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Tired of Spinning Plates

A Rapid Scoping Review of the Mental Health Needs and Mental Health Support of Carers of Adults with Learning Disabilities in the United Kingdom

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ABSTRACT

Family carers of adults with learning disabilities provide support that is not only valuable to the person they love and care for but is critical care labour for society in the UK. This care fills gaps in health and social care provision, is lifelong, and often entails longer hours of caring in comparison to other groups of carers. Despite this phenomenal and often invisible care work, how this group of carers experience their roles in relation to their mental health is poorly understood. We conducted a rapid scoping review to explore these mental health experiences, drawing upon evidence in the UK context, post the 2014 Care Act and during a period of sustained economic austerity politics. The review offers an original co-production approach to evidence scoping and synthesis, produced collaboratively from conception to synthesis with family carers and self-advocates with learning disabilities. As a political commitment to centralising the lives of people with learning disabilities and family carers in policy and research, we critique discourse and terminology choices throughout the review. Our thematic analysis of 18 evidence items resulted in four key themes constructing the mental health experiences of family carers: the unique temporalities of this group of carers; the economic value of family care; the importance of community; and ongoing ableism constructing mental health experiences. An Easy Read summary of findings is provided as an Appendix. More research is needed to assess the types and cultures of services, resources, and interventions that are utilised and perceived as effective by this group of carers in supporting their mental health and to share findings

with those that are implicated in the ongoing constructions of negative mental health experiences. There is a need to shift responsibilities for caring beyond the enclosures of hyper-individualised family carer responsibility.

KEYWORDS
people with learning disabilities, family carers, mental health, well-being.

Introduction

Adults with learning disabilities require different types of support throughout life in order to flourish (Jordan et al., 2025). For many, one of the most valuable sources of care and support is that provided by family or other not formally employed carers (Congreve and Watts, 2021). We use the term “family carer” to encompass this type of care, not as a term limited to care provided by family members. Despite the immense value of this care, not only in the life of the person with learning disabilities but to society in terms of the high economic value to the taxpayer with the filling of multitudes of cracks in the care system (NIHR SSCR, 2020), this value is neither reflected nor fully acknowledged across policy, welfare, and social care systems.

The review takes place as the UK continues to experience a sustained period of austerity politics (O’Hara, 2024); the demands on family carers are rising while the support available to them and to people with learning disabilities is falling. In 2020, a study found that 40% of people with learning disabilities said that they had lost care and support as a result of cuts to social care funding (NIHR SSCR, 2020).

Family incomes are impacted by very low rates of employment for people with learning disabilities (Nuffield Trust, 2023), and for family carers (Carers UK, 2022). Only 41% of all carers are in paid employment and of those carers only 21% have full-time employment (Carers UK, 2022). Family carers in England who care for another person for more than 35 hours a week can claim the welfare benefit Carers Allowance; however, the benefit rate currently stands at £81.90 a week (January 2025). A recent policy change means carers can now earn up to £196.00 per week (a rise of £45) (Carers UK, 2024); however, earning one penny over the limit leads to the full allowance being revoked. As carers reach state pension age, they are no longer eligible for Carers Allowance though they continue to care (GOV.UK, 2024).

The support provided by family carers is too often invisible (Ward, 2011; Congreve and Watts, 2021; Petrillo and Bennett, 2021), perpetuating discourses of isolation and restricting the recognition of work that deserves to be valued by wider communities. Throughout this often intense caring labour, there are discourses of the joy and positive fulfilment this role brings (DoHSC, 2020). However these discourses entangle with the practical challenges and uncertainties that intersect with this role that can impact family carer mental health (DoHSC, 2020; Meltzer, 2018).

Research evidences a correlation between family caring and poorer mental health (DoHSC, 2020). However, this evidence is largely drawn from research exploring the mental health experiences of mothers, fathers, and siblings of disabled children (Rydzewska et al., 2021; Dunn et al., 2019; Caliendo et al., 2020; Sibs, 2018) and other groups of family carers supporting people with dementia (NHS, 2017) and acquired health conditions (Bermejo-Toro et al., 2020). This literature review aims to explicitly address the mental health experiences of family carers of adults with learning disabilities who remain under-represented in carer mental health research and policy. In the UK before the pandemic, this group of carers accounted for a quarter of the nine million people providing this type of family support (DoHSC, 2020). However, we do not have a clear evidenced knowledge base about their mental health experiences or what good services or support look like from the perspective of this group of carers.

Consistent with this limited evidence base, the mental health of this group of family carers of adults with learning disabilities is not explicitly attended to in NICE guidance on supporting adult carers (NICE, 2020) and is not acknowledged in its research recommendations. We have been unable to locate any published research addressing the prevalence or use of medications such as antidepressants in this specific group of carers. While supporting mindfulness practices in the context of this group of family carers has been addressed in previous research (Flynn et al., 2020), we have been reminded by family carers throughout the study of the challenges of finding the time and space to engage with these practices (Runswick-Cole et al., 2024).

