsuitable placements her son had been offered to prove that they were not "*relevant*". When Janet wanted funding for Lucy's residential college, she was ignored until a clinical psychologist produced a report that said what she had been saying: "*-and all of a sudden that clicked with the local authority. This is, I have to say, this has really pissed me off.*"

Some parents considered legal action. Emma said that there was an ongoing dispute with the local authority about Jack's out-of-area placement funding that was eventually resolved when "*my husband called them and said 'right, this is it. It's either lawyers or you sort this out'.*" Samantha spoke about how her local authority wanted to find somewhere local for her son and argued about who the "*placing authority*" responsible for funding was. Samantha was concerned about Taylor's safety with the local options on offer: "*everybody has seen the programmes of hospitals and care homes that are, personally, I wouldn't entrust* *a gerbil to them.*" Eventually, Samantha "*won the argument by literally threatening*" to take legal action.

Concern for other parents

When discussing how they had to fight with professionals, participants also talked about how they were worried about other parents who were less well-resourced or otherwise less able to fight those battles. Some participants said they were advantaged because of their careers and/or education: Elizabeth said her experience as a GP meant she knew about "*services*" available to support parents, and Stephen felt that "*being an ex-lawyer, my wife being a GP*" was "*immeasurable*" during the transition process. Abigail spoke about being afraid that parents who did not speak English as a first language might be pressured by professionals: "*They are getting absolutely ram-rolled or whatever you want to call it…because they go, 'oh, well, they don't understand. So it's all right, we can just run ram shod, you know, around them.'*" Andrea said that the amount of "*pushing and pushing*" involved in her son's transition made her worry that parents who were "*more meek, and less organised*" would not be able to fight for their children's care in the same way.

Parents feeling responsible for their children's transitions

Having to do the work themselves

When participants spoke about their children's transitions, they often talked about feeling forced to do most of or all the labour involved. Janet said that she "*basically organised the whole thing*" with other parents when it came to Lucy moving into a parent-commissioned placement. When talking about her role working with parents going through the transition process for their children, Janet said she advised parents that they "*have to be on top of it all because there is not going to be another person who can take it over for you.*"

Participants also felt that they were doing more work than their children's caseworkers. Stephen said that he was grateful that David's care and housing was CCG-funded, but he felt that they had to find placements for David with "*little or no assistance from the institutions that are supposed to help you*". There were some exceptions, however: Emma spoke about having to do a lot of work herself, but also said that there was one "*very nice woman*" from the local authority who was helpful: "*what happened then was, we got the support to find somewhere. So, [the local authority] were brilliant. They were emailing everybody, calling everybody…We were then onto the world and his wife.*"

Continuing to feel responsible

Some participants also spoke about their ongoing responsibility for taking care of their children after they moved out. Elizabeth said that she was not "*feeling 100%*" about her son's care and spoke about her "*guilt*" for not doing more because of her busy, stressful job: she also expressed feeling guilty for wanting to be less involved in his care for the sake of her health. Samantha said she kept her phone on "*right through the night*" in case "*there's that call*" about her son running away from his carers again, and she felt "*always on high alert.*" Sarah spoke about how she was still trying to separate her "*parent*" and "*carer*" roles, finding that she spent a lot of her time "*in carer mode*" doing "*jobs with them.*"

> *Often, I'll go and visit with a particular job to do. Umm, you know, so I'll want to check up on their weights or I'll want to…you know, sometimes want to clip their toenails. I'm slightly baffled by nail-clipping, in that I'm getting mixed messages and that some people say carers are not allowed to clip toenails and fingernails…it seems to not happen unless I do it. So I go and do it.* (Sarah)

Parents feeling uninformed and searching for guidance

Not knowing what was available

Many participants reported feeling unprepared for their child's transition, on the basis that they did not know enough about care and housing options: parents wanted more specific information about how the transition process worked and places where their children might live, but they also wanted to know more about the types of placements. Although she had a role "*specifically advising parents*", Janet said she was still learning new things about the transition process, and she argued that the most challenging part of the process was understanding the different "*threads*" that parents needed to prioritise: "*all of the parents I've dealt with, once they know what they need to be doing, they're quite able to go off and do it.*"

Emma said she did not understand the differences between residential and supported living placements, and she did not know that Jack's current care arrangement "*could exist*": "*And we didn't know what needed to be set up for it to exist*". Emma said that she still did not understand everything about her son's care, and she felt that parents needed a lot more information than she had. Some participants also talked about what they thought would be helpful to inform other parents. Emma said there should be a "*list*" or "*guidebook*" for parents to tell them what they needed to know about transition. Abigail talked about how learning about transition "*frazzles your brain*".

> *There needs to almost be some government-led thing where there's a central repository for all sorts of information…I think as parents we all feel they make it very hard for us to, to be able to do anything without spending hours and hours and hours and hours.* (Abigail)

Professionals lacked knowledge (or did not share it)

Participants also reported feeling that their children’s social care and CCG caseworkers did not know enough about transition. Stephen spoke about his experience with David being transferred from children’s services to the CCG, who lacked the “*expertise*” to help find somewhere appropriate for David: the CCG worker was “*of negative help, because every now and then she would suggest a place that was demonstrably unsuitable*”. Elizabeth also reported that the CCG “*just did not have the knowledge*” and that the caseworker was “*clearly just beyond out of her depth*”. Janet said that her daughter’s social worker was not unhelpful but “*if you don't know that you can parent commission, social workers don't tell you that you can*”, and she said that she relied on other parents for information.

Parents’ hopes for their children’s future, before and after they moved out

Most of the participants talked about what they wanted for their children as part of their narratives, both in thinking back about what they hoped to get from the transition process and in thinking about the future.

Doing the things they love

Participants spoke about wanting their children to be active and engaged in the pursuits that were particularly important to them. Elizabeth said that she hoped David’s care would improve, that she wanted him to have “*a really enriched and fulfilled life*”, and that she wanted his carers to be “*doing so much good stuff with him*” so that he “*shouldn't be wanting or needing us so much*”. Andrea spoke about how her son’s life was “*way better*” in his new home: “*he has people there to look after him, that he loves, who love him, he does, things that Thomas enjoys, every single day*”. Emma said her son was “*a young man who* *needs a full fricking life*", which was why his supported living placement was inappropriate. Fortunately, Jack's residential placement was much better for him: "*he's got a gazebo, he's got his picnic bench, we have barbecues out there, you know, it's just like real life. It's like he's really alive. He's really living, you know."*

Having a community

There was also a sense that participants wanted their children to an appropriate peer group in their new home, to have people around to befriend. Sarah said she found it difficult to assess placements that were empty when she viewed them: "*I wanted to get a feel for what the community would be like, what the relationships would be like*". Sarah visited a faith-based community and hoped that it would be right for her daughters: unfortunately, most of the people living there were much older, and Sarah felt "*like it wasn't going to be appropriate for my girls at 20.*" Janet was worried about Lucy living with people "*who would be in your face*" or "*who made a lot of noise*", as this had previously put her off engaging in activities: commissioning a placement with parents they knew helped Janet find "*young people who will live well together*." Samantha spoke about her son and how she "*absolutely didn't want him to be lonely*".

