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## ORIGINAL ARTICLE OPEN ACCESS

# Transitions-Related Support for Ageing Family Carers of Older People With Intellectual Disabilities Who Convey Behaviours That Challenge Others: A Systematic Rapid Scoping Review

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## ABSTRACT

**Background:** There are increasing numbers of ageing family carers of older (40+) adults with intellectual disabilities who convey behaviours that challenge others in the UK. It is important to understand the needs and experiences of these carers as they support their older family member to transition to different care contexts.

**Method:** A rapid scoping review of published and unpublished literature, using systematic methods of data searching, extraction and analysis.

**Results:** Exhaustion, reluctance to burden others, distrust of alternative living arrangements and deep interpersonal ties with their family member with intellectual disabilities mean ageing carers can avoid planning ahead. There is a lack of appropriate information, support and professional advice available. Developing trust in services is critical, as is a 'whole family' approach to planning.

**Conclusions:** More research is vital to understand the support ageing carers receive to make choices, and how it meets their needs.

## 1 | Introduction

In line with an overall United Kingdom (UK) ageing population (Office of National Statistics (ONS) 2021) people with intellectual disabilities are living longer. While in the UK and internationally people with intellectual disabilities continue to die prematurely—on average between 12 and 23 years earlier than the general population—(O'Leary, Cooper, and Hughes-McCormack 2017; Tyrer, Kiani, and Rutherford 2021; White et al. 2022), the overall picture is one of an ageing population. In England, an estimated 53% of the total population of people

with intellectual disabilities were aged 45+ in 2020 (almost 5% aged 85+), a figure which is predicted to rise to 56% by 2040 (almost 7.5% aged 85+) (Institute of Public Care (IPC) 2020). Increased longevity is a key contributory factor in the predicted rise in older people with intellectual disabilities requiring social care services in England over the period 2012–2030 (Emerson et al. 2012). While directly comparable figures are not available for Scotland, Wales and Northern Ireland, people with intellectual disabilities across the UK are living longer, mirroring wider international trends (Ahlström et al. 2022; Dieckmann, Giovis, and Offergeld 2015; McCarron et al. 2011; Tilley et al. 2023).

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These figures are likely to underestimate the true scale of need as many people with intellectual disabilities are not known to health or social services (Public Health England 2016; National Institute for Care and Excellence (NICE) 2018a) and the known proportion falls as people age (Emerson, Robertson, Coles, and Hatton 2012).

Around 20% of adults with intellectual disabilities convey behaviours that challenge others (Bowring et al. 2017; Jones et al. 2008; Lundqvist 2013), typically described as involving varying degrees of aggression, and being (self) destructive and/or (self) injurious (Griffiths and Hastings 2014; Waite et al. 2017). They are variously described as a form of communication, an indication of distress, a means of producing sensory stimulation and/or an attempt to seek help (Baker and Osgood 2019; NICE 2015; The Challenging Behaviour Foundation 2021a). Behaviours that challenge others is often deployed in research and services as a 'catch all' term, covering a wide range of individual behaviours. It has been argued that this lack of specificity can make it difficult to assess the efficacy of interventions to improve people's quality of life (Groves et al. 2023). There is limited evidence concerning the epidemiology of these behaviours amongst older people with intellectual disabilities (Davies and Oliver 2013). While some studies indicate a decline with advancing age (Holden and Gitlesen 2006; Jones et al. 2008; Murphy et al. 2005), others demonstrate the persistence of relatively high levels (Lundqvist 2013; O'Dwyer et al. 2018; Taylor, Oliver, and Murphy 2011).

Two-thirds of adults with intellectual disabilities in England live with their families, in most cases having been cared for by their parents from birth through to older age (Emerson et al. 2012; Foundation for People with Learning Disabilities. 2010; NICE 2018b). As people with intellectual disabilities are living longer, family carers are now routinely providing care as they also age (Forrester-Jones 2021; Pryce et al. 2017; Ryan et al. 2014). Figures suggest that at least 40% of adults with intellectual disabilities in England live with a parent aged 60 and over, and over 30% with a parent aged 70+ (NICE 2018b; Digital 2022). As many older people with intellectual disabilities in the UK are not known to services (NICE 2018b) these figures are likely to be underestimations. However, they do underscore the fact that day-to-day caregiving by family members can now span many decades (Mulvany, Barron, and McConkey 2007; Public Health England 2016; Ryan et al. 2014).

Alongside the satisfaction and intrinsic benefits of caring, research has consistently demonstrated multiple dimensions of burden amongst family carers (Ray, Bernard, and Phillips 2009; Milne and Larkin 2023). For carers of a family member with an intellectual disability these encompass physical and psychological ill-health (Aksamit and Wehmeyer 2021; Grey, Totsika, and Hastings 2018; Gutowska 2022; Totsika, Hastings, and Vagenas 2017); social and economic disadvantage (Public Health England 2016; Totsika, Hastings, and Vagenas 2017) and diminished quality of life (Jenaro et al. 2020; Yoong and Koritas 2012). As family caregivers age and their health may decline, the toll of caring is accompanied by increasing worry about what the future holds for themselves and their adult child (Baumbusch et al. 2017; Forrester-Jones 2021; Mahon et al. 2019). In this context, the particular stresses associated

with caring for an adult who conveys behaviours that challenge others have been highlighted. These include the physical impact of aggression, the burden of chronic emotional distress on well-being, and elevated levels of social isolation (Cooke, Noone, and Thomson 2019; Griffiths and Hastings 2014; Waite et al. 2017). The latter is explicitly linked to carer reluctance to take their family member out of the family home because of fear of an occurrence of a challenging behaviour episode (Waite et al. 2017). In combination with insufficient and unreliable support services for the person for whom they care and themselves (Griffiths and Hastings 2014), such stresses lead to a high proportion of these family carers experiencing anxiety and depression at clinically significant levels (Waite et al. 2017). Although stress and burden are characteristic, evidence demonstrates the profound fulfilment and sense of identity and self-worth carers of a family member with an intellectual disability can derive from their role (Mahon et al. 2019; Pryce et al. 2017; Walker and Hutchinson 2018).

Family carers can find the transition of their family member to other accommodation extremely challenging. This is the case whether the transition is out of the family home or between external care settings. Irrespective of the setting, lack of confidence in available accommodation and associated care alternatives can leave carers reluctant to countenance change (Barron, McConkey, and Mulvany 2006; Gilbert, Lankshear, and Petersen 2008; Nankervis, Rosewarne, and Vassos 2011). For carers of family members living at home, avoidance of emotive and complex consideration of their family member moving out are well documented (Cairns et al. 2013; Gilbert, Lankshear, and Petersen 2008; Taggart et al. 2012). Strong emotional bonds (Brennan et al. 2020) and the growing reciprocal nature of their relationship (Ryan et al. 2014; Taggart et al. 2012) as family carers age, their health declines, and they become dependent on the family member with an intellectual disability for care and support (Knox and Bigby 2007; Truesdale et al. 2021; Walker and Hutchinson 2018) contribute to both carers and their family member striving to maintain home residence (Brennan et al. 2020). Transition is further complicated by a care system that is complex to navigate, a lack of contingency planning by local councils and cuts to services (Sense 2018). Nonetheless, studies have shown that family carers can and do actively consider transition (Lee and Burke 2020; Walker and Hutchinson 2018) and can be encouraged to do so with appropriate support (Brennan et al. 2020; Carers Trust 2020; Lee and Burke 2020).

Although an evidence base on how best to support family carers in relation to their adult family member's transition to another setting is beginning to emerge (Brennan et al. 2020; Carers Trust 2020; Mahon et al. 2019), it tends to concentrate on the making of plans, to the detriment of other aspects of the move, such as activity over the long term that can work to facilitate effective transition. Such activity might include, for example, preparing their adult family member for greater independence or being able to ensure that their adult child's health and social care needs are appropriately addressed to help avoid crisis situations. In addition, the particular circumstances and needs of ageing family carers are not explicitly addressed.