This rapid scoping review was undertaken as a part of an NIHR funded project based in England: Tired of Spinning Plates: An Exploration of the Mental Health Experiences of Adults and/or Older Carers of Adults with Learning Disabilities (NIHR135080, October 2022–November 2024). The research explores how family carers of adults with learning disabilities conceptualise and experience mental health throughout different stages of life, aligning with the challenges presented in the NHS Long Term Plan (NHS, 2019). These challenges persist in this time of post-pandemic recovery and have resulted in revisions to mental health targets (Thorlby et al., 2021). The project aims to explore family carers' perceptions of mental health experiences and how services and support systems construct these experiences, with a view to informing the development of targeted mental health support for this group.

Throughout this review, we remain critically attentive to the ways in which terminology constructs the lives of those it attempts to represent. Terminology choices are of profound social, cultural, and political consequence to people with learning disabilities, family carers, and allies (Cluley, 2018). Throughout this paper, we offer provocations for "staying with the trouble" of terminology and its ongoing ontological assumptions and repercussions (Haraway, 2016, 1). We argue for a collective responsibility in academic, policy, and legislative writing and for health and social care practices to be attentive to the consequences of terminology (Barad, 2014). Our definitions remain purposefully unstable as we find meaning through ongoing engagements with terminology as a part of a responsible and responsive research approach.

We are committed to centralising the *lives and experiences* of people with learning disabilities throughout this paper. We agree with Cluley and colleagues in our understanding of learning disabilities as referring to heterogeneous human lives in flux and that "there is no one way of being a learning-disabled person and people given this label have diverse needs and abilities" (Cluley et al., 2020, 236). Just as we recognise the risks and difficulties attempting to settle on a definition of "learning disabilities", we are mindful that relations of care are constantly in flux. It is equally difficult to settle on definitions of "care", "carer", and "care recipient", and yet UK legislation remains largely untroubled by these uncertainties. The Care Act 2014 defines a "carer" as "an adult who provides or intends to provide care for another adult" (HMSO, 2014, 11). Whilst "Informal carer", "family carer", and "unpaid carer" are often used interchangeably (Lloyd, 2006), we recognise the heterogeneity of carers, including parents (Dillenburger and McKerr, 2011), siblings (Rawson, 2010), siblings-in-law (Vanhoutteghem et al., 2014), and grandparents (Bigby and Ozanne, 2004), and use the term "family carer" throughout in this expansive unsettled spirit.

Review Methods

This rapid scoping review is shaped by the scoping review framework (Arksey and O'Malley 2005) and the PRISMA-ScR (preferred reporting items for systematic reviews and meta-analyses extension for scoping reviews) (Tricco et al., 2018). A scoping review methodology suited the broad exploratory research questions and met the ongoing project commitment to inclusion of evidence and perspectives that would otherwise be excluded by traditional systematic review approaches and academic and policy making discussions (Munn et al., 2018). Rapid review principles ensure credibility and reproducibility of knowledge synthesis through transparent reporting, balanced with purposeful streamlining of methods for timeliness (Tricco et al., 2017). For this study, streamlining involved restricting evidence searches by date, language, and location context (see Table 1), limiting researchers involved in data extraction and screening, not registering a protocol and narratively synthesising the evidence thematically; all of which are acceptable approaches for rapid synthesis (Langlois et al., 2019).

Aligning with the optional consultation stage of Arksey and O'Malley's (2005) framework and the broader project's commitment to co-production (Beresford and Croft, 2012), collaborative consultation was sought throughout the review process. Members of the project's public involvement group, comprising self-advocates with learning disabilities, family carers of adults with learning disabilities, and members of the research team, were consulted throughout.

2.1 Identifying the Review Question and Objectives

This review aims to answer the following research questions:

1. What are the mental health needs and experiences of adult/older family carers of adults with learning disabilities?
2. What factors influence the mental health of this group of family carers and how?
3. What services, interventions, and support systems do this group of family carers engage with and what evidence exists of their perceived effectiveness?
4. How are people with learning disabilities, family carers, and mental health experiences conceptually constructed in the evidence?

2.2 Eligibility Criteria

Our eligibility criteria were developed and refined using the population, contexts, and concepts (PCC) framework (Peters et al., 2020). Table 1 details the full inclusion and exclusion criteria. Published and unpublished (grey) evidence items were included for review. We excluded clinical trials, protocols, and commentaries as these were not considered useful sources for answering the exploratory research questions of this review.