> *You know, I live in a very kind, caring community here. (Interviewer: Yeah) And I wanted that to exist for him, that he would be part, that he would be part of something, that he would feel that sense of kinship and belonging, and he wouldn't feel excluded, and on the outskirts.* (Samantha)

Keeping what they have

Some participants talked about hoping that their children would continue to stay in their homes and maintain the same standard of living and care. Abigail spoke about her concern that her son James' 1:1 care hours would be reduced: "*it's more of a concern, of a massive battle to try and keep those hours if they're not being used*". Andrea said she wished that Thomas' care arrangements had "*a lifelong contract"*: "*I'm always very worried that they will take this place away because Thomas is challenging, it's, uhh, a more expensive provision, than some of the ones they were trying to push us down.*" Samantha spoke about her fear that her son's care would change for the worse: "*we wait and see. Because people always feel that they have to make their mark by altering something [laughs] And sometimes, actually, what's already there is working exceedingly well.*"

Parents valuing collaboration from their child's carers

Celebrating openness and honesty

Several participants had positive experiences with their children's carers and spoke about how the carers shared information and responded to them. Sarah said she appreciated that her daughters' carers "*tell it as it is*" rather than trying to cover up when their care is "*not how it's meant to be*". Sarah also spoke about working collaboratively with carers: "*I'm really glad I'm with this agency that aims to have a partnership with parents…aiming to work closely together and they're very easy to talk to, umm, and connect with.*" Emma said that Jack's care team helped them through some "*hairy moments*" by working together: "*really it was only the teamwork that figured it out. Like, you still need a support system.*" Janet spoke about how having a good relationship with Lucy's school team had been really helpful: "*so that when I said 'I think we have a problem here', they were like, 'okay, let's talk this* *through' because they know I wasn't constantly going [raising voice] 'we have a problem, we have a problem!'*"

Frustration with poor involvement and communication

Unfortunately, some participants had negative experiences with carers, and complained that carers did not work or communicate with them. Abigail voiced her frustration with having to push her son's carers to do things with him, and with needing to travel across the country to investigate what was going on herself: "*the fact that I'm down here for three months is just ridiculous, that I've had to do that to, um, to ensure that I wasn't getting bullshit fed to me, because I can physically just go to James' house*". Elizabeth wanted David's carers to include her in his life but found communicating with them stressful: "*we just couldn't cope somehow with the, not the fighting, but the whole, any communication, it just feels like, 'oh, I don't want to go there.'*". Emma spoke about how she felt Jack's residential college staff avoided telling her about his challenging behaviour and how this contributed to his failed placement: "*they hide things to you because they don't want you to know things are difficult…so they didn't tell us, therefore we didn't know that probably, you know, that supported living wasn't a good fit for him*".

Discussion

The study aimed to help understand more about older parent carers' experiences of their children's transitions, to support professionals to improve transitions for people with ID with older parent carers. Narrative interviews were conducted with eight parent carers, and narrative analysis was used to analyse interview transcripts. Overall, the results of this study indicate that transition was a difficult, emotional journey for participants, often involving challenges with unhelpful professionals, insufficient information about the processes involved in transition, and the pressure of responsibility. Participants' narratives appeared to have a range of functions, with many seeking to educate parents and professionals to help other people with their children's transitions, and others venting about their negative experiences.

What stories do older parent carers of people with ID tell about their adult children moving out of the family home?

Participants' stories about their children moving out were marked by struggle. In line with the research outlined in Section A that reported on parent carers' negative transition experiences, participants spoke about how and why they found the transition process difficult (Grey et al., 2015; Roos & Søndenaa, 2020; Vereijken et al., 2023). Participants felt they had to "*fight*" for the care they wanted by taking responsibility for finding appropriate care and "*pushing back*" against local authorities when they appeared to be pushing for alternative, inappropriate options. Lack of information and guidance about the transition process was also a key feature of participants' narratives: other studies have reported similar findings, with parent carers feeling unsupported and uninformed (Vereijken et al., 2023; Grey et al., 2015; Blood et al., 2024; Gant, 2010). Participants did not report challenges with transition relating to how it felt to separate from their children, possibly indicating that they and their adult children were securely attached; this might relate to the fact that participants' children had actually moved out, as parent carers of people with insecure attachments might be more likely to want to avoid transition (Seiffge-Krenke, 2006).

Some participants spoke about their age as a factor in their transition journeys, as their fears about their age and health preventing them from being able to care for their children motivated them to start thinking about transition. This is consistent with research reviewed in Section A with older parent carers who reported concerns about the future, particularly about what would happen to their children when they died (Brennan et al., 2018; Taggart et al., 2012; Bowey & McGlaughlin, 2007). It is also consistent with the idea that older parents experiencing Erikson's final life stage seek to feel that their children will be safe and provided for after their deaths (Erikson, 1950), as was the way that some participants spoke about hoping that their children would live happy lives in future. There were a range of other factors involved in participants' narratives about the decision to start the transition process, including being unable to cope with caring and wanting their children to be more independent. These factors have been reported in studies with parent carers in general: Alborz (2003) reported that most participants sought transition because of difficulties in continuing to care for their family member, and Codd and Hewitt (2020) reported that independence was important to parents of children with ID who were transitioning to adulthood.

Generally, stories told by the older parent carers who participated in the present study were consistent with those of parents involved in other studies, including relatively younger parents. The average age of participants in this study was lower than that of participants in other studies with older parent carers (Walker & Hutchinson, 2019; Taggart et al., 2012; Bowey & McGlaughlin, 2007): it is possible that participants in this study were at a comparatively earlier stage of life, and older parents might have emphasised the role that age-related health issues and concerns about the future played in their narratives regarding transition. Participants' descriptions of fighting for their children's care could relate to Erikson's penultimate life stage, i.e. generativity versus stagnation (Erikson, 1950), as they appear to relate to a more active approach; this might be related to participants being relatively younger than older parents in other studies. Older parents' stories might include more discussion of anxiety and regret, particularly if those parents are less physically able.

How do health and social care professionals feature in these stories of moving out?

Broadly, social workers were featured in participants' stories as being unhelpful, uninformed, and oppositional: some participants talked about positive experiences with individual social workers, but the majority of participants' experiences with social care were negative. Participants reported they had to do their own research for different placement options because the social workers either did not have that information or did not share it, and some felt that the social workers were pushing them to accept cheaper placements to save money. Participants generally reported having little involvement with healthcare professionals during the transition process. Similar to participants' experiences with social workers, participants generally reported that their children's CCG health workers were unhelpful and ill-informed about the transition process.

Some participants spoke about wanting more from professionals involved in transition: suggestions included providing guidance for parents about the options available and how to decide what is right for their children and being more supportive. However, other participants wanted to help parents directly without involving professionals, with some arguing that parents were ultimately the ones responsible for their children's transition.

Limitations

Although the present study aimed to interview older parent carers, the average age of participants was lower than that in other studies involving older parents: it is possible that the decision to ask participants to self-define as older parent carers led to relatively younger parents joining the study. Participants' experiences might be different compared to those of parents aged 70 and above, for example, who would likely be more affected by age-related health issues. The study might have struggled to recruit older parents that were not connected to the carer support organisations that advertised the study; some organisations used online newsletters to distribute the posters, which might be less accessible to some older parents. The advertisement poster's title (appendix 2) did not include an explicit reference to participants' ages, and the information sheet (appendix 3) could have included more explicit information about the study's focus on older parents. It might have been possible to reach older parent carers by using more targeted recruitment materials, visiting parent support organisations in person to advertise offline, and working with other agencies (e.g. adult social care) to contact more potential participants.

Despite efforts to recruit participants from other ethnic backgrounds, the sample was entirely White, and all participants spoke English as a first language. Older parent carers from other backgrounds and cultures might have very different experiences of the transition process: considering some participants' combative relationships with professionals, parents from minoritised ethnic backgrounds could have been significantly disadvantaged or fearful of confrontation with professionals due to racism. Data was not collected on participants' social class, but the majority appeared to have professional backgrounds and spoke about being relatively advantaged compared to other parents. As only one of the participants was male, fathers might have different narratives about transition and require different support from professionals. Additionally, for seven of the eight participants, their children had moved to residential college prior to moving out permanently: transition might be different for parents whose children were living at home without interruption until they moved out as adults. Participants' narratives about transition might have also been different according to the degree of disability experienced by their children: as no data was collected on this in the present study, it is unclear whether disability affected participants' experiences.