To address this evidence gap, we reviewed the evidence on the health and social care experiences, service interventions and

resources to support ageing family carers of older adults with intellectual disabilities who convey behaviours that challenge others in the context of the latter's transition between contexts of care.<sup>1</sup> Given the involvement of carers in the lives of their family members irrespective of where they reside (Larkin and Milne 2021), we were interested in transitions from the family home, as well as from other care settings. This UK focused review was nested within a wider project which aimed to improve support for family carers and older people with intellectual disabilities who convey behaviours that challenge others. In line with the wider project, we define 'older' adults with intellectual disabilities as aged 40+. Likewise, mirroring the wider project, in this paper we use the phrase 'behaviours that challenge others' as a means of acknowledging their inherently relational and socially constructed nature (Baker and Osgood 2019; Mansell 2007; Hassiotis 2023). As such, they are a product of environmental factors (e.g., the response of professional carers; the quality of the material environment; how well a service is organised; the quality of commissioning processes) and individual characteristics (e.g., the presence of sensory disabilities or mental health issues; the onset of new conditions such as dementia) and, events in a person's life history (Mansell 2007; Board 2021). While UK policy and guidance since the 1990s has stressed the socially constructed nature of 'challenging behaviour', in some contexts the term continues to be used to label people (Randell et al. 2017). Such use can be driven by a need to serve agendas other than improving a person's care or outcomes, such as to enhance the legitimacy of a service, justify service practices, or empower management decisions (Haydon-Laurelut and Nunkoosing 2016).

Use of the term 'learning disability' is standard in the UK (Malli et al. 2018; Truesdale and Brown 2017), where the authors are based. However, in line with international usage, we use the term 'intellectual disability' in this paper (British Institute of Learning Disabilities (BILD) 2011; Grey, Totsika, and Hastings 2018). The World Health Organisation (WHO) (2012) defines intellectual disability as: '[a] significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development' (WHO 2012).

## 2 | Methods

Given that we were seeking a broad range of evidence, we undertook a scoping review to systematically synthesise evidence from diverse sources according to its nature, features and findings/outcomes (Peters et al. 2015). As the review constituted the early stage of a broader study, we utilised a rapid review methodology (Tricco, Langlois, and Straus 2017). Rapid reviews are a pragmatic and robust approach to evidence generation (Langlois et al. 2019; Pluddemann et al. 2018). Table 1 details our approach.<sup>2</sup>

### 2.1 | Review Question and Objectives

#### 2.1.1 | Research Question

What are the health and social care needs, experiences, service interventions and resources of and for family carers<sup>3</sup> of older people with intellectual disabilities who convey behaviours that challenge others as they move to different care contexts<sup>4</sup> in the UK?

#### 2.1.2 | Research Objectives

1. Identify relevant UK evidence according to key features such as: nature, focus, content, target population, design, methodology and findings/outcomes.
2. Systematically integrate the research evidence on health and social care needs, experiences, service interventions and resources relating to the family carers of older people with intellectual disabilities who convey behaviours that challenge others, as they transition to different care contexts.
3. Use the learning delivered by (2) to consider the status of transition-related care and support for family carers of older people with intellectual disabilities who convey behaviours that challenge others, drawing out implications for how this care and support might be most effectively planned and undertaken to fit with their needs and preferences.

TABLE 1 | Approach to rapid scoping review.

| Component                                    | Guidance/reporting guidelines used   |
|--|--|
| Scoping review                               | Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al. 2018).  |
| Rapid review                                 | SelecTing Approaches for Rapid Reviews (STARR) (Pandor et al. 2019) decision tool to help make broad decisions concerning the overall review process. The Oxford Centre for Evidence Based Medicine (Pluddemann et al. 2018) and the World Health Organisation (WHO) (Tricco et al. 2018) to help make decisions concerning specific methods/techniques. |
| Consultation underpinning the overall review | Throughout the review we consulted with our expert advisory group, which included people with intellectual disabilities, family carers, health and social care professionals, policy-makers, commissioners and service providers. The group contributed ideas, discussed ongoing findings, and helped to ensure clarity and relevance of analysis.       |

## 2.2 | Eligibility Criteria

We included published and unpublished (grey) literature, including research articles, reports and guidance. Within the published research we included primary (using quantitative, qualitative and mixed methods) and secondary (e.g., review) level evidence. To enhance the relevance of our review findings, we included evidence made available after 2001, to coincide with the publication of the Government's *Valuing People* White Paper for England and Wales (Department of Health 2001) and *The Same As You*, the Scottish Government's review of intellectual disability supports and services in Scotland (Scottish Executive 2000). *Valuing People* and *The Same as You*, consolidated a decade later in *The Keys to Life* (Scottish Government 2013), included an explicit focus on the needs of older people with intellectual disabilities, people who convey behaviours that challenge others, and their family carers. *Valuing People*, *The Same as You* and *The Keys to Life* were government strategies that informed policy, practice, commissioning and funding arrangements for people with intellectual disabilities and their families across the UK, thus providing the foundation for much research that subsequently followed.

Using the Population, Concepts and Context (PCC) framework (Peters et al. 2020), our inclusion criteria were:

- Published/made available in English after 2001
- Concerned with family carers of older (40+) <sup>5</sup> adults with intellectual disabilities who convey behaviours that challenge others resident in the UK
- Concerned with the health and social care needs, experiences, service interventions and resources of and for these carers as their family member with an intellectual disability who conveys behaviour that challenges others transitions from one context of care to another, for example:
  - From family care to service care;
  - From one context of service care to another (e.g., supported living to residential/nursing home care);
  - From one context of family care (e.g., parent-led) to another (e.g., sibling-led).

We excluded discussion papers, position papers, expert opinion pieces, editorials and study protocols, as we were interested in the nature of and findings of evidence, which could be used to draw conclusions regarding our phenomena of interest.

## 2.3 | Information Sources

The development of search strategies and database searches were undertaken with the support of a subject specialist librarian. An initial set of potential databases were reviewed using 'Healthcare Databases Advanced Search' (part of NHS Evidence), as a means of determining those (academic and grey literature) most likely to yield relevant evidence. We then identified and searched the following priority electronic databases: Carer Research Knowledge Exchange Network (CAREN); CINAHL; Healthcare Management Information Consortium

(HMIC); NHS Evidence; Social Care Institute for Excellence (SCIE); Scopus; Turning Evidence Into Practice (TRIP); Web of Science (WoS); Google (first 5 pages); and, Google Scholar (first 5 pages).

We generated search terms (words and phrases, including synonyms and terminology variations), combined using the Boolean operators 'and/or' and appropriate truncation and phrase symbols to form initial search strategies, which we piloted against selected key databases. Using the insights gained concerning the sensitivity and specificity of our terms, we confirmed our final search strategies to be used for each database, as well as the Google search strings, limited by file type (PDF) (Appendix S1). As initial database searching was completed in December 2020, we ran an updated search (12 June 2023), based on the original search strategies, <sup>6</sup> limited from 1 January 2020-current (Appendix S2). In addition, we used the expertise of the research team and project advisory group to identify other potentially relevant evidence. Finally, we undertook an ancestry search by hand searching the reference lists of all included evidence, as well as those of key papers (e.g., systematic reviews), to identify other potentially relevant evidence. These sources of evidence are included in the PRISMA Flow diagram under 'records identified through other sources'.

## 2.4 | Selection of Sources of Evidence

We imported the electronic search datasets into Excel; duplicate records were removed before initial screening. All records were independently screened by four members of the research team using titles and abstracts (where available) against the inclusion criteria. Discrepancies were discussed between relevant team members, and a final decision reached. This process enabled the exclusion of evidence that clearly did not meet the inclusion criteria and identified evidence for full text review.

Full text copies were obtained, and independently read by four members of the research team. To reduce the potential for bias and to promote transparency and consistency, a standardised tool to aid decision-making was used (Appendix S3). Discrepancies were discussed and a final decision reached. Evidence excluded on the basis of full text review was recorded, including the reasons for exclusion. In cases where evidence was not immediately available, we attempted to source it using various means (e.g., contacting relevant authors). Given time constraints, if not available within a one-month period, evidence was recorded as 'missing'.

## 2.5 | Data Extraction

A data extraction form was developed, piloted on three sources of evidence selected to ensure variation in focus and content, and a final version (Appendix S4) used to extract data from included evidence. Data extraction was led by one author; all completed forms were shared amongst the research team as a means of checking for gaps and inconsistencies.