2.3 Search Strategy

The research team conducted an initial manual scoping of existing systematic reviews. However no existing systematic reviews centralised or explicitly addressed the mental health of family carers of adults with learning disabilities in the UK or England/devolved nations. The reference lists of reviews were then manually searched by the lead author, Martina Smith. A health science information specialist

Table 1 Evidence Eligibility Criteria

PCC Element Definition	Inclusion Criteria	Exclusion Criteria
Population • Persons with learning disability ≥18 years. • Unpaid carers ≥18 years. *Concept* • Carer mental health and/or well-being. • Carer mental health and/or experiences of mental health support/services/interventions/medications. *Context* • United Kingdom OR England OR devolved nations. • Made available in 2014 or later to coincide with the Care Act 2014.	a) UK context (or England/individual devolved nations). b) Produced or written in English. c) Made available in 2014 or later (to coincide with the Care Act 2014). d) Full text/complete source available online. e) Caring for someone with a learning disability.	a) Paid/professional carers. b) Non-UK context. c) Pre-2014 publication. d) Caring for a person with a specific medical/psychological diagnosis or autism with no reference to learning disability. e) Explicitly and only focused upon the transition period from child to adult services.

identified three appropriate databases for systematic searching: Scopus, Web of Science, and PsycInfo. Search strategies were developed with the support of the information specialist and project research team. Database searches were carried out in November 2022. Search strategies used for each database are available as an Appendix. The search resulted in 1,111 studies which were exported to EndNote X9 where 153 duplicates were removed (See Figure 1). The remaining items were screened by title and abstract by Martina Smith.

In addition to the rapid database searches, the information specialist recommended databases Overton, Kanopy, and Box of Broadcasts. These databases were manually searched by Martina Smith, as were the first five pages of Google and Google Scholar. The public involvement group and wider research team were consulted to identify additional evidence sources. Manual searches were conducted on the reference lists of included evidence items and of key journals suggested by research team members.

2.4 Source of Evidence Selection

Thirty-three full-text articles and sources of evidence were reviewed. These were 26 articles identified via database search and seven evidence items found via manual reference, journal, and multimedia database searches and research team and public involvement group (the Tea and Cake Group) member recommendation (Figure 1). Four members of the research team were involved in this process with each article reviewed by two team members. Queries were discussed and disagreements resolved during review meetings, resulting in the final inclusion of eighteen papers for in depth review and analysis.

2.5 Charting the Data

Martina Smith charted relevant information summaries about each included evidence item through the lens of this review's exploratory research questions. Single reviewer data extraction is recommended as an expediting option in rapid reviewing methodology (Tricco et al., 2017). The characteristics of included evidence sources were organised in a table adapted from the data extraction instrument suggested by Peters et al. (2020). For characteristics of evidence sources included see Table 2.

2.6 Narrative Thematic Synthesis of Findings

A critical reflexive thematic analysis was conducted on the included evidence items (Braun and Clarke, 2021), led by Martina Smith and supported by co-authors. Braun and Clarke's (2022) thematic analytical process was adopted as a scholarly companion rather than rigid procedural manual to align with the political commitment to resist the status quo of proceduralism and ensure responsiveness to the complexities of the human lives in "data" (Braun and Clarke, 2022). This is not analysis for analysis' sake; we wanted to get into the cracks, find the voids, and explore the underbelly of the mental health experiences and needs of family carers of adults with learning disabilities.