Future research

Researchers could investigate whether parent carers from different ethnic and social backgrounds and parents of children with specified degrees of disability tell similar stories about their children's transitions. For professionals to meet families' needs, it is important to understand whether issues such as lack of information and support, conflict with local authorities, and concerns about ability to care for their children are experienced by other parent carers, as well as how those experiences might vary for different parents and whether other parents might have different concerns. Raghavan et al. (2013) reported that some Pakistani and Bangladeshi families of people with ID struggled to access support and benefits, and that economic deprivation, social disadvantage, and degree of disability also affected family carers' experiences. Researchers could also explore sibling carers' experiences related to age and transition.

Future research could focus on more elderly parent carers, using set age categories, to see whether parent carers aged 70 and above would talk about experiencing different challenges during the transition process. Additional questions aimed at explicitly exploring participants' experiences of ageing could be added to the interview schedule, e.g. "can you tell me how getting older features in your story?”. Researchers could also use a quantitative measure to assess participants’ views on and experience of ageing such as the Attitudes to Ageing Questionnaire (Laidlaw et al., 2006) to help explore how ageing parent carers might have different experiences compared to younger parents.

Clinical implications

As the present study found that participants wanted more information about the transition process and felt unsupported and ignored by professionals, being more collaborative with parent carers and providing more information about transition might help to reduce parent carers’ stress and help them to support their children during the process. As participants spoke about their children’s needs not being understood by professionals, clinical psychologists could support the transition process for people with ID by conducting detailed assessments, with information from parent carers, to understand their needs better; this could support social workers in finding appropriate placements. Psychologists could encourage social workers to refer service users for psychological assessment, as service users’ particular needs might not be immediately obvious. Psychologists could also work with people with ID, their family, and their paid carers, organising network meetings and encouraging collaboration and clear communication to reduce the likelihood of placement breakdown. Professionals supporting older parent carers should be aware that they could be considering transition for a variety of reasons, including concerns about not being able to continue to care for their children because of their age and health.

As the transition process can be emotionally difficult, professionals should make sure that support is available to them: this could include signposting to support groups or counselling. Clinicians could support experts by experience to share information with other parent carers, given that several participants spoke about wanting to help other families; this could involve clinicians organising and co-facilitating peer support groups and/or meetings between experts by experience and service leads to discuss how to plan and deliver transition support services. Information packs about different types of care and housing as well as about potential local care providers and other resources could help parents to find placements that meet their children's needs. These resources could be developed in partnership between clinicians and focus groups of experts by experience, so that they could aim to supply information that is most helpful for parents.

Conclusion

The older parent carers of people with ID who participated in this study generally found their children's transitions difficult. Participants wanted their children to move out for a variety of reasons: they hoped that their children would continue to be happy and cared for into the future, but they felt unsupported and uninformed about how to find placements for them. Health and social care professionals were experienced as unhelpful overall, and for some participants their relationship with professionals was a "*battle*". Participants wanted professionals to offer more information and support for parents and children going through transition.

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Appendix 1: MMAT quality assessment

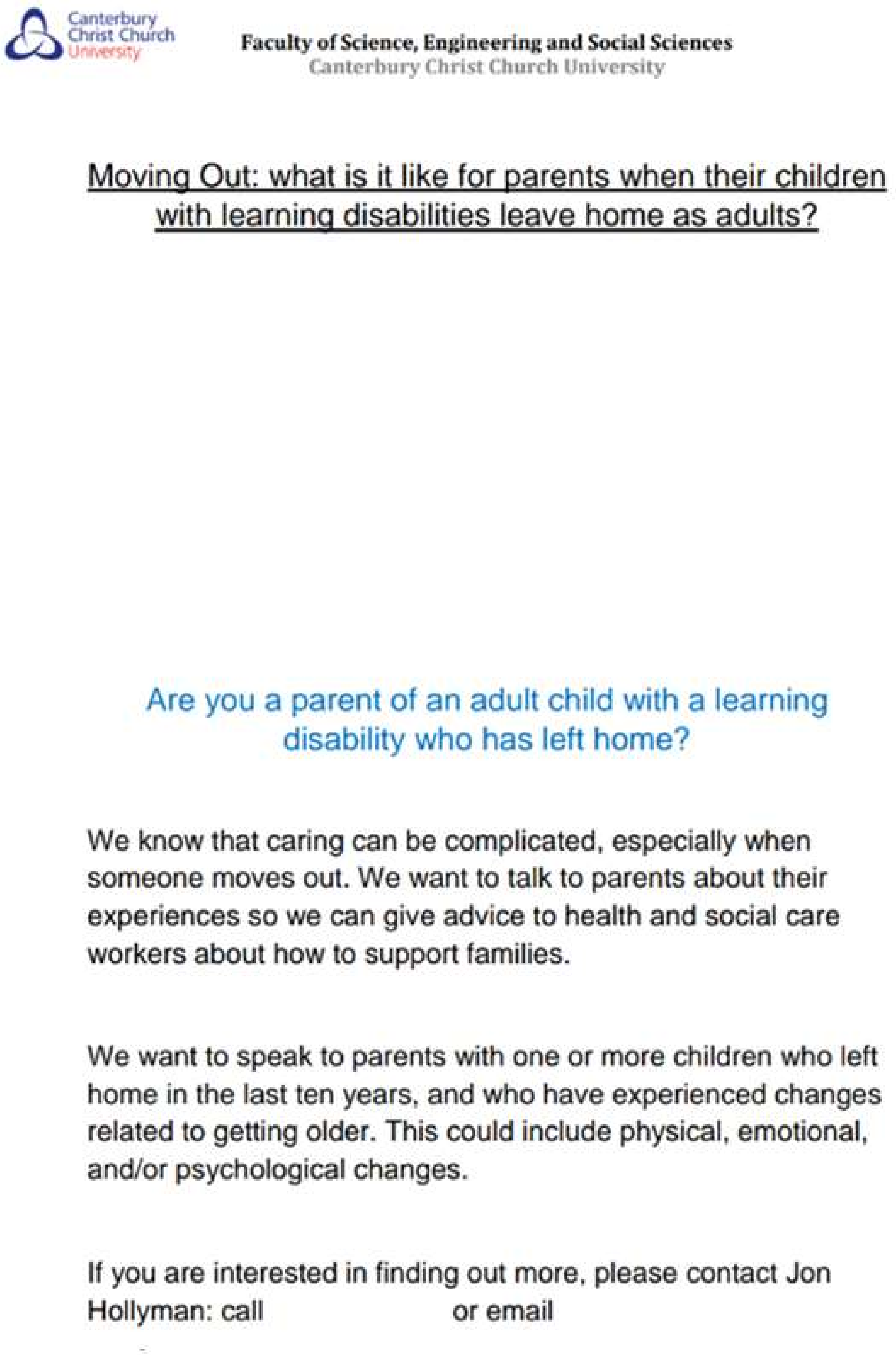
	Study	**Brennan et al. (2018)**	**Grey et al. (2015)**	**Alborz (2003)**	**Roos & Søndenaa (2020)**	**Vereijken et al. (2023)**	**Walker & Hutchinson (2019)**
MMAT questions (qualitative)	Is the qualitative approach appropriate to answer the research question?	Yes	Yes	Yes	Yes	Yes	Yes
	Are the qualitative data collection methods adequate to answer the research question?	Yes	Yes	Yes	Yes	Yes	Yes
	Are the findings adequately derived from the data?	Yes	Yes	Yes	Yes	Yes	Yes
	Is the interpretation of results sufficiently substantiated by data?	Yes	Yes	Yes	Yes	Yes	Yes
	Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes	Yes	Yes	Yes	Yes	Yes

	Study	**Taggart et al. (2012)**	**Bowey & McGlaughlin (2007)**	**Mansell & Wilson (2010)**	**Prosser (1997)**
MMAT questions (mixed methods)	Is there an adequate rationale for using a mixed methods design to address the research question?	Yes	Yes	Yes	Yes
	Are the different components of the study effectively	Yes	Yes	Yes	Yes

	integrated to answer the research question?				
	Are the outputs of the integration of the qualitative and quantitative components adequately interpreted?	No	Yes	Yes	Yes
	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Yes	Yes	Yes	Yes
	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Yes	No	Yes	No

	Study	**Grey et al. (2020)**
MMAT questions (quantitative - descriptive)	Is the sampling strategy relevant to address the research question?	Yes
	Is the sample representative of the target population?	Can't tell
	Are the measurements appropriate?	Yes
	Is the risk of non-response bias low?	No
	Is the statistical analysis appropriate to answer the research question?	Yes

Appendix 2: project poster



Canterbury Christ Church University

Faculty of Science, Engineering and Social Sciences
Canterbury Christ Church University

Moving Out: what is it like for parents when their children with learning disabilities leave home as adults?