## 2.6 | Critical Appraisal of Individual Sources of Evidence

The conduct of critical (quality) appraisal in scoping and rapid reviews is generally considered optional (Peters et al. 2020; Stevens et al. 2018; Tricco, Langlois, and Straus 2017). For scoping reviews, the central issue is inclusion of many types of evidence (Peters et al. 2020) and for rapid reviews it concerns the nature of the evidence and time available (Langlois et al. 2019). Given the variety in included evidence and the project time-plan, we took a pragmatic decision not to undertake critical appraisal. We were also cognisant of more fundamental issues relating to the paucity of evidence in this field, and the consequent need to capture this evidence not only for what it suggested regarding our population and focus of interest, but also the implications for future research (Dixon-Woods et al. 2004). We did consider how included papers framed the concept ‘behaviours that challenge others’ and the extent to which the research took a critical stance towards this concept. In particular, we were alert to papers that presented a medicalised perspective on behaviours that challenge others, and considered how this may have impacted upon the findings presented.

## 2.7 | Synthesis of Findings

Alongside primary and secondary empirical research findings, evidence included non-research case studies, and resources providing information and guidance relevant to family carers of older (40+) people with intellectual disabilities who convey behaviours that challenge others. Such diversity necessitated a flexible approach to bringing together the evidence in its entirety.

We identified patterns and trends in the volume, focus and content of included evidence. The *findings of* included evidence were integrated using a narrative approach (Popay et al. 2006; Ryan, 2013). An iterative process of reviewing the entirety of the research evidence allowed us to identify patterns in what the evidence was suggesting, however derived and expressed. The aim was to achieve new conceptual understanding based on original (author) findings, which we generated using a dual deductive and inductive process. Deductively, we took the focus of the review—transitions—as our point of entry into the data, using the question ‘What does this evidence mean for carers of older people with intellectual disabilities who convey behaviours that challenge others?’. Inductively, we interrogated the data for what they were suggesting in relation to our guiding question, using a three stage process: (a) initial coding of sections of the data according to their essential meaning; (b) comparing the content and meaning of these sections to identify how they clustered or connected in terms of common meaning; (c) and, expressing this meaning through the development of overarching themes and attendant content.

Analysis was led by one member of the research team. To promote rigour, ongoing drafts were shared with the wider review team, who provided feedback on fit with the original data, as well as overall sense and insight provided. Drafts were also shared with our project advisory group (which included people

with intellectual disabilities, family members and professionals), enabling the analysis to benefit from the input of a range of expert knowledge and understandings.

## 3 | Results

### 3.1 | Search Results

Our initial database searches yielded 157 returns, of which 110 were excluded on initial screening (using titles/abstracts). Of the remaining 47 read in full, 46 were excluded and one was included. A total of 40 items of evidence were identified by the research team and/or our advisory group, all of which were read in full. Of these, four were included. A total of 35 returns were identified from the reference lists of database included articles, all of which were read in full. Of these, one article was included. Our follow-up database searches yielded 242 returns, of which 238 were excluded on initial screening. The remaining four were read in full, and all excluded. No items of evidence were identified by the research team/advisory group during the follow-up search. Therefore, a total of six items of evidence were included in our review (Figure 1).

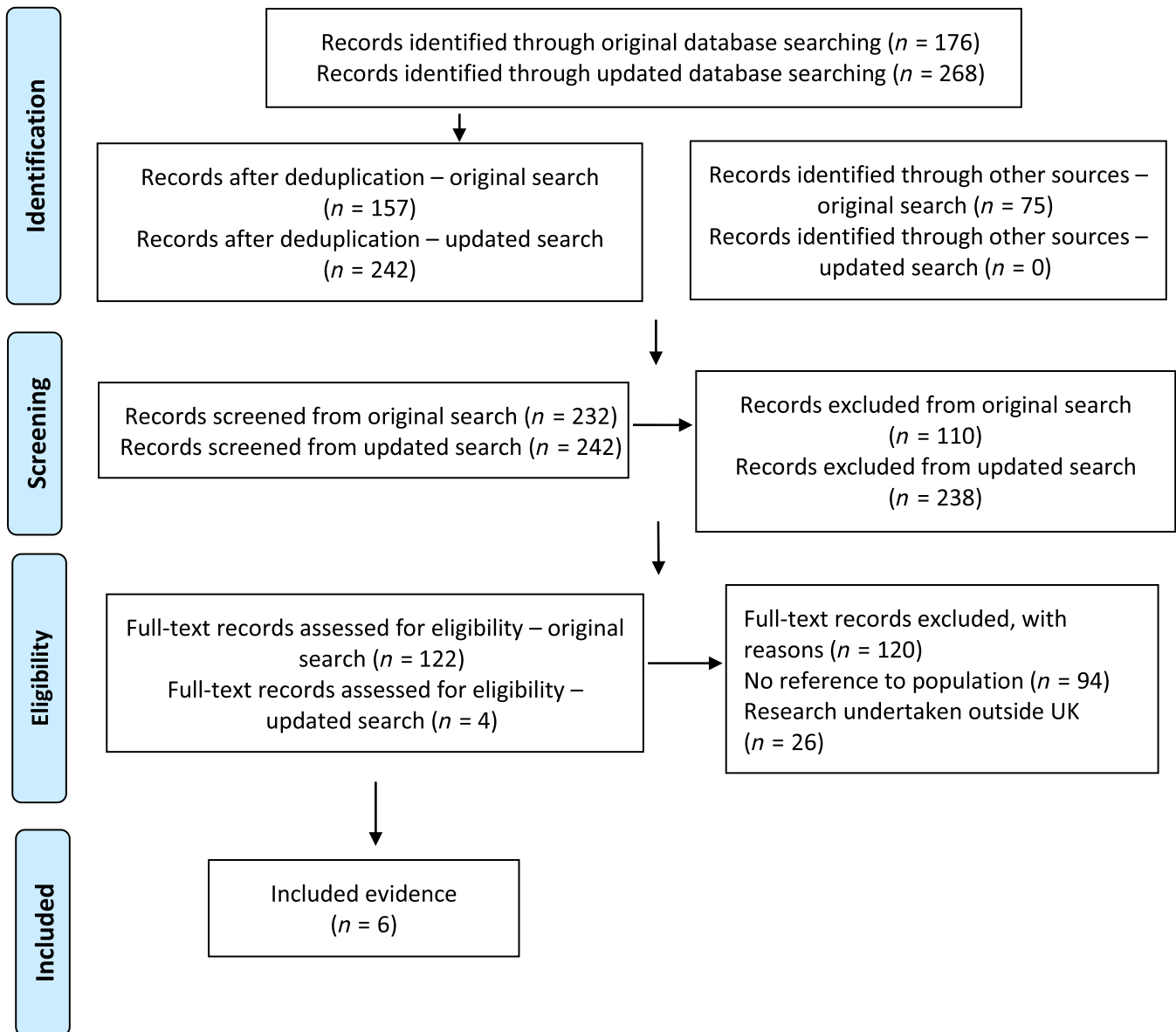
### 3.2 | Study Characteristics

We found no evidence specifically addressing our population of interest in the context of transition. Two empirical papers focused on ageing carers of adults with intellectual disabilities who do *and* do not convey behaviours that challenge others (Black and McKendrick 2010; Forrester-Jones 2019). Another review focused on adults and children with intellectual disabilities who convey behaviours that challenge others and their caregivers and, separately, on older people with intellectual disabilities and their caregivers (Slevin et al. 2011). The remainder of our included evidence constituted guides or toolkits, all of which addressed the population of people with intellectual disabilities and their caregivers in its broadest sense (Sense 2018; The Housing and Support Partnership 2011; Towers 2015). Table 2 summarises the characteristics of included evidence.

The key themes and sub-themes that emerged from the research evidence and the identified transition-related resources for family carers of older people with intellectual disabilities who convey behaviours that challenge others are summarised in Table 3. Each theme is discussed below.

### 3.3 | Supporting Ageing Family Carers of Adults With Intellectual Disabilities Who Convey Behaviours That Challenge Others

Ageing family carers are attempting to care at a point in their lives when their own and their partners' health is declining, they may be experiencing profound mental and physical exhaustion because of the cumulative effects of years of caring and are likely to have lost at least some of their family and wider social support network (Black and McKendrick 2010; Forrester-Jones 2019; Slevin et al. 2011). All of these issues are



\* From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

**FIGURE 1** | Search flow chart.

Source: Moher et al. (2009).

set against a backdrop of a reduction in the source of informal support that has traditionally helped parental carers, namely other children, due to a declining birth rate since the 1950s (Slevin et al. 2011). The following two sub-sections address the range of issues that emerged from the evidence concerning the longer-term or ‘upstream’ transition-related support of family carers, including lessons for how this support can be provided effectively.