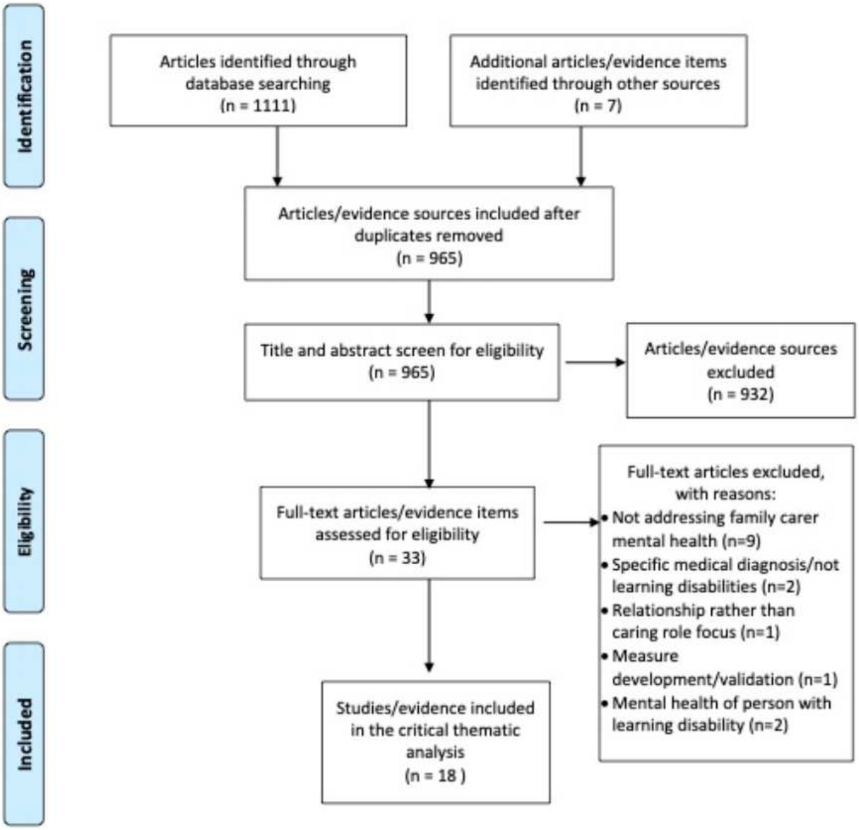

Figure 1. PRISMA 2009 Flow Diagram (Moher et al., 2009) Detailing the Evidence Search Process.

We initiated thematic synthesis through familiarisation with the data, thinking critically together with the research questions (Braun and Clarke, 2022). Martina Smith read each evidence item, making notes in documents for discussion with co-authors. This process enabled the research team to share thoughts and reflect on assumptions (Braun and Clarke, 2022). The data were coded using inductive and deductive approaches; in practice this meant staying vigilant to data that were relevant to family carer mental health and the research questions whilst also reading the data through the theoretical lens of critical disability studies and the social model of mental health (Braun and Clarke, 2022). Themes and subthemes were subsequently developed, (re)refined and (re)named.

2.7 The Tea and Cake Group

In advance of a group meeting members of the project public involvement group, the Tea and Cake Group, were sent an Easy Read summary of the themes (availa-

Table 2 Summary Table of Included Evidence

Author, Year of Publication	Title	Type of Evidence and Mode of Collection (if applicable)	Stated Aim/ Purpose and Suitability for this Review's Aims	Population and Geographical Location	Conceptualisation of Key Terminology and Chosen Key Terminology Usage (learning disability, family carer, mental health and/ or well-being)	Main Findings in Relation to Family Carer Mental Health and Well-Being
Action for Carers, n.d. (accessed Nov 2022–Feb 2023)	Carer Stories	Online short stories by individual carers sharing their experiences	To share common themes across adult carers stories whilst acknowledging individual experiences.	Carers of adults with learning disabilities, England	The term learning disabilities is used in stories.	Becoming more appreciative of positives in life. The importance of being around other carers who understand and can support. The future becoming an increasing concern and feeling invisible. Embracing creativity and managing stress through recreational musical, art, and sports activities.
Congreve and Watts, 2021	Learning disabilities and the value of unpaid care	Report and analysis drawing upon primary research using diaries, questionnaires, and focus groups with unpaid carers.	To examine the extent and value of unpaid care for people with learning disabilities in Scotland and the impact on carer's lives, well-bein,g and financial prospects.	17 unpaid carers of adults with learning disabilities, Scotland	Uses the term unpaid carers and the term learning disabilities. Well-being associated with a self-judgement of positive state of mental well-being.	Much higher number of family carers report feeling lonely in comparison to the general population. Impact on employment and sustaining labour force engagement entangling with mental health. Income impacting well-being scores. Lower scores for this group of carers than average population for well-being in relation to loneliness, the future, self-worth, energy and burnout. Issue highlighted that you can't compare to self-worth, energy and levels of burnout felt prior to becoming a carer. The well-being of the person they care for is central to the carer's well-being. Pandemic exacerbating exhaustion and burnout.

Author, Year of Publication	Title	Type of Evidence and Mode of Collection (if applicable)	Stated Aim/ Purpose and Suitability for this Review's Aims	Population and Geographical Location	Conceptualisation of Key Terminology and Chosen Key Terminology Usage (learning disability, family carer, mental health and/ or well-being)	Main Findings in Relation to Family Carer Mental Health and Well-Being
Davys et al., 2014	Futures planning – adult sibling perspectives	Qualitative semi-structured interviews and thematic analysis	To explore older families' perceptions of the future and experiences of lifelong caring	15 adult siblings of people who have a learning disability, UK	Not explicitly defined. "Learning disability" and parent or sibling or family carers terminology used.	"The future" is reported as a complex superordinate theme. The future is a source of worry for sibling and parent carers. Whilst good future planning can support better mental health and well-being it is often difficult to discuss and/or inadequately done.
Davys et al., 2016	Adult siblings consider the future: emergent themes	Qualitative, semi-structured interviews, IPA approach	To explore sibling expectations and wishes for the future and expectations for future support	15 adult siblings (same sample as Davys et al., 2015 but expands to explore all themes), UK	Uses the term "intellectual disability", sibling caring is discussed separately and as a part of the "sibling role". Intellectual disability is frequently referenced without the person and at times reads as a human-less entity.	In the context of this review, the impact of intellectual disability upon sibling life, transitions, services, and the future all offer some evidence of sibling caring roles including the anticipatory nature of care role transitions as parent carers age and the role this plays in carer well-being. Sibling well-being is directly addressed and "advice" to other siblings shared. The lack of involvement of the person with intellectual disability in decision making and planning is mentioned.A call for help for sibling mental health needs but leaves a gap of what these are and how they could be met.