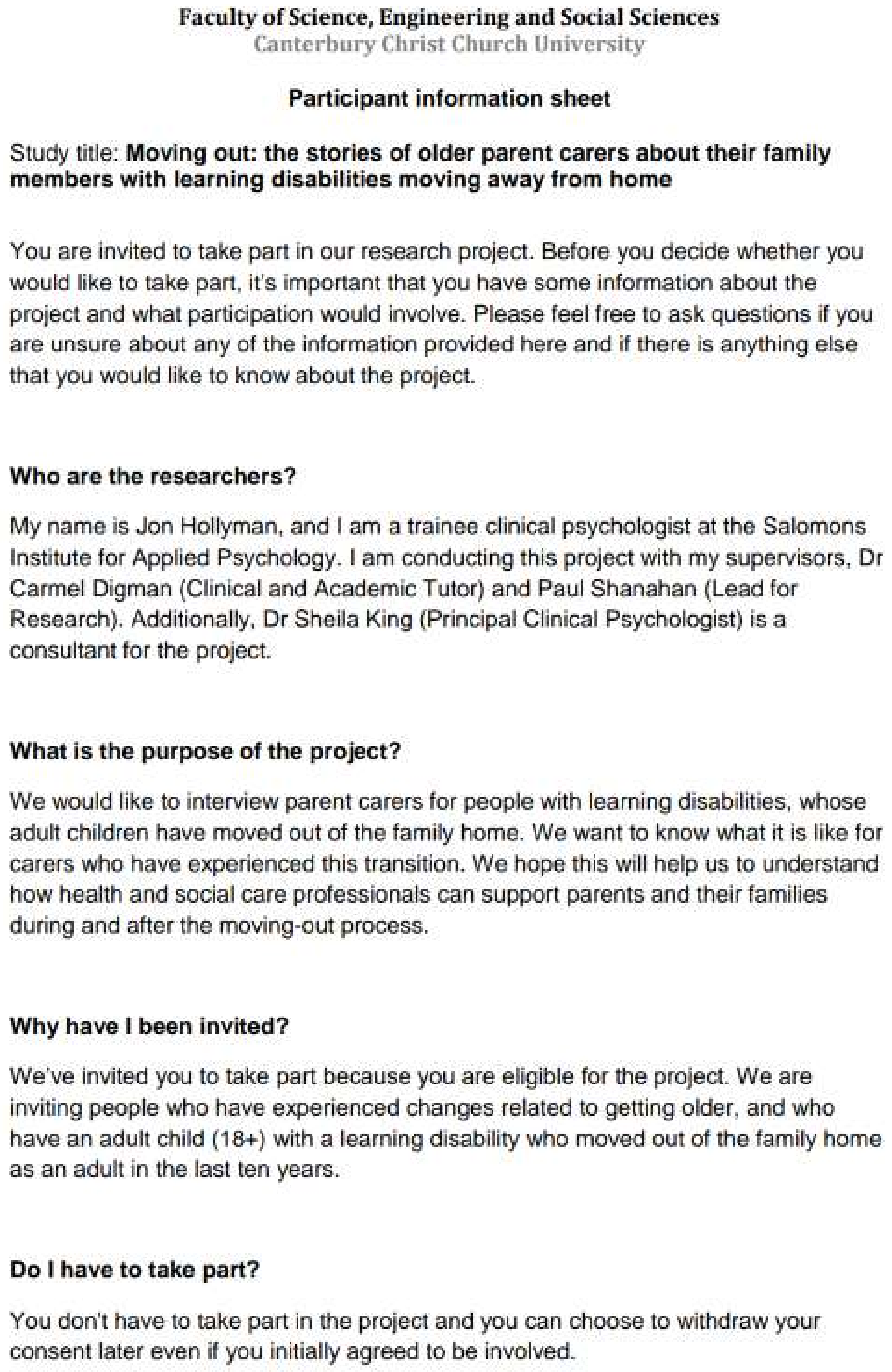
Are you a parent of an adult child with a learning disability who has left home?

We know that caring can be complicated, especially when someone moves out. We want to talk to parents about their experiences so we can give advice to health and social care workers about how to support families.

We want to speak to parents with one or more children who left home in the last ten years, and who have experienced changes related to getting older. This could include physical, emotional, and/or psychological changes.

If you are interested in finding out more, please contact Jon Hollyman: call or email

Appendix 3: information sheet



Faculty of Science, Engineering and Social Sciences
Canterbury Christ Church University

Participant information sheet

Study title: **Moving out: the stories of older parent carers about their family members with learning disabilities moving away from home**

You are invited to take part in our research project. Before you decide whether you would like to take part, it's important that you have some information about the project and what participation would involve. Please feel free to ask questions if you are unsure about any of the information provided here and if there is anything else that you would like to know about the project.

Who are the researchers?

My name is Jon Hollyman, and I am a trainee clinical psychologist at the Salomons Institute for Applied Psychology. I am conducting this project with my supervisors, Dr Carmel Digman (Clinical and Academic Tutor) and Paul Shanahan (Lead for Research). Additionally, Dr Sheila King (Principal Clinical Psychologist) is a consultant for the project.

What is the purpose of the project?

We would like to interview parent carers for people with learning disabilities, whose adult children have moved out of the family home. We want to know what it is like for carers who have experienced this transition. We hope this will help us to understand how health and social care professionals can support parents and their families during and after the moving-out process.

Why have I been invited?

We've invited you to take part because you are eligible for the project. We are inviting people who have experienced changes related to getting older, and who have an adult child (18+) with a learning disability who moved out of the family home as an adult in the last ten years.

Do I have to take part?

You don't have to take part in the project and you can choose to withdraw your consent later even if you initially agreed to be involved.

What will happen to me if I decide to take part?

I will arrange a one-off interview with you. I will ask you to tell us about being a carer and what happened when your child moved out. I can meet you at home, or if you would prefer we can hold the interview online or at another location: we can discuss this when we arrange the interview.

The interview will involve meeting with me and answering questions about your experiences. We're interested in your story of what happened and what it was like when your child left home, and I will ask you to tell that story.

The interview will last about an hour, with some additional time before and after the interview so you can ask questions and talk about anything difficult that came up. The interview will be audio recorded so that I can transcribe it later.

Are there any possible disadvantages or risks for taking part?

We understand that asking you to talk about being a carer might involve thinking about painful experiences. We know that it can be very difficult for parent carers when their children move away from home, and talking about these experiences is likely to be distressing. There is a risk that you might find the interview more distressing than you expect and that it could bring up memories that are very painful.

You can stop the interview at any time or take breaks if it becomes distressing. You don't have to answer a question if you would prefer not to. We will allow time for a debrief conversation at the end of the interview so you can talk more about anything that was difficult.

What are the possible benefits from taking part?

The project will inform health and social care professionals about what it is like for carers to have children with learning disabilities moving out as adults. We hope that professionals will be able to use this understanding to offer more, effective support to carers in similar situations in future.

Will my part in the project be confidential?

Yes, any information you give to us will be kept confidential. We may be required to break confidentiality and share information with your local safeguarding authority to protect people if we are concerned that someone is at risk of harm, but we will notify you before we do this. Each interview will be transcribed anonymously and all identifying information will be removed before the interview data is combined. Only my supervisors and I will listen to recordings and look at data. The interview recordings will be deleted when the transcription is completed.