### 3.3.1 | Deficits in Professional Engagement With and Support of Carers to Continue to Care

Despite the clear need, the evidence consistently demonstrated carers’ difficulties in obtaining relevant advice,

information, and other support to help them to continue to care for their adult family member in the home. Amongst the participants in Black and McKendrick’s (2010) study, 80% reported lack of knowledge concerning available help. Significantly, 77% reported lack of regular contact with their social worker, meaning that they did not have consistent access to an important source of such information. Participants in the Forrester-Jones’ (2019) study described their upset at social workers’ patronising attitudes, compounded by brevity of appointments and poor information-provision, all of which diminished the perceived effectiveness of social work involvement. Further deficits in social work support highlighted by both Forrester-Jones 2019 and Slevin et al. (2011) concerned the high-turnover of social workers and consequent lack of continuity of appointed staff.

**TABLE 2 |** Characteristics of included evidence.

| Authors/date of publication | Title   | Source/type of evidence                           | Stated aim/purpose   | How evidence assembled  | Population  | Definition of 'behaviour that challenges others' | Country   | Main findings   |
|-----------------------------|---|---|--|---|---|--|---|---|
| Black and McKendrick (2010) | Careful plans report. Positive futures report.  | Report  | Scoping study of the self-identified needs of all older carers of people with intellectual disabilities, known to the local Health & Social Care Trust | Empirical research; data collected via semi structured questionnaire survey; descriptive and inferential statistical analysis | Carers: (n = 36; 81% female/19% male; mean age = 70 years). Health status: Majority self-reported as 'OK'; 24% as 'poor' or 'very poor'; 5% as 'excellent'. High levels of chronic and debilitating illness. Relationship to person with intellectual disability: Son n = 17 (47%); Daughter n = 14 (39%); Sister n = 3 (8%); Niece n = 1 (2.8%); Brother-in-law n = 1 (2.8%)<br>People with intellectual disability: (n = 36; 18 male/18 female; mean age = 41.8 years; all identified with severe intellectual disability; n = 8 identified as conveying complex/challenging needs; n = 11 (30%) given more than one additional diagnosis for example, autistic spectrum disorder and profound deafness; n = 7 with additional diagnosis of epilepsy; 'other' diagnoses (no numbers provided) included spina bifida, hydrocephalus, cerebral palsy, and physical disabilities). | None provided                                    | Northern Ireland                                    | Support (formal and informal) considered vitally important in helping carers to cope. Many carers ill-prepared, pessimistic, anxious and sad about the future. Emergency planning typically arranged with other family members to 'step in' until crisis is over. Only 47% of families reported having a plan for the future care of their family member. Most popular future housing option was to remain in the family home with support. If moving out of the home, carers consistent preference was for the family member to remain near to current accommodation, and that other family do not take over caring to the same level of commitment. Future care of person with an intellectual disability is a difficult and emotional subject for families |
| Forrester-Jones (2019)      | Confronting a Looming Crisis. People with intellectual disabilities or autism and their carers getting older.   | Report  | To explore the experiences of older family carers as they continue to care for their older adult relatives with intellectual disabilities              | Empirical research; data collected via interviews; data analysed using Interpretative Phenomenological Analysis (IPA)         | Carers (n = 21; 16 female/5 male; mean age = 75). Health status: Not reported. Relationship to person with an intellectual disability: Not reported. People with intellectual disabilities (n = 16; mean age = 45 years); 50% over age of 50; gender not stated, but mixed; mild to severe intellectual disabilities. Other conditions: Smith-Magenis Syndrome/ Down Syndrome (n = 5); cerebral palsy (n = 2); autism (n = 2); n = 2 who convey behaviours that challenge others (n = 2)  | None provided                                    | England   | Older carers struggle to continue to care for their family members with an intellectual disability. Few opportunities for respite and the possibility of meaningful retirement is remote. Lack of continuity of social worker input, variable levels of expertise, and pejorative attitudes towards carers. Carers remain understanding of pressures on health and social care service providers. Carers fear for the future in terms of who will care for their family member when they are no longer able to do so  |
| Sense (2018)                | Decisions to make, steps to take. A guide to planning long-term care and support for adults with intellectual disabilities and their families. A Sense Toolkit. | Resource—sets out information, guidance and tools | To provide information for people with intellectual disabilities and their families to start making plans for the future                               | Non-research; No information provided   | People with intellectual disabilities; family carers of people with intellectual disabilities   | None provided                                    | Not made explicit; Sense is a UK based organisation | Comprehensive, easy-to-read guide, setting out main options available, legal rights possessed, and key decisions that need to be made regarding making plans for the future care for people with intellectual disabilities. Also includes tools to help with decision-making  |

(Continues)



TABLE 2 | (Continued)

| Authors/date of publication | Title  | Source/type of evidence | Stated aim/purpose  | How evidence assembled | Population  | Definition of 'behaviour that challenges others'   | Country  | Main findings  |
|-----------------------------|--|-------------------------|---|------------------------|---|--|--|--|
| Slevin et al. (2011)        | A rapid review of the literature relating to support for people with intellectual disabilities and their family carers when the person conveys behaviours that challenge others and/or mental health problems; or they are advancing in age. | Report                  | 1. What services and support do people with intellectual disabilities who convey behaviours that challenge and their caregivers require to meet their needs?<br>2. What services and support do older people with intellectual disabilities and their caregivers require to meet their needs? | Rapid review           | People with intellectual disabilities who convey behaviours that challenge others; Carers of people with intellectual disabilities who convey behaviours that challenge others. Socio-demographic and health status information on people with intellectual disabilities and carers included in evidence not reported. People with intellectual disabilities who convey behaviours that challenge others 'inclusive of mental health problems' (p.9). Older people with intellectual disabilities; Carers of older people with intellectual disabilities. Socio-demographic and health status information on people with intellectual disabilities and carers included in evidence not reported | Working definition of behaviours that challenge others provided (p.9): '... severely challenging behaviour refers to culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities' (Emerson (1995, 44)' | No geographical restriction, only studies published in English include | People who convey behaviours that challenge others Support should be based on the use of resources to maintain the person in their own home, if this is their wish. Identified interventions and services (e.g., PBS, use of community specialist teams, short breaks, teaching and supporting caregivers) were found to be successful in doing so. Appropriate day opportunities also essential, but have not been adequately researched, as is family support to allow adults with intellectual disabilities who convey behaviours that challenge others and their family to lead fulfilling lives. Use of medication is high, but behavioural management should be pursued as appropriate. Interventions most likely to be effective when delivered via a family support and education approach, in partnership with formal carers. Active support appears a promising approach. Specialist community teams are a highly effective service. Specialist assessment and treatment units can provide a useful service, but admission should be for a short period, with aim of return to the community. To this end, a model that provides combined specialist support services is recommended. Evidence suggests limited use of full range of mental health services, suggesting deficits in terms of their accessibility and value for adults with intellectual disabilities who convey behaviours that challenge others.                        |
|                             |  |                         |   |                        |   |  |  | Older people<br>Most older adults with intellectual disabilities wish to continue to live in their family home, and ageing family carers want to continue caring. However, lack of future planning is the norm. Ageing adults with intellectual disabilities may face the same range of health-related issues as others earlier in their lives. In addition, there are higher rates of some conditions (e.g., dementia). Medications that can help are seldom offered. Appropriate health screening is needed, but scarce evidence that this happens, or that detected health problems are properly investigated and treated. Positive mental health is promoted by such health-improving behaviours, continuing to remain active, and having a meaningful and valued life. Relevant training is required for frontline staff to develop skills to provide appropriate care, both in supported living arrangements or in partnership with family carers. Evidence suggests that facilities geared towards the needs of older adults with intellectual disabilities are at best scarce and at worst non-existent. Nursing or residential placement should not be the 'go-to' option; a range of intermediate care facilities should be used as appropriate to promote opportunity to return to their home. It should not be assumed that because a person is a particular age that they may not be able to return to their normal home or residence |

(Continues)