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Forrester-Jones, 2021	The experiences of older carers of people with learning disabilities: "I just carry on with it."	Qualitative, interviews and thematic analysis	To explore the experiences of older carers of people with learning disabilities from their own perspectives	21 older carers (65+), UK	Uses the abbreviation LD in reference to people with learning disabilities. Older carers are defined as being 65 years + The discussions of upskilling through care demands and management push the boundaries of traditional constructs of family carer.	Complexity of transformation in caring role and mutual care as health deteriorates and traditional notions of "retirement" become un/done. These transformations in time entangle with negative feelings of loneliness, reduced support, lack of a break, which all negatively impact well-being. The complexities and challenges of future planning and the impact of this on well-being are discussed.
Grey et al., 2018	Physical and psychological health of family carers co-residing with an adult relative with learning disabilities	Online and postal questionnaires, including the positive gains [from caring] scale, comparative quantitative analysis	To examine the well-being of family carers co-residing with an adult with learning disabilities and explore the differences in self-reported health status of UK family carers and general population in the UK	110 family carers co-residing with an adult with a learning disability, UK	The terms "family carers" and "intellectual disability" are used, no definitions provided.	The transformation of carers through time and "stages" of caring impact self-reported mental health outcomes. Postulated as a result of becoming accomplished at caring and the transformation to reciprocal caring roles with age. Whilst compared to female carers, fewer male carers took part in the study, which is reflective of wider society. However, gender differences did highlight that being male was associated with higher levels of caregiver burden, family stress and lower positive gains from caring. Active coping strategies are important for reducing the negative psychological impact of caregiving. Reports higher levels of SES as associated with lower levels of mental distress.

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Hayden et al., 2022a	Adult siblings of people with intellectual disabilities and/ or a diagnosis of autism. An evidence review	A narrative review of international literature/evidence about adult sibling relationships, caregiving, needs, and gaps in evidence	1) To explore if adult siblings are at risk of increased psychological and social problems 2) To identify positive outcomes for siblings 3) To explore the sibling relationships 4) To explore caregiving roles and expectations 5) To explore the impacts on life choices 6) To identify what support exists and where there are gaps in evidence	Not applicable	Uses the term "intellectual disabilities" whilst locating the term "learning disabilities" in the UK context. A sense of 'becoming' caregiver and the caring role of the future.	Siblings are often considered as potential carers once parent carers are no longer able to provide care which can cause conflict and challenges. Sibling life decisions such as marriage, starting a family, and career choices may be shaped by having a disabled sibling and impacts mental health. Notes research tends to exclude perspectives from disabled siblings. The study highlights some positive outcomes which the authors associate with what they describe as particular diagnostic categories.

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Hayden et al., 2022b	Subjective poverty moderates the association between carer status and psychological outcomes of adult siblings of people with intellectual and developmental disabilities.	Online survey, quantitative comparative between-group analysis	1) To explore the moderating impact of SES and level of independence of siblings with a learning disability on sibling carer status and health and well-being 2) To compare the health and well-being of sibling carers with other adults	851 siblings of a person aged 16 or over with a learning disability, UK	Uses terminology "people with intellectual and developmental disabilities" and abbreviation IDD. Sibling caring is contextualised as a potential part of sibling role alongside friendship and support. Refers to sibling potential for becoming "compound carers" over time where siblings may be caring for other family members such as children or parents(-in-law) and thus manage multiple different caring roles concurrently.	Mental health, well-being, and quality of life significantly associated with the level of independence and support needs of siblings with learning disabilities. Evidence of sibling carer status negatively impacting sibling health in comparison to siblings who are not carers.

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Herron et al., 2020	Supporting people with an intellectual disability and dementia: a constructivist grounded theory study	Qualitative, semi-structured interviews, constructivist grounded theory methodology	1) To explore family and paid carers' experiences of supporting people with an intellectual disability and dementia 2) To explore experiences with the *Intellectual Disability and Dementia Care Pathway (IDDCP)* 3) To create a useful theory for understanding these experiences	18 participants, 2 of whom are family carers, England	Family carers are defined as "informal carers who support a member of their family, unpaid, usually in the home" (146). Uses the term "intellectual disability".	Uncertainty for carers due to the lengthy diagnostic period for people with intellectual disability. Equipping carers with appropriate knowledge and strategies for support associated with better well-being outcomes (i.e., reducing carer burden which is associated with carer well-being). Support for specialist intellectual disability and dementia pathways to enhance person-centred planning and equip carers with appropriate skills and knowledge which is associated with better carer outcomes.