Will I be reimbursed for taking part?

You will receive a payment of £15 for taking part in the project. We will also cover up to £10 in travel costs, depending on whether you need to travel to participate.

What will happen to my data?

Your interview data will be collected with interviews from other participants. We will summarise the interviews in our research paper and look for common experiences and ideas across the different participants. You can choose to withdraw your data until it has been anonymised and combined with data from other interviews, at which time it will no longer be possible to withdraw from the study. As a result, you can only withdraw your data from the project up to one week after your interview.

What happens at the end of the project?

We will produce a project report, which will be submitted to the University of Canterbury Christ Church as an academic piece of work. We also aim to publish the report as an article in a research journal. All information in the report will be anonymised and won't refer to specific people, places, or services.

How has the public been involved?

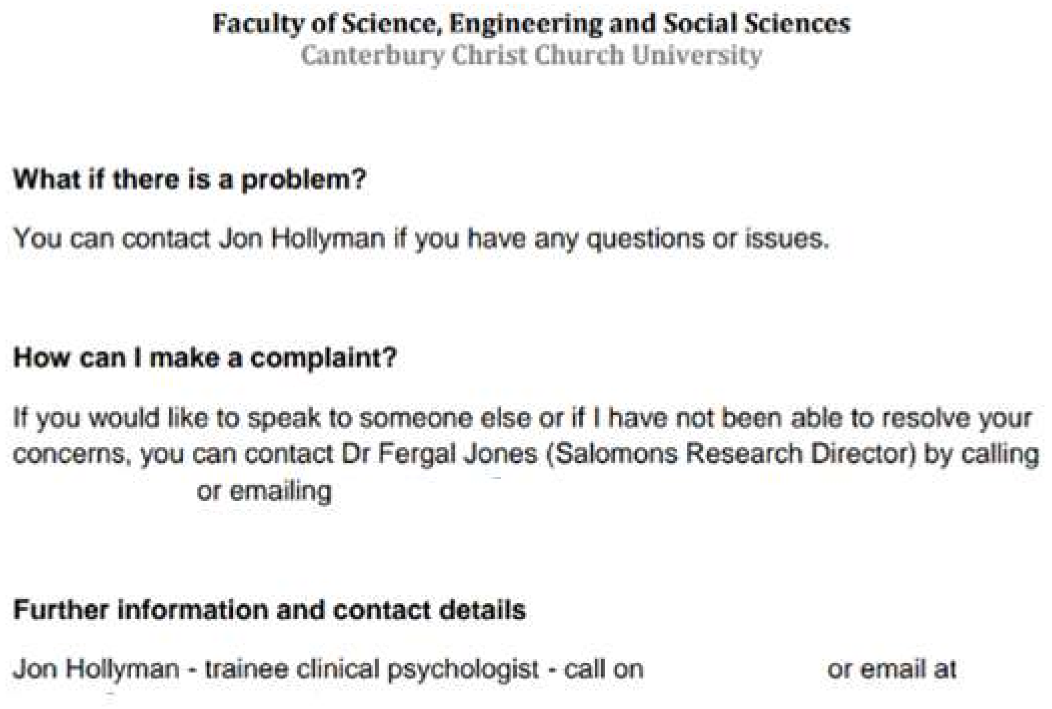
We consulted carers for our project. They gave us advice and some suggestions about what to ask in our interviews.

Who is organising and funding the project?

The project is being funded by Canterbury Christ Church University. It is my thesis project as one of the university's clinical psychology doctoral students.

Who has reviewed the project?

The Salomons Research Ethics Committee has reviewed the project for the university and has given its approval.



Faculty of Science, Engineering and Social Sciences
Canterbury Christ Church University

What if there is a problem?

You can contact Jon Hollyman if you have any questions or issues.

How can I make a complaint?

If you would like to speak to someone else or if I have not been able to resolve your concerns, you can contact Dr Fergal Jones (Salomons Research Director) by calling or emailing

Further information and contact details

Jon Hollyman - trainee clinical psychologist - call on or email at

Appendix 4: consent form

Consent Form

Study title: Moving out: the stories of older parent carers about their family members with learning disabilities moving away from home

Name of researcher:

Please initial each box

1. I confirm that I have read the information sheet for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time prior to data analysis being completed, without giving any reason and without my legal rights or care being affected.	
3. I agree to audio recording and the use of anonymised quotes in research reports and publications.	
4. I understand that, if they have concerns that someone may be at risk of harm, the interviewer may share information with appropriate safeguarding agencies (but will communicate this to me first when it is possible to do so)	

Name of participant Date Signature

Name of researcher Date Signature

Appendix 5: demographic form

Demographic questionnaire

1. What is your gender?

☐ Female
☐ Male
☐ Non-binary
☐ Other (please specify) ______________________________
☐ Prefer not to say

2. What is your age in years?

_____Years

3. What category best describes your ethnicity?

White
☐ White British
☐ White Irish
☐ White Gypsy/Irish Traveller
☐ Roma
☐ Other White ethnic background (please specify)______________________________

Black/African/Caribbean/Black British
☐ Black African
☐ Black Caribbean
☐ Black British
☐ Other Black ethnic background (please specify)______________________________

Mixed/multiple ethnic groups
☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Other Mixed/Multiple ethnicity (please specify)______________________________

Asian/Asian British
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Other Asian ethnic background (please specify)______________________________

Other
☐ Arab
☐ Other ethnic background (please specify)______________________________
☐ Prefer not to say

Appendix 6: interview schedule

Interview schedule

Reminder regarding confidentiality

We will anonymise your interview by taking out all information that could be used to identify anyone we discuss. My supervisors and I will be the only people to listen to the interview recordings and read transcripts. If I am concerned that you or someone else is at risk of harm then I will break confidentiality and contact an appropriate safeguarding agency – I will talk to you about this beforehand unless I think that doing so would increase the risk of harm.

You can ask for a break at any time and I will pause the recording – you can also withdraw from the interview. We will have some time after the interview to talk about how you are feeling.

Interview questions

- Tell me about what happened when your child moved out, starting from whatever point in time you choose and moving forward from that
- Please tell me about being a carer for your child

Prompts

- How do health and social care professionals feature in that story?
- What happened next?
- Can you recall anything else about that?
- What do you remember most about that time/event/experience?
- What were the reasons for your child moving out?
- Can you tell me about the impact of that on you and your family?

Appendix 7: letter of ethical approval

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Appendix 8: full transcript with coded table of annotations

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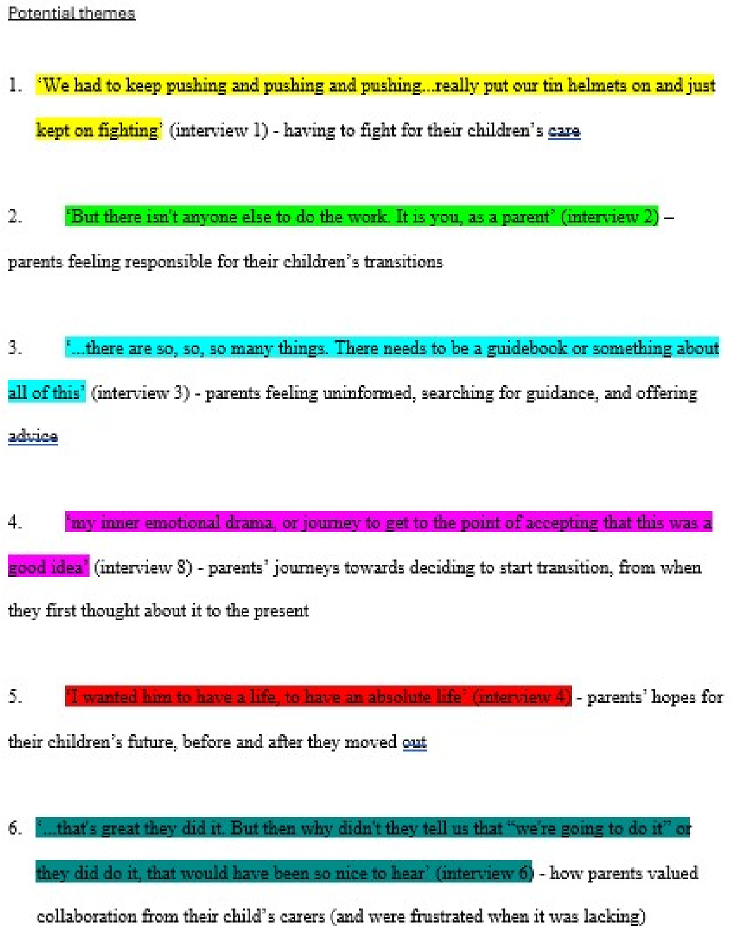