**TABLE 2 |** (Continued)

| Authors/date of publication                | Title   | Source/type of evidence   | Stated aim/purpose  | How evidence assembled  | Population  | Definition of 'behaviour that challenges others' | Country  | Main findings   |
|--|---|---|---|---|---|--|--|---|
| The Housing and Support Partnership (2011) | Planning and Commissioning Housing for People with Learning Disabilities. A Toolkit for Local Authorities | Report  | Resource ('toolkit')  | Non-research; No information provided   | Local authorities responsible for the planning/commissioning of housing for people with intellectual disabilities | None provided                                    | All references made in respect of England, and all examples drawn from England | Toolkit, to assist local authorities/their partners to plan for the housing requirements of adults with intellectual disabilities. Set out in two parts (a) Planning—the steps likely to be required to plan for a wider choice of housing options. (b) Delivery—the steps and actions likely to be required to commission a choice of housing options. Each section of the toolkit is designed for independent or sequential use and contains a checklist series of questions and suggestions for possible approaches to make progress |
| Towers (2015)                              | Thinking ahead: a planning guide for families   | Resource—planning guide for families with an adult relative with intellectual disabilities to help them think about and plan for the future | To provide information and ideas about how different people can help parents and contribute to thinking and planning for the future | Resource based on series of workshops held with people with intellectual disabilities, their parents and siblings and a national survey of parents. All consultation focused on what participants thought about making plans for the future | Adults with intellectual disabilities, their parents and siblings   | None provided                                    | Not made explicit; Thinking Ahead is a UK based organisation                   | Comprehensive, easy to read resource, divided into nine sections that cover different aspects of thinking about and preparing for the future. Sets out a wide range of options and ideas, and includes templates for people to use when undertaking specific tasks, and to record information and ideas   |

TABLE 3 | Main themes and sub-themes.

| Main theme   | Sub-themes   |
|--|--|
| Supporting ageing family carers of adults with intellectual disabilities who convey behaviours that challenge others | Deficits in professional engagement with and support of carers to continue to care<br>Promoting the capacity of carers to continue to care |
| Considering transition: ‘Tolerating uncertainty’   | Supporting family carers to plan ahead   |
| Resources to support transition planning and decision-making   | —  |

Forrester-Jones (2019) suggests that lack of continuity in personnel, especially social workers, means that the goal of successive legislation regarding ‘family-professional partnership working’ remains largely aspirational. She goes on to argue that problematic relationships run the risk of leaving ageing family carers distrustful of services, believing that they prioritise ‘crises’, instead of managing the long-term well-being of either adults with intellectual disabilities or their carers. Similarly, Slevin et al. (2011) link resource constraints with a tendency for social work services to concentrate on priority need, so that people with intellectual disabilities who reside in environments that are ‘working’ are less likely to meet the threshold set for active involvement. They stress the need for commissioners to be aware of the longer-term detrimental impact of this approach, including in respect of the financial outlay ‘down-the-line’.

These issues are brought into sharp focus in the Forrester-Jones (2019) study. The introduction of The Care Act (2014) entitles carers to a Carers Assessment, separate to any assessment of needs or eligibility relating to the person they care for. It also confirms their entitlement to support if they meet national eligibility criteria (Gant and Bates 2019; Forrester-Jones 2019). However, like many other carers affected by the lack of realisation of the Care Act 2014 ambitions (Milne and Larkin 2023), participants in the Forrester-Jones (2019) study reported struggling to receive a carer’s assessment, and when they did, to get it implemented. As a result, local authorities were unable to provide or purchase services to enable carers to continue in their caring role. In addition, despite two participants stating that the person they care for conveyed ‘challenging behaviour’ (and other participants referring to behaviours that might be considered ‘challenging’), Forrester-Jones reported that no family carers in her study had been approached by professionals about a potential functional assessment or positive behaviour support plan for their relative (Forrester-Jones (2019)). These participant accounts therefore confirm yet another failure in the implementation of The Care Act 2014—a lack of the ‘whole family approach’ to needs assessment, designed to proactively promote the lives of carers and those for whom they care as advocated within the Act (Forrester-Jones 2019).

### 3.3.2 | Promoting the Capacity of Carers to Continue to Care

Black and McKendrick (2010) outline core prerequisites of meaningful communication between professional carers and people with an intellectual disability and their family carers. Arguing

that such communication involves more than the reactive provision of information, they stress a need for proactive work to ensure that carers and the person they care for are fully aware of all options and services available. This work includes making judgements as to the appropriate timing, amount, and format of information-provision, tailored to (ongoing changes in) individual family dynamics and needs, so that communication and information strategies are ‘creative, continuous and proactive’ (p.30). Examples of how this process can be achieved include:

- Periodic information days (once or twice a year, or a series of short events over several weeks) in which housing and service providers come together to provide information on the process and options;
- Extending the role of day centres to serve as a resource for adults with intellectual disabilities and their carers in an environment with which they are already familiar.

In a similar vein, Slevin et al. (2011) discuss a range of interventions which can act ‘as a form of prevention, maintenance and also crisis management’ (Slevin et al. 2011, p. 85). Examples include: future planning, support groups, support co-ordination, direct services, and sibling support, all of which can serve as vehicles for providing information, as well as emotional and instrumental support. Most of the examples of such interventions provided by Slevin et al. (2011) are drawn from countries other than the UK, suggesting relative disadvantage on the part of ageing family carers in the UK who continue to sustain care with only limited or no support capable of protecting their own and their adult family member’s well-being. Further, it suggests the need for statutory agencies to help redress these deficits. One form of the ‘direct services’ identified by Slevin et al. (2011)—short breaks, providing respite to family carers—are described by the authors as an ‘essential’ (p.40) component of a wider set of services supporting family carers over the long-term. Drawing on the evidence of studies included in their review, Slevin et al. (2011) demonstrate that provision of *effective* respite is more than just the creation of somewhere to which the people with intellectual disabilities can go; respite services need to be appropriate to the needs of the person *and* to be perceived as such by their family carer. If the latter doubt their suitability, it is more likely that the services will not be used, or that the doubts will engender additional stress.

Another form of a direct service is the direct payments scheme, which allows adults with intellectual disabilities who convey behaviours that challenge others and their family carers to choose

and to manage their own supports. Funding can be used to pay for services such as personal/support assistants, domiciliary care, day care, transport, supported employment, home modification, respite care and therapies. Slevin et al. (2011) claim the success of the scheme for older family carers of people with intellectual disabilities living in the UK, with their evidence demonstrating increased choice and flexibility, enhanced feelings of confidence and optimism, and a reduction in anxiety about leaving their family member. The importance of day-care provision in helping ageing family carers to continue to care for their loved one in the family home is reflected in Black and McKendrick's (2010) findings. Carers talked about day centres as vital in helping them to cope, and described feeling stressed when, for example, they were closed at holiday times. As Black and McKendrick (2010) state, although these services are provided to meet the needs of adults with intellectual disabilities, carers view them as vital to their own well-being.

In terms of how the above services should be provided, Black and McKendrick (2010) stress a need for proactivity on the part of front-line professionals. Two core reasons are outlined. Not only do carers tend to focus on the needs of their family member to the detriment of their own, but also ageing carers may have only limited or no access to informal support networks. Black and McKendrick (2010) reported that 36% of the participants in their study did not have access to *any* type of informal support network, mainly due to a change in the composition of the household, either through the death of a spouse, or other children leaving home. The evidence from Slevin et al. (2011) again confirms the need for proactivity on the part of front-line professionals in facilitating ageing carers' engagement with available services, showing that they are less likely than their younger counterparts to use services such as day-care, respite care, and social work involvement. Several overlapping factors contribute to this disinclination, including mistrust of services, previous negative encounters, lower expectations of such services, and fear that their son/daughter will be removed from the family home (Slevin et al. 2011).

### 3.4 | Considering Transition: 'Tolerating Uncertainty'

Forrester-Jones (2019), Slevin et al. (2011) and Black and McKendrick (2010) all highlight ageing carers' profound anxieties about the fate of their adult family member with intellectual disabilities when they are no longer able to care. In addition, all three identify the sensitivities and stresses of approaching other family members, particularly siblings, concerning future care arrangements. Forrester-Jones (2019) describes participant avoidance of such conversations, while Black and McKendrick (2010) highlight participant guilt in asking their other children to assume caring responsibilities, seeing this as placing an unfair burden on them. Even when carers were hopeful of sibling involvement, they rejected the idea that siblings should replicate the 'hands-on' intensity of their own caring (Black and McKendrick 2010; Slevin et al. 2011). Such thinking suggests that transition to care by another relative is likely to result in less intensive familial involvement, which Black and McKendrick (2010) link to possible future demands on services.