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Mitter et al., 2018	Stigma experienced by family members of people with intellectual and developmental disabilities: multidimensional construct relative with a learning disability	Quantitative. Development and validation of a self-measurement tool of stigma and subsequent assessment of family experiences of stigma. Data collected via online survey shared through social media and newsletters by UK organisations supporting carers of people with learning disabilities.	To develop a self-report measure of family stigma for families of people with intellectual disabilities and explore the association between family stigma and other variables. Has included positive aspects of caregiving that have previously been neglected in family stigma research in this context.	407 family carers, UK	Uses the term "intellectual and developmental disabilities" (IDD); acknowledges learning disabilities as a UK health service term and uses this in questionnaires.Family carers not explicitly defined.	More than half of family carers report their caring has given them a more positive outlook on life. Perceived burden of caring and perceived family stigma associated with increased emotional and psychological distress. Higher levels of affiliate stigma apparent in younger family caregivers. Important to pay attention to affiliate stigma as suggested as insightful to carer mental health.

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Patel et al., 2021	The experiences of carers of adults with intellectual disabilities during the first COVID-19 lockdown period	Qualitative online interviews (due to pandemic restrictions)	1) To explore recent experiences of COVID-19 lockdown on parent-carers of adults with learning disabilities 2) To inform future care planning for any further lockdowns	8 parents who were the main unpaid carers for an adult with a learning disability, UK	Term "intellectual disability" is used and abbreviated through the paper to ID. Refers to parents of adults with ID.	Parents reported feeling powerless and a lack of control. Resilience born of lifelong caring enabling better coping. The lack of in-person support can be mediated by online support - transformation of commons. The relentlessness of caring during lockdown and inability to mentally "switch off" or engage with self-care such as mindfulness.
Pryce et al., 2015	Tolerating uncertainty: perceptions of the future of ageing parent carers and their adult children with intellectual disabilities	Qualitative semi-structured interviews and thematic analysis	To explore the experiences of lifelong caring and care of older carers and adults with intellectual disabilities and perceptions of the future	12 participants (9 older family carers and 3 adults with intellectual disabilities, UK	Uses the term "intellectual disabilities". Refers to family caregivers, older carers identified as age 65 years + Carer responses that challenge assumptions such as "I am just her mum and that's that." Where are the parent and carer definition boundaries?	Main theme of "tolerating uncertainty" as an often-passive process focusing on the present. The contradictory feelings of adults with learning disabilities who did not have the same negative feelings for the future. Profound fear and anxiety noted in carers in relation to the future. Not knowing where to go or what to do makes these situations worse, negatively impacting mental health.

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Sibs, n.d. (accessed 2022–2023)	Sibling stories	Self-reported sibling stories about a variety of aspects of siblinghood with a disabled sibling. Only drawn from those stories relating to mental health, caring and a sibling with a learning disability.	Aimed at siblings of adults with disabilities as a beneficial opportunity to identify similarities of experiences with the stories of other siblings.	53 individual sibling short stories available online, UK		The challenges of caring and trying to maintain work/careers; caring spilling over into paid work life. Many stories invoke the idea of not feeling completely understood, the uniqueness of the sibling-carer role. Strong threads of love and stepping up to care whilst also getting a lot out of the caring experience too. Needs continue to exist even when being well met. Managing is not the same as being well through the role.
Sibs, 2020	Self-care for siblings	An e-book for adult siblings in the UK who have grown up with a disabled sibling(s)	To help adult siblings recognise that they are not alone, offer self-care ideas and encourage siblings to get further support if needed	UK	Being a sibling and being a carer clearly differentiated and issues impacting depending on care role or relationship clearly demarcated.	Highlights the assumption of siblings assuming a caregiving role that can be made by services. The im/possible choice of siblings to become a carer or not and the negative impact of being faced with these choices compared to other siblings. Acknowledges intense feelings of love and this love not being understood, increasing risk of isolation. Overshadowing effect of disabled siblings' mental health problems.Evidence of anxiety, depression, OCD, PTSD.