Potential themes

1. 'We had to keep pushing and pushing and pushing...really put our tin helmets on and just kept on fighting' (interview 1) - having to fight for their children's care

2. 'But there isn't anyone else to do the work. It is you, as a parent' (interview 2) – parents feeling responsible for their children's transitions

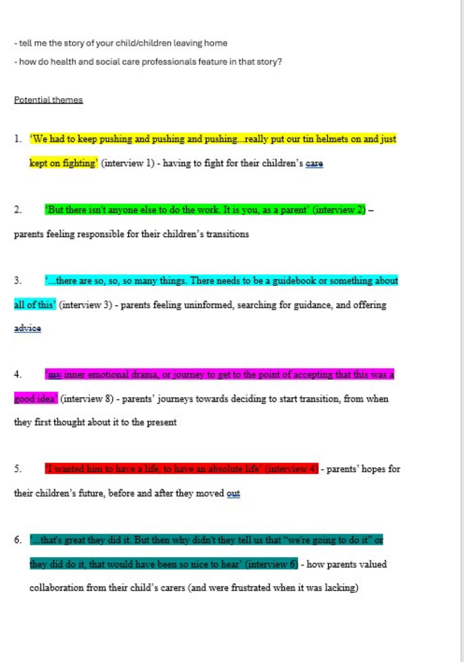
3. '...there are so, so, so many things. There needs to be a guidebook or something about all of this' (interview 3) - parents feeling uninformed, searching for guidance, and offering advice

4. 'my inner emotional drama, or journey to get to the point of accepting that this was a good idea' (interview 8) - parents' journeys towards deciding to start transition, from when they first thought about it to the present

5. 'I wanted him to have a life, to have an absolute life' (interview 4) - parents' hopes for their children's future, before and after they moved out

6. '...that's great they did it. But then why didn't they tell us that "we're going to do it" or they did do it, that would have been so nice to hear' (interview 6) - how parents valued collaboration from their child's carers (and were frustrated when it was lacking)

Appendix 9: developing themes



- tell me the story of your child/children leaving home
- how do health and social care professionals feature in that story?

Potential themes

1. 'We had to keep pushing and pushing and pushing...really put our tin helmets on and just kept on fighting' (interview 1) - having to fight for their children's care

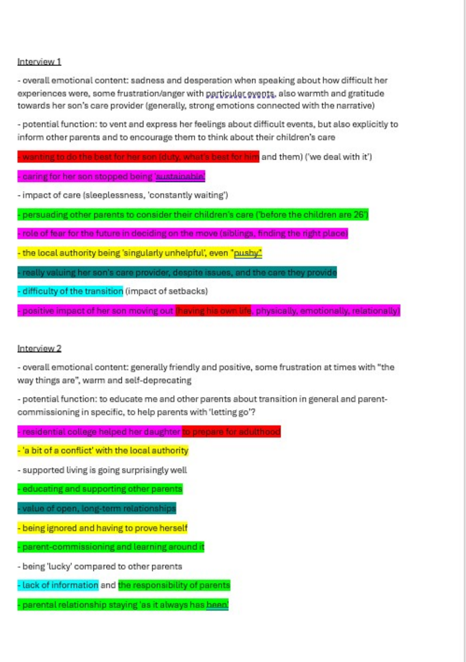
2. 'But there isn't anyone else to do the work. It is you, as a parent' (interview 2) – parents feeling responsible for their children's transitions

3. '...there are so, so, so many things. There needs to be a guidebook or something about all of this' (interview 3) - parents feeling uninformed, searching for guidance, and offering advice

4. 'my inner emotional drama, or journey to get to the point of accepting that this was a good idea' (interview 8) - parents' journeys towards deciding to start transition, from when they first thought about it to the present

5. 'I wanted him to have a life, to have an absolute life' (interview 4) - parents' hopes for their children's future, before and after they moved out

6. '...that's great they did it. But then why didn't they tell us that "we're going to do it" or they did do it, that would have been so nice to hear' (interview 6) - how parents valued collaboration from their child's carers (and were frustrated when it was lacking)

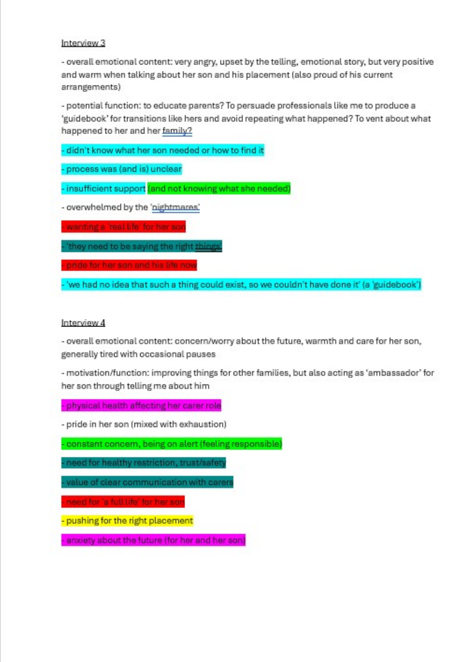


Interview 1

- overall emotional content: sadness and desperation when speaking about how difficult her experiences were, some frustration/anger with particular events, also warmth and gratitude towards her son's care provider (generally, strong emotions connected with the narrative)
- potential function: to vent and express her feelings about difficult events, but also explicitly to inform other parents and to encourage them to think about their children's care
- wanting to do the best for her son (duty, what's best for him and them) ('we deal with it')
- caring for her son stopped being 'sustainable'
- impact of care (sleeplessness, 'constantly waiting')
- persuading other parents to consider their children's care ('before the children are 26')
- role of fear for the future in deciding on the move (siblings, finding the right place)
- the local authority being 'singularly unhelpful', even "pushy"
- really valuing her son's care provider, despite issues, and the care they provide
- difficulty of the transition (impact of setbacks)
- positive impact of her son moving out (having his own life, physically, emotionally, relationally)

Interview 2

- overall emotional content: generally friendly and positive, some frustration at times with "the way things are", warm and self-deprecating
- potential function: to educate me and other parents about transition in general and parent-commissioning in specific, to help parents with 'letting go'?
- residential college helped her daughter to prepare for adulthood
- 'a bit of a conflict' with the local authority
- supported living is going surprisingly well
- educating and supporting other parents
- value of open, long-term relationships
- being ignored and having to prove herself
- parent-commissioning and learning around it
- being 'lucky' compared to other parents
- lack of information and the responsibility of parents
- parental relationship staying 'as it always has been'