Forrester-Jones (2019), Slevin et al. (2011) and Black and McKendrick (2010) all link these findings to a tendency on the part of carers to avoid thinking about the future, or, as Forrester-Jones (2019, p. 72) puts it, to adopt an approach of 'tolerating uncertainty'. Forrester-Jones (2019) identifies two further contributory factors in carers' disinclination to consider the possibilities of and for transition. Firstly, their reluctance to relinquish their caring role, which is a source of profound life satisfaction and sense of purpose. Second, an increase in mutual caring and interdependence that occurs as family carers age, meaning that carers become increasingly reliant on their family member with intellectual disabilities for emotional, practical and financial support.

#### 3.4.1 | Supporting Family Carers to Plan Ahead

As might be expected, given the emotional stress and/or practical difficulties involved, evidence shows that even when carers wanted to engage in transition planning, few actually did so. Furthermore, when plans were made, they were mainly informal, typically involving verbal discussions and/or agreements with other family members and lacking any legal or financial confirmation. Slevin et al. (2011) cite the findings of Taggart et al.'s (2012) then ongoing study of ageing family carers, which reported that just less than half had made future plans, most of which were informal. Only a third of the participants in the Black and McKendrick (2010) study had an emergency plan in place (these were mainly informal and in terms of family members 'stepping-in' until the crises passed) and less than half had made any longer-term plans. Of these, the majority involved other family members, and only two included any formal arrangements.

Given the reticence surrounding transition planning, professional support, using a 'whole family' approach to address the issues around transition planning that are acceptable to carers, is strongly advocated by included authors (Black and McKendrick 2010; Forrester-Jones 2019; Slevin et al. 2011). The process should start early, before problems associated with ageing in both people with intellectual disabilities and their family carers become manifest (Slevin et al. 2011). Particular mention is made of the need to proactively involve siblings regarding their (potential) role as future main caregivers (Black and McKendrick 2010; Forrester-Jones 2019; Slevin et al. 2011). Sensitivity is required (Black and McKendrick 2010; Forrester-Jones 2019), as not all siblings will be able, or wish, to assume a caregiving role (Forrester-Jones 2019), as is the creation of a space for them to be able to talk about their needs, priorities and preferences (Black and McKendrick 2010). Both Forrester-Jones (2019) and Slevin et al. (2011) recommend regular revisiting of plans, so that changes in family circumstances and needs can be considered, and plans amended accordingly.

Evidence collectively suggests that family carers would be receptive to such proactive service support. Half of the participants in Black and McKendrick's (2010) study explicitly stated that they would welcome information on future planning, particularly in relation to financial matters. Moreover, some participants stressed their desire to have the person they cared for move out of the family home as a positive choice, rather than because of the carer's inability to cope. Similarly, Slevin et al. (2011) conclude

that ageing family carers of people with intellectual disabilities want to continue to care for as long as possible *and* to prepare emergency and longer-term plans, so long as the issues involved were dealt with sensitively.

Despite all of the evidence suggesting the potential benefits of professional involvement, the evidence suggests that family carers do not receive the support required to enable them to both ‘confront’ and progress transition planning. Forrester-Jones (2019) highlights participant difficulties in, for example, securing information from social workers concerning options for accommodation of their family member, availability of supporting services, how to access these options/services, and length of time taken to secure alternative accommodation. Both dissatisfaction with the level and nature of support, and the burden of trying to overcome the resultant challenges, meant that family carers simply abandoned or delayed their efforts (Forrester-Jones 2019).

### 3.5 | Resources to Support Transition Planning and Decision-Making

Our review found no targeted resources to guide ageing family carers of people with intellectual disabilities who convey behaviours that challenge others, or professionals (both front-line care providers and planners/commissioners) in transition planning and decision-making. A limited number of generic resources were found, some of which included limited relevant content. These are listed in Table 4. Where available, details of relevant content are provided. The list should not be considered exhaustive; as a rapid review, some may have been missed. Furthermore, the resources are dated and, due to the lapse in time since publication, we were unable to access the majority of those we identified.

## 4 | Discussion

### 4.1 | Addressing Our Research Question

The review points to the vulnerability of family carers of older people with intellectual disabilities who convey behaviours that challenge others; as a result of caring for many years they are likely to be mentally and physically exhausted. Their caring responsibilities and changing demographics mean that they may also be socially isolated because of a reduction in their family and social networks. In addition, there is evidence they experience anxieties about future care arrangements, including the quality of this care and involvement of other family members, most notably siblings. A tendency to avoid considering transition is further compounded by a disinclination to relinquish their caring role because it suggests they can no longer cope, the sense of purpose it provides and/or the mutuality in caring that has developed over time.

Furthermore, systemic failings result in carers feeling distrustful of professionals. Various ways of addressing this issue were put forward in the included evidence. It is suggested that front-line professionals should be more proactive in promoting older carers’ capacity to continue to care and preventing crises, for

example, by facilitating their engagement with services such as day-care, respite care and social work involvement. Helping these carers to develop trust in professionals and services more generally is also seen as critical. A third set of proposals centred on the processes of transition planning, advocating that these start well before problems associated with ageing in both adults with intellectual disabilities and their family carers emerge, to allow plenty of time and space for all those involved to express their views and wishes and for the re-visiting of plans as required. The adoption of a ‘whole family’ approach, particularly with respect to the involvement of siblings was also recommended.

### 4.2 | Implications for Policy and Practice

Since the 2000s, there is evidence of international policy and guidance moving away from an understanding of ‘challenging behaviour’ as something located in the individual to emphasise its socially constructed nature (Australian Government Department of Social Services 2016; New Zealand Ministry of Social Development 2016; NICE 2015; Royal College of Psychiatrists 2016;). Nonetheless, it is clear that ‘challenging behaviour’ continues to function as a diagnostic label that prevents proper care and support of adults with intellectual disabilities (Hastings et al. 2018; Haydon-Laurelut and Nunkoosing 2016; Jorgensen, Nankervis, and Chan 2023; Leif et al. 2023; Mansell 2007; The Challenging Behaviour Foundation 2021b). Indeed, such is the ‘stickiness’ of the label and the harm it perpetuates that Mikulat et al. (2024) call for it to be dismissed entirely.

Although we did not carry out formal quality appraisal, we considered how our included evidence critically engaged with the construct of ‘challenging behaviour’ in terms of the implications for transition-related care and support of family carers. Unsurprisingly, given that the primary focus of most of the evidence was not on behaviours that challenge others, we found such engagement was limited. Slevin et al. (2011) briefly reference a need to move beyond the individual problemisation of (in their terms) ‘challenging behaviour’ in the context of ensuring appropriate environmental management, not only in terms of physical infrastructure, but also the ‘mind-set, attitudes and education’ (p.53) of staff. It is crucial that any research that includes a focus on behaviours that challenge others directly addresses the social processes through which they take on their particular nature, function and impact. This is no less true regarding the transition-related experiences of ageing carers of adults with intellectual disabilities.