Author, Year of Publication	Title	Type of Evidence and Mode of Collection (if applicable)	Stated Aim/ Purpose and Suitability for this Review's Aims	Population and Geographical Location	Conceptualisation of Key Terminology and Chosen Key Terminology Usage (learning disability, family carer, mental health and/ or well-being)	Main Findings in Relation to Family Carer Mental Health and Well-Being
						Need for coping strategies with stress and compassion fatigue. Suicidal feelings among caregivers.Caring responsibilities to parent carers who may have caring related mental health issues. Complexities regarding the anticipated future.
Totsika et al., 2017	Informal caregivers of people with an intellectual disability in England: health, quality of life and impact of caring	Survey, face-to-face interviews with a selection of survey respondents. Quantitative, between-group comparison study	To examine the quality of life, health, and the impact of caring for a person with intellectual disability	258 carers of a person with an intellectual disability, 1945 comparison carers, England	Uses the term "informal caregivers". Defined as people who give unpaid care to relatives, friends or partners. Uses the term intellectual disability. Highlights issues in policy of generalising caregiving when it is a homogenous role. Caregiver well-being synonymised with perceived quality of life. Quality of life measure has good validity.	Gendered dimension to care – this has an impact for mental health research in this field as women are suggested as coping differently to men. Carers of adults with intellectual disabilities are not found to report worse quality of life than any other groups of carers but at higher risk of poorer health status, although this is not definitively associated and may be linked to other life factors. Subjective poverty is associated with poorer well-being outcomes for carers. Interplay of financial well-being.

Author, Year of Publication	Title	Type of Evidence and Mode of Collection (if applicable)	Stated Aim/ Purpose and Suitability for this Review's Aims	Population and Geographical Location	Conceptualisation of Key Terminology and Chosen Key Terminology Usage (learning disability, family carer, mental health and/ or well-being)	Main Findings in Relation to Family Carer Mental Health and Well-Being
Turnpenny et al., 2021	Family carers managing personal budgets for adults with learning disabilities or autism	Qualitative, interviews and a descriptive phenomenological approach	To investigate the experiences of carers who manage personal budgets on behalf of people with complex needs	13 family carers who manage a personal budget on behalf of a person with a learning disability	Refers to family carers and informal carers as usually being family members. Uses the UK contextualised term "learning disabilities and autism".	Managing personal budgets can enable carer peace of mind and the balancing of caring with increasing capacity/opportunity for self-care therefore positive impact on well-being. Not consistently positive experience due to issues of choice and control and there is evidence of high mental load and emotional toll for carers navigating complex systems and processes.
Walker, 2015	Ageing and people with learning disabilities, in search of evidence	Narrative evidence synthesis of research in the field of learning disability, ageing and family and social care.	To find out what is known and where evidence gaps remain about the support older people with learning disabilities and their carers need.	UK	Uses the UK term "learning disabilities" and ageing carers as people aged 65 years +	Reports the unique challenges facing this group of older carers in relation to lifelong caring; the effects of this on earlier job market participation and later life financial consequences which are known to impact mental health. Lack of financial resilience. Highlights the changes in caring dynamics and the need to address ageing much earlier in the lifespan to alleviate negative effects later in life.

Author, Year of Publication	Title	Type of Evidence and Mode of Collection (if applicable)	Stated Aim/ Purpose and Suitability for this Review's Aims	Population and Geographical Location	Conceptualisation of Key Terminology and Chosen Key Terminology Usage (learning disability, family carer, mental health and/ or well-being)	Main Findings in Relation to Family Carer Mental Health and Well-Being
Willner et al., 2020	Effect of COVID-19 pandemic on the mental health of carers of people with intellectual disabilities.	Online survey, quantitative analysis comparing carers of children and adults with intellectual disabilities and carers of children who don't have intellectual disabilities.	1) To document the mental health of family carers of children and adults with intellectual disabilities during the pandemic. 2) To relate carer mental health status to the support available to them and to their strategies for coping with stress.	107 carers of adults with a learning disability (plus 100 carers of children with a learning disability and 37 carers of children without a learning disability, UK	Uses term "informal carers" to describe (mainly) parent carers.Uses the term "intellectual disabilities". Mental health assessed using a measure for depression (synonymised with depression).Coping is defined as adaptive and maladaptive coping.	Significantly high scores for severe depression and anxiety in this group of carers compared to comparison groups of carers. Comparison data from previous research suggests mental health worsened for carers of children and adults with learning disabilities during the pandemic. Carers of adults received less family and professional support - ever-decreasing networks of support. Did receive support from neighbours.

ble as an Appendix). This group was made up of five family carers and four adults with learning disabilities. We met with the group for discussion and feedback of the early themes and subthemes. Group members helped us to clarify and define the themes and shaped the analysis in by noting the absences of love and attention paid to the care provided by people with learning disabilities. Their analysis emphasised the relational nature of care and fundamentally shaped the emphasis of the review.

3. Findings

3.1 Description of Included Evidence

Summaries of the characteristics of the eighteen items included for narrative thematic synthesis are presented in Table 2. More detailed descriptors of evidence, including modes of data collection, terminology conceptualisations, and main findings are summarised in the Appendix.

3.2 Thematic Synthesis

Table 3

3.3 Theme: The Complex Temporalities of Caring and Mental Health

This theme focuses upon the complexities of the temporalities of the life course of family carers and adults with learning disabilities. We draw attention to the ways in which the experiences of family carers disrupt normative assumptions of unilinear life trajectories that are bound with ableist assumptions of progress, independence, and familial relationships and structures.