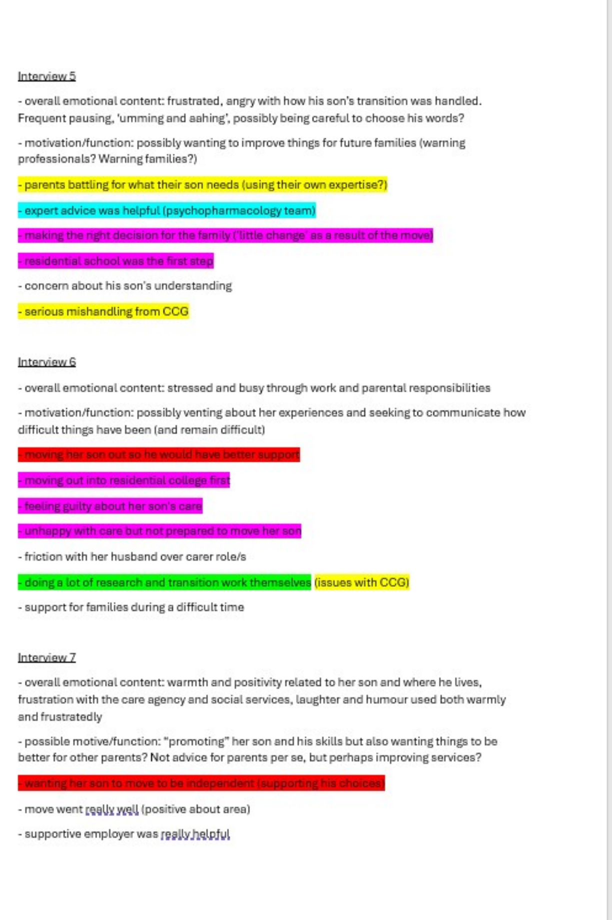


Interview 3

- overall emotional content: very angry, upset by the telling, emotional story, but very positive and warm when talking about her son and his placement (also proud of his current arrangements)
- potential function: to educate parents? To persuade professionals like me to produce a 'guidebook' for transitions like hers and avoid repeating what happened? To vent about what happened to her and her family?
- didn't know what her son needed or how to find it
- process was (and is) unclear
- insufficient support (and not knowing what she needed)
- overwhelmed by the 'nightmares'
- wanting a 'real life' for her son
- 'they need to be saying the right things'
- pride for her son and his life now
- 'we had no idea that such a thing could exist, so we couldn't have done it' (a 'guidebook')

Interview 4

- overall emotional content: concern/worry about the future, warmth and care for her son, generally tired with occasional pauses
- motivation/function: improving things for other families, but also acting as 'ambassador' for her son through telling me about him
- physical health affecting her carer role
- pride in her son (mixed with exhaustion)
- constant concern, being on alert (feeling responsible)
- need for healthy restriction, trust/safety
- value of clear communication with carers
- need for 'a full life' for her son
- pushing for the right placement
- anxiety about the future (for her and her son)



Interview 5

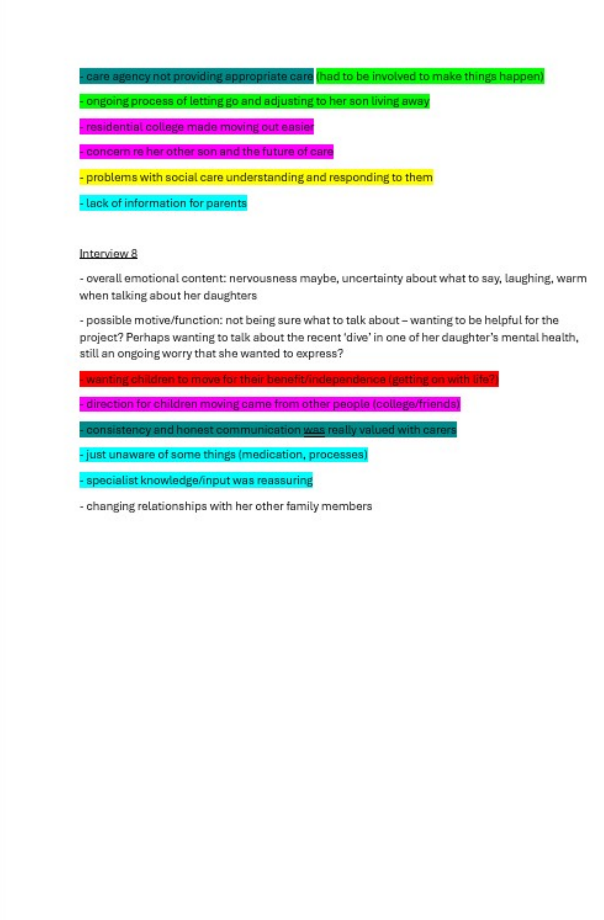
- overall emotional content: frustrated, angry with how his son's transition was handled. Frequent pausing, 'umming and aahing', possibly being careful to choose his words?
- motivation/function: possibly wanting to improve things for future families (warning professionals? Warning families?)
- parents battling for what their son needs (using their own expertise?)
- expert advice was helpful (psychopharmacology team)
- making the right decision for the family ('little change' as a result of the move)
- residential school was the first step
- concern about his son's understanding
- serious mishandling from CCG

Interview 6

- overall emotional content: stressed and busy through work and parental responsibilities
- motivation/function: possibly venting about her experiences and seeking to communicate how difficult things have been (and remain difficult)
- moving her son out so he would have better support
- moving out into residential college first
- feeling guilty about her son's care
- unhappy with care but not prepared to move her son
- friction with her husband over carer role/s
- doing a lot of research and transition work themselves (issues with CCG)
- support for families during a difficult time

Interview 7

- overall emotional content: warmth and positivity related to her son and where he lives, frustration with the care agency and social services, laughter and humour used both warmly and frustratedly
- possible motive/function: "promoting" her son and his skills but also wanting things to be better for other parents? Not advice for parents per se, but perhaps improving services?
- wanting her son to move to be independent (supporting his choices)
- move went really well (positive about area)
- supportive employer was really helpful



- care agency not providing appropriate care (had to be involved to make things happen)
- ongoing process of letting go and adjusting to her son living away
- residential college made moving out easier
- concern re her other son and the future of care
- problems with social care understanding and responding to them
- lack of information for parents

Interview 8

- overall emotional content: nervousness maybe, uncertainty about what to say, laughing, warm when talking about her daughters
- possible motive/function: not being sure what to talk about – wanting to be helpful for the project? Perhaps wanting to talk about the recent 'dive' in one of her daughter's mental health, still an ongoing worry that she wanted to express?
- wanting children to move for their benefit/independence (getting on with life?)
- direction for children moving came from other people (college/friends)
- consistency and honest communication was really valued with carers
- just unaware of some things (medication, processes)
- specialist knowledge/input was reassuring
- changing relationships with her other family members

Appendix 10: excerpts from research diary

This has been removed from the electronic copy

Appendix 11: feedback to ethics committee

Dear Salomons Institute for Applied Psychology Ethics Panel,

Thank you again for granting me ethical approval for my Major Research Project (MRP). I am pleased to report that my MRP has been completed. Here is a summary of my project: the report itself has been submitted for assessment.

Summary

People with intellectual disabilities (ID) often receive care from their parents, partly because parents worry about the quality of care that their children will receive elsewhere. Caring can be stressful, but parent carers sometimes continue to care for their children into old age, when they are more likely to experience physical and mental health problems. Transition from the family home can be particularly stressful for people with ID and their parents, and some older parents avoid thinking about or planning transition because they are worried about what will happen.

My project sought to understand more about older parent carers' experiences of their children moving out, as this is a group who have particular difficulties surrounding transition. I interviewed eight older parent carers about their experiences of what happened when their adult children with ID moved out of their family home. Interview transcripts were analysed using thematic narrative analysis to explore participants' narratives about transition, as well as the emotional tone and possible functions of those narratives.

Six themes were developed using thematic narrative analysis. Themes included: how the decision was made to start transition, having to fight for their children's care, feeling responsible for their children, feeling uninformed, hopes for their children's futures, and valuing collaboration from carers. The narratives were emotional, with parents frequently expressing anger, despair, and occasionally happiness and gratitude. Participants' narratives appeared to have a variety of functions, including educating parents and professionals as well as venting about negative transition experiences.