In line with international evidence (Baumbusch et al. 2017; Cairns et al. 2013; Carers Trust 2020; Egan and Dalton 2019; Innes, McCabe, and Watchman 2012; Pryce et al. 2017), our review has shown how ageing can seriously impact the ability of family carers to sustain the care of their adult family member with an intellectual disability, including in the context of transition. Although not addressed directly in the evidence included in our review, other research highlights how difficulties in maintaining care may be further compounded by the particular challenges associated with caring for an adult who conveys behaviours that challenge others (Grey, Totsika, and Hastings 2018; Griffiths and Hastings 2014), Evidence also

**TABLE 4** | Identified resources.

|   | Access   |
|---|--|
| <i>Resources for professionals responsible for care planning and provision</i>  |  |
| The Housing and Support Partnership (2011) lists:<br>ARC: ARC is a membership organisation, which supports providers of services to people with intellectual disabilities. <a href="http://www.arcuk.org.uk">www.arcuk.org.uk</a> .<br>No content specific to ageing carers of adults with intellectual disabilities who convey behaviours that challenge others.   | Accessed 30 May 2021                                 |
| <i>Resources for carers of adults with intellectual disabilities</i>  |  |
| The Housing and Support Partnership (2011) lists:<br>Bath and North East Somerset: ‘My Own Home; <a href="#">guide to housing for people with intellectual difficulties</a> ’—the guide provides advice regarding different housing and support options available, including information about funding for supported living. It is available on tape and CD. <a href="http://www.bathnes.gov.uk/BathNES/healthandsocial/helpforadults/adultslearning/supportedliving">www.bathnes.gov.uk/BathNES/healthandsocial/helpforadults/adultslearning/supportedliving</a> | Tried and failed to access this resource 30 May 2021 |
| The Housing and Support Partnership (2011) lists:<br>Mencap: factsheet providing information on consent, decision-making and financial matters. <a href="http://www.mencap.org.uk/displaypagedoc.asp?id=12744">www.mencap.org.uk/displaypagedoc.asp?id=12744</a><br>No content specific to ageing carers of adults with intellectual disabilities who convey behaviours that challenge others.  | Accessed 30 May 2021                                 |
| The Housing and Support Partnership (2011) lists:<br>Making Money Easier: a set of guides designed to help adults with intellectual disabilities to think about money, banking and planning their lives. <a href="http://www.making-money-easier.info">www.making-money-easier.info</a> .   | Tried and failed to access this resource 30 May 2021 |
| The Housing and Support Partnership (2011) lists:<br>Housing Options: ‘Your Place to Live’—a guide to housing options of people with intellectual disabilities available to download free. <a href="http://www.housingoptions.org.uk/general_information/gi_publications_vpn_publications.html">www.housingoptions.org.uk/general_information/gi_publications_vpn_publications.html</a> .   | Tried and failed to access this resource 30 May 2021 |
| The Housing and Support Partnership (2011) lists:<br>Housing Options: A Guide on Discretionary Trusts—available for families to download. <a href="http://www.housingoptions.org.uk/general_information/gi_publications_vpn_publications.html">www.housingoptions.org.uk/general_information/gi_publications_vpn_publications.html</a> .  | Tried and failed to access this resource 30 May 2021 |
| The Housing and Support Partnership (2011) lists:<br>BILD: A guide on financial decision-making. <a href="http://www.bild.org.uk/03books_pca.htm">www.bild.org.uk/03books_pca.htm</a> .   | Tried and failed to access this resource 30 May 2021 |
| The Housing and Support Partnership (2011) lists:<br>Housing Options: ‘Finding a Place to Live’—a guide to help with planning housing and support options—available to download free. <a href="http://www.housingoptions.org.uk/general_information/gi_publications_vpn_publications.html">www.housingoptions.org.uk/general_information/gi_publications_vpn_publications.html</a> .  | Tried and failed to access this resource 30 May 2021 |
| The Housing and Support Partnership (2011) lists:<br>Dimensions UK & Housing Options: ‘My home and money’—a guide for people supporting adults with an intellectual difficulty to manage their money, available to download free from Dimensions UK. <a href="http://www.housingoptions.org.uk/general_information/gi_publications_vpn_publications.html">www.housingoptions.org.uk/general_information/gi_publications_vpn_publications.html</a> .   | Tried and failed to access this resource 30 May 2021 |
| The Housing and Support Partnership (2011) lists:<br>Growing Older with Learning Disabilities (GOLD)—a UK wide programme that operated throughout 1998–2002. It aimed to improve the lives of older people with intellectual disabilities. They set up a range of projects to increase our understanding of their concerns and how best they could be addressed. <a href="http://www.learningdisabilities.org.uk/our-work/person-centred-support/gold">www.learningdisabilities.org.uk/our-work/person-centred-support/gold</a> .                                 | Tried and failed to access this resource 30 May 2021 |
| The Housing and Support Partnership (2011) lists:<br>Department of Health and Department for Communities and Local Government: Housing Resource Pack—designed to help people with intellectual disabilities have greater choice and control in where they live. Overall aim is to increase the number of adults with moderate to severe intellectual difficulties in settled accommodation. <a href="http://www.valuingpeoplenow.dh.gov.uk/valuing-people-now/housing">www.valuingpeoplenow.dh.gov.uk/valuing-people-now/housing</a> .                            | Tried and failed to access this resource 30 May 2021 |

(Continues)

TABLE 4 | (Continued)

|  | Access  |
|--|---|
| <p>The Housing and Support Partnership (2011) lists:<br/>Housing Options: HOLD programme—a factsheet downloadable for free. <a href="http://www.housingoptions.org.uk/general_information/gi_publications_vpn_leaflets.html">www.housingoptions.org.uk/general_information/gi_publications_vpn_leaflets.html</a>.</p>  | <p>Tried and failed to access this resource 30 May 2021</p> |
| <p>The Housing and Support Partnership (2011) lists:<br/>Further information and advice about ‘Home Ownership for People with Long Term Disabilities’ is available from <a href="http://www.advanceuk.org">www.advanceuk.org</a> and <a href="http://www.homesandcommunities.co.uk">www.homesandcommunities.co.uk</a>.<br/>No content specific to ageing carers of adults with intellectual disabilities who convey behaviours that challenge others.</p>  | <p>Both sites accessed 30 May 2021</p>                      |
| <p>The Housing and Support Partnership (2011) lists:<br/>Housing Options: ‘Your Place to Live’—a guide to housing options for people with intellectual disabilities available to download free. <a href="http://www.housingoptions.org.uk/general_information/gi_publications_vpn_publications.html">www.housingoptions.org.uk/general_information/gi_publications_vpn_publications.html</a>.</p>  | <p>Tried and failed to access this resource 30 May 2021</p> |
| <p>The Housing and Support Partnership (2011) lists:<br/>Housing Options: ‘Overview of Housing Choices’—a factsheet available free to download, which introduces a series of leaflets explaining how a person with disabilities may get housing along with whatever care or support they need. The leaflets are intended to help care managers, families, advocates and others who may play a role in the life of a person with disabilities to get a quick overview of the main housing possibilities. <a href="http://www.housingoptions.org.uk/general_information/gi_publications_vpn_leaflets.html">www.housingoptions.org.uk/general_information/gi_publications_vpn_leaflets.html</a>.</p>  | <p>Tried and failed to access this resource 30 May 2021</p> |
| <p>The Housing and Support Partnership (2011) lists:<br/>Housing Options: ‘Residential Care Homes’—one of a set of leaflets available free to download from Housing Options [<a href="http://www.housingoptions.org.uk">www.housingoptions.org.uk</a>] explaining the residential care housing option.<br/><a href="http://www.housingoptions.org.uk/general_information/gi_publications_vpn_leaflets.html">www.housingoptions.org.uk/general_information/gi_publications_vpn_leaflets.html</a>.</p>   | <p>Tried and failed to access this resource 30 May 2021</p> |
| <p>Sense—a UK national disability charity that supports people with complex communication needs—published a ‘toolkit’, <i>‘Decisions to Make, Steps to Take’</i> (2018), intended for use by people with intellectual disabilities and their families when making plans for the future. It outlines key decisions that need to be made, sets out the steps to take in making these decisions and includes detailed information on the main options available, resources to support and legal rights possessed in respect of both processes. Notwithstanding its generic ‘pitch’, some of the content is extremely useful for ageing carers of adults with intellectual disabilities who convey behaviours that challenge others. This content includes details on NHS Continuing Healthcare Funding, Personal Health Budgets, statutory advocacy provision, entitlement under The Care Act (2014) and practical resources (templates) to be used to aid planning and decision-making. <a href="http://www.sense.org.uk">www.sense.org.uk</a>.</p>  | <p>Accessed 30 May 2021</p>                                 |
| <p>Together Matters—a UK registered charity, which promotes communication and collaboration to improve the lives of people with intellectual disabilities and their families—published a planning guide <i>‘Thinking Ahead: a planning guide for families’</i> (2015). It explains the content and implications of relevant legislation, as well as how family carers can use this legislation to take action in support of their family member. The guide is also an effective practical resource. It sets out a wide range of options and ideas, and includes templates to use for specific tasks, as well as useful decision-making aids for example, for facilitating communication. Although the resource is generic in nature, several sections deal with issues relevant to ageing family carers of adults with intellectual disabilities. For instance, the section ‘Getting older’ provides practical advice about how to support a family member in ways that are appropriate to their needs. There is a detailed section on ‘Housing and support’, which offers practical guidance on the options available, and how to plan for transition, particularly if the family member has ‘complex needs’.</p> | <p>Accessed 30 May 2021</p>                                 |

demonstrates the additional distress when this happens in the context of lack of future planning (Brennan et al. 2020; Lee and Burke 2020; Walker and Hutchinson 2018) exacerbated by (often severe) limitations in the availability of appropriate community residential accommodation (Eley et al. 2009; Grey et al. 2015; NICE 2018a; Taggart and Hanna-Trainor 2017).