Overall, transition was a difficult and emotional process for participants, who frequently found professionals unhelpful and/or oppositional. Some participants did talk about worries about their age and their health as a motivating factor to start transition, but there were other factors involved as well. Further research could explore the narratives of older parent carers from different backgrounds, or interview participants defined as 'older parents' using age categories to see if they would have different stories about transition. Professionals could provide more information and support to parent carers and their children during transition to make it easier for them and reduce stress, as well as considering the different factors that might be affecting them and their decision to seek transition.

Take care,

Jon Hollyman

Trainee Clinical Psychologist

Appendix 12: author guideline notes for submission to the British Journal of Learning Disabilities

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publicataion elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

New submissions should be made via the Research Exchange submission portal https://wiley.atyponrex.com/journal/BLD. Should your manuscript proceed to the revision stage, you will be directed to make your revisions via the same submission portal. You may check the status of your submission at anytime by logging on to submission.wiley.com and clicking the “My Submissions” button. For technical help with the submission system, please review our FAQs or contact submissionhelp@wiley.com.

If you cannot submit online, please contact the Editorial Office by email: BLDedoffice@wiley.com

Free format submission

The *British Journal of Learning Disabilities* now offers Free Format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this should be an editable file including text, figures, and tables, or separate files—whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers, and the editorial office will send it back to you for revision. Your manuscript may also be sent back to you for revision if the quality of English language is poor.
- An ORCID ID, freely available at https://orcid.org. *(Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)*
- The title page of the manuscript, including:
    - Your co-author details, including affiliation and email address. *(Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)*
    - Statements relating to our ethics and integrity policies, which may include any of the following *(Why are these important? We need to uphold rigorous ethical standards for the research we consider for publication)*:
        - data availability statement

- funding statement
- conflict of interest disclosure
- ethics approval statement
- patient consent statement
- permission to reproduce material from other sources
- clinical trial registration

Important: the journal operates a double-blind peer review policy. Please anonymize your manuscript and supply a separate title page file.

To submit, login at https://wiley.atyponrex.com/journal/BLD and create a new submission. Follow the submission steps as required and submit the manuscript.

Data protection

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Preprint policy

Wiley believes that journals publishing for communities with established pre-print servers should allow authors to submit manuscripts which have already been made available on a non-commercial preprint server. Allowing submission does not, of course, guarantee that an article will be sent out for review. It simply reflects our belief that journals should not rule out reviewing a paper simply because it has already been available on a non-commercial server. Please see below for the specific policy language.

However, Wiley also knows that the use of preprint servers is not universally accepted and that individual journals and/or societies may approach submission of preprints differently.

This journal will consider for review articles previously available as preprints on non-commercial servers such as ArXiv, bioRxiv, psyArXiv, SocArXiv, engrXiv, etc. Authors may also post the submitted version of a manuscript to non-commercial servers at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

The *British Journal of Learning Disabilities* is an interdisciplinary international peer-reviewed journal that draws contributions from a wide community of international researchers. It encompasses contemporary debate/s and developments in research, policy and practice that are relevant to the field of learning disabilities. Learning disabilities here refers to intellectual (global) disabilities and not to specific learning disabilities like dyslexia. The scope includes:

- activism and advocacy
- communication, interaction and relationships
- community lives and quality of life
- education and employment
- families and advocacy
- health and wellbeing
- policy, law and rights
- profound and multiple learning disabilities/additional needs
- research methods and inclusive research
- social care and professional roles.

The journal publishes original papers, commissioned keynote reviews on major topics, and book/resource reviews with some Special Issues giving comprehensive coverage to specific subject areas. The editor welcomes suggestions of topics for future Special Issues.

The journal supports dialogue with people with learning disabilities. *In Response* pieces provide feedback on the issues arising in the journal papers and their relevance for the lives of people with learning disabilities and those supporting them.

The international audience for *British Journal of Learning Disabilities* includes academics, professionals, practitioners, families and people with a personal and professional interest in learning disability. Authors are expected to consider this wide readership, to communicate in an accessible manner, and to exhibit knowledge of previously-published articles when submitting their work for consideration for publication. Careful attention to respectful terminology and ethical treatment is essential. You can see the journal’s position on ethics here.

The *British Journal of Learning Disabilities* is the official journal of the British Institute of Learning Disabilities. The opinions expressed in articles, whether editorials or otherwise, do not necessarily represent the official view of the British Institute of Learning Disabilities and the Institute accepts no responsibility for the quality of goods or services advertised.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

- All Manuscripts submitted to *British Journal of Learning Disabilities* should include: Accessible Summary, Keywords, Abstract, Main Text (divide by appropriate sub headings) and References.
- Manuscripts should not be more than 7,000 words in length including references.

4. PREPARING THE SUBMISSION

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures.

Title page

The title page should contain:
i. A short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);
ii. A short running title of less than 40 characters;
iii. The full names of the authors;
iv. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
v. Acknowledgments.

Abstract and Accessible Summary

Papers should include a structured abstract (maximum 200 words) incorporating the following headings: Background, Methods, Findings, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. As well as an abstract, authors must include an easy-to-read summary of their papers. This was introduced in 2005, and was done so in the spirit of making research findings more accessible to people with learning disabilities. The editorial board also believe that this will make 'scanning' the Journal contents easier for all readers. Authors are required to:

- Summarise the content of their paper using bullet points (4 or 5 at most),
- Express their ideas in this summary using straightforward language, and
- State simply why the research is important, and should matter to people with learning disabilities.

Authorship

Please refer to the journal's authorship policy the Editorial Policies and Ethical Considerations section for details on eligibility for author listing.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement

Authors will be asked to provide a conflict of interest statement during the submission process. For details on what to include in this section, see the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section below. Submitting authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

Main Text File

As papers are double-blind peer reviewed the main text file should not include any information that might identify the authors.

Manuscripts can be uploaded either as a single document (containing the main text, tables and figures), or with figures and tables provided as separate files. Should your manuscript reach revision stage, figures and tables must be provided as separate files. The main manuscript file can be submitted in Microsoft Word (.doc or .docx).

Your main document file should include:

- A short informative title containing the major key words. The title should not contain abbreviations
- The full names of the authors with institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
- Acknowledgments;
- Abstract structured (Background, Methods, Findings, Conclusions)
- Keywords;
- Main body;
- References;
- Tables (each table complete with title and footnotes);
- Figures: Figure legends must be added beneath each individual image during upload AND as a complete list in the text.

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Color Figures. Figures submitted in color may be reproduced in colour free of charge. Please note, however, that it is preferable that line figures (e.g. graphs and charts) are supplied in black and white so that they are legible if printed by a reader in black and white.

Data Citation

In recognition of the significance of data as an output of research effort, Wiley has endorsed the FORCE11 Data Citation Principles and is implementing a mandatory data citation policy. Wiley journals require data to be cited in the same way as article, book, and web citations and authors are required to include data citations as part of their reference list. Data citation is appropriate for data held within institutional, subject focused, or more general data repositories. It is not intended to take the place of community standards such as in-line citation of GenBank accession codes. When citing or making claims based on data, authors must refer to the data at the relevant place in the manuscript text and in addition provide a formal citation in the reference list. We recommend the format proposed by the Joint Declaration of Data Citation Principles:

[dataset] Authors; Year; Dataset title; Data repository or archive; Version (if any); Persistent identifier (e.g. DOI)

References

This journal uses the *Publication Manual of the American Psychological Association* (6th edition) reference style; as the journal offers Free Format submission, however, this is for information only and you do not need to format the references in your article. This will instead be taken care of by the typesetter.

Additional Files

Appendices

Appendices will be published after the references. For submission they should be supplied as separate files but referred to in the text.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

Click here for Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

The following points provide general advice on formatting and style.

- **Abbreviations:** All symbols and abbreviations should be clearly explained. Abbreviations should not be used when they refer to people (e.g. learning disabilities, not LD; developmental disabilities, not DD; intellectual disabilities, not ID)
- Please also use "people with learning disabilities" wherever possible, not "learning disabled people".
- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
- **Trade Names:** Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name and the name and location of the manufacturer in parentheses.

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