For all these reasons, it is vital that ageing family carers of adults with intellectual disabilities are proactively supported so they can simultaneously (a) sustain care in the family home for as long as this is the preferred option for both them and their adult family member, and (b) be fully aware of the possibility and options for their adult family member’s move out of the

family home. However, irrespective of how well versed a carer may be about such options, if they lack confidence in the alternative accommodation available, they are likely to feel obliged to continue to care when they might otherwise be prepared to relinquish this role (Barron, McKonkey, and Mulvany 2006; Gilbert, Lankshear, and Petersen 2008; Nankervis, Rosewarne, and Vassos 2011). Hence, the only *real* option they have is to maintain care in the family home.

### 4.3 | Strengths and Limitations

Although necessarily expedited, our rapid review adopted ‘additional steps’ recommended by Pluddeman et al. (2018, p. 202) to reduce the potential for bias. This included searching multiple datasets (including grey literature), thereby increasing our confidence that relevant evidence was not missed. Inter-rater involvement at all stages further increases the robustness of our review process. Focusing our search strategy on ‘challenging behaviour’ rather than associated conditions (e.g., dementia; profound mental ill health) and/or specific forms of behaviour (e.g., self-injury; aggression etc.) runs the risk of having missed articles that pertain to our population of interest. However, a trial of alternative approaches generated an immense number of returns, unmanageable for the purposes of a rapid scoping review. Moreover, on scanning these returns, they showed no relevance to our research question. Therefore, we made a pragmatic decision to build a search strategy around the key terms of ‘intellectual disability’, and ‘challenging behaviour’.

As we were interested in transition over the long-term, this meant that data not originally conceptualised in the immediate context of transition were considered relevant. For example, support for carers to promote the health and well-being of their adult family member is relevant to avoiding unwanted or crisis transition. Where included evidence did address transition more immediately, no detail was provided on transition settings, although the data were overwhelmingly oriented towards transition from the family home. This means that issues pertaining to the experiences of carers in cases where their adult family member is transitioning from one service setting to another are less likely to have been addressed by our review. From our collective evidence, we had to carefully extract relevant data and consider how they could be brought together within an overarching analysis that pertained to our population and focus of interest. That we succeeded in gathering a diverse range of data is one of the main strengths of our review. However, the lack of targeted evidence increases the chances that not all relevant issues have been identified. This is the inevitable consequence of the dearth of research in this area. In addition, with the exception of one report published in 2019 (Forrester-Jones 2019), included evidence dates from 9+ years ago (i.e., published between 2010 and 2015), pre-dating a number of significant developments in the UK context, notably the impact of austerity (Forrester-Jones et al. 2021), and the constraints that have emerged around personalisation and the implementation of personal budgets, including direct payments (Schwehr 2022).

Only two of our sources of evidence reported primary research (Black and McKendrick 2010; Forrester-Jones 2019) and both

used qualitative methods. Although statistical generalisability is therefore not possible (Leung 2015; Polit and Beck 2010), the evidence from these two sources provided much needed detail, which allowed us to draw out implications for transitions-related support. The remaining empirically based evidence (Slevin et al. 2011) synthesised a broad range of evidence. Except for Black and McKendrick (2010) details on participant characteristics are either missing or limited; those available suggest some diversity in the sample populations in respect of gender, age and carer-cared for relationship. In this context, the high degree of correspondence in findings across all three of the empirically based sources of evidence increases our confidence in their broad applicability. However, this means that differential impact according to, for example, older carers’ specific characteristics, health status, and/or social circumstances, may not have been captured.

Black and McKendrick (2010) and Forrester-Jones (2019) were the only sources which provided details on the population of people with an intellectual disability being cared for. Characteristics showed mixed male and female participation, assessed across mild to severe/profound intellectual disability, and with a range of additional physical and mental health conditions. Some, but not all, participants were identified as conveying behaviours that challenge others. The remaining source of empirical evidence (Slevin et al. 2011) did not detail the characteristics of people with intellectual disabilities who convey behaviours that challenge others involved in their data synthesis. Close reading confirmed them to be mixed in terms of gender, degree of intellectual disability and additional health conditions. The collective mixed characteristics of included populations of people with intellectual disabilities who convey behaviours that challenge others further supports the broad relevance of our findings. Such breadth means that our findings may have less relevance to particular sub-populations not addressed within our included evidence. These include, for example, older carers of adults whose degree of intellectual disability and/or attendant health status may prompt a need for specific care and support.

We did not operate with a specific definition of ‘behaviours that challenge others’ to enable the inclusion of all potentially relevant evidence. Only one of our included sources (Slevin et al. 2011) provided a working definition, using that provided by Emerson (1995). The remaining sources of evidence did not provide any indication of the type of behaviour under consideration or offered any discussion of the context in which this behaviour was being understood. In essence, it seems that the authors were operating with an implicit assumption that ‘challenging behaviour’ constituted any behaviour considered and/or experienced as such. Although, or perhaps precisely because, we are unable to say with certainty the specific behaviours that were under consideration, it is likely that our findings pertain to a broad range of behaviours that challenge others, as these are socially located.

## 5 | Conclusion

Our review has confirmed a currently inadequate evidence base concerning transition related experiences, needs and support of a growing population of carers. That which does exist



demonstrates major deficits in how ageing carers of older adults with intellectual disabilities, including those who convey behaviours that challenge others, are being supported to both maintain care in the family home when this is the preferred option, and to consider and achieve transition that fits with their own needs and preferences and those of their adult family member. Although premised on a limited evidence-base, our review provides important insights into the ways in which effective approaches can be developed with regard to both ongoing, as well as transition-specific, support for older people with intellectual disabilities who convey behaviours that challenge others and their family members. In addition, it provides a clear steer for the direction of future research in this area.

### Author Contributions

J. Jordan made a substantial contribution to study design, and was the lead in the acquisition, analysis and interpretation of data, and drafting of the manuscript. M. Larkin, E. Tilley and J. Vseteckova J made a substantial contribution to study conception and design, substantial contribution to analysis and interpretation of data, and were involved in critical revision of the manuscript. S. Ryan and L. Wallace made a substantial contribution to study conception and design and were involved in critical revision of the manuscript.

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### Conflicts of Interest

The authors declare no conflicts of interest.

### Data Availability Statement

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

### Endnotes

<sup>1</sup> A sister review, focusing on older people with intellectual disabilities who convey behaviours that challenge others has also been published (Tilley et al. 2023).

<sup>2</sup> A protocol detailing all aspects of this review has been published (Vseteckova et al. 2022).

<sup>3</sup> We opted to use the term ‘family carers’, as it best reflects the terminology used in the current academic, policy and practice literature. Parents and siblings were included in our definition. However, we appreciate that this term can be contentious.

<sup>4</sup> We adopted a wide-ranging definition of ‘care contexts’ for the purpose of this review. This encompassed the following environmental factors: service type (is the person living in a congregate setting, independently, or in a family home); provider type (health/local authority, private provider, third sector organisation, family care); relationships (who provides the care e.g., different family members; paid carers; personal assistants); place (the geographical location of care, taking particular note of the urban/rural dimension); and commissioning and

funding arrangements. Our definition of care contexts also takes into account the dynamic and fluid ways in which different contextual factors interact at the micro, meso and macro levels.

<sup>5</sup> Our rationale for defining ‘older adults with intellectual disabilities who convey behaviours that challenge others’ as 40+ in this context was twofold: (a) it allowed the early onset of some chronic health conditions, such as dementia, for this group to be reflected (b) it enabled the inclusion of more family carers who might be described as ‘older’ and in need of new/additional support.

<sup>6</sup> Of necessity, our search strategy for the updated search differed from the original search. Two databases (SCIE and NHS Evidence) were no longer in existence; also, access to several databases was via different host platforms, requiring changes to the search strategies.

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## Supporting Information

Additional supporting information can be found online in the Supporting Information section.