3.3.1 Subtheme: Facing the (Unfaceable) Future

The future weaves through the evidence, invoking temporal experiences that impact well-being in ways specific to this group of family carers (Action for Carers, n.d.; Congreve and Watts, 2021; Sibs, 2020; Davys et al., 2014; Davys et al., 2016; Forrester-Jones, 2021; Hayden et al., 2022b; Pryce et al., 2017; Sibs, n.d.). For parent and sibling carers, the future can invoke anxieties (Pryce et al., 2017; Sibs 2020). Pryce et al. (2017) report a complex process through which parent carers manage fears by remaining focused in the present. This aligns with evidence from Forrester-Jones (2021) that emphasises the high stakes of resisting the future in relation to a consequential lack of robust planning, with potentially catastrophic consequences (Pryce et al., 2017). The emotional complexities associated with future planning reinforce the need for planning ahead and for this to be acknowledged as a highly sensitive and ongoing endeavour (Forrester-Jones, 2021). For parent carers, fears and hopelessness centre around financial and service precarity and the deeply emotional challenges in facing mortality (Pryce et al., 2017).

Evidence regarding siblings as carers and/or carers for the future is complex and inconsistent. While some studies report the idea of assumed parental expecta-

Table 3 Themes, Subthemes, and Supporting Evidence

Theme	Subtheme	Evidence
The Complex Temporalities of Caring and Mental Health	Facing the (Unfaceable) Future	Action for Carers, n.d.; Congreve and Watts, 2021; Davys et al., 2014; Davys et al., 2016; Forrester-Jones, 2021; Hayden et al., 2022; Pryce et al., 2017; Sibs, 2020; Sibs, n.d.
	Temporal Disruptions	Congreve and Watts, 2021; Forrester-Jones, 2021; Grey et al., 2018; Hayden et al., 2022; Herron et al., 2020; Sibs, 2020; Totsika et al., 2017; Walker, 2015
Economic Labours of Love	The (Un)Valued Economics of Caring and Its Life Long Shadows	Congreve and Watts, 2021; Grey et al., 2018; Hayden et al., 2022; Totsika et al., 2017; Walker, 2015
	The Love of a Skilled Care-Force	Congreve and Watts, 2021; Davys et al., 2014; Grey et al. 2018; Forrester-Jones, 2021; Hayden et al., 2022; Patel et al., 2021; Pryce et al., 2017; Sibs, 2020; Turnpenny et al., 2020; Willner et al., 2020
Commoning and the Multiplicities of Carer Mental Health	The Responsibilities of Service Provision	Congreve and Watts, 2021; Davys et al., 2016; Grey et al. 2018; Forrester-Jones, 2021; Pryce et al., 2017; Sibs, 2020; Totsika et al., 2017; Turnpenny et al., 2020; Sibs, 2020; Sibs n.d.
	Commoning for Care	Action for Carers, n.d.; Congreve and Watts, 2021; Davys et al., 2016; Grey et al., 2018; Patel et al., 2021; Pryce et al., 2017; Sibs 2020; Sibs n.d.
Confronting Inhumanity	Disrupting Ableism for Mental Health	Mitter et al., 2018; Pryce et al., 2017
	Language Matters: (Re)Constructing (All) Lives for Justice	Congreve and Watts, 2021; Davys et al., 2014; Grey et al. 2018; Forrester-Jones, 2021; Hayden et al., 2022; Herron et al., 2020; Mitter et al., 2018; Patel et al., 2021; Pryce et al., 2017; Sibs, 2020; Totsika et al., 2017; Turnpenny et al., 2020; Walker, 2015; Willner et al., 2020

tion for non-disabled siblings to eventually assume caring responsibility (Davys et al. 2014, Davys et al. 2016, Hayden et al, 2022a; Forrester-Jones 2021), this is contested by Pryce et al. (2017) who report a unanimous judgement of unfairness by older parent carers in regard to placing caring expectations upon siblings. Sibs (2020) conveys potential sibling carer frustration when parent carers are resistant to futures planning whilst Davys et al. (2014, 222) report futures planning as a “transitional process”. Throughout this process, siblings as carers-for-future invoke a temporal “anticipatory” component to caring (Sibs, 2020). There is a profound sense of parent carer distrust that anyone else could provide their standard of care (Davys et al., 2016; Pryce et al., 2017). Only one paper attends to the perspectives of adults with learning disabilities in relation to the future and found people expressed optimism and excitement for increased independence and positive gains from possibility-generating conversations regarding the future (Pryce et al., 2017).

3.3.2 Subtheme: Life Course Nuances for Family Carers of Adults with Learning Disabilities

The temporal life course nuances of family carers of adults with learning disabilities are explored in this subtheme, and we engage with a dis/temporality that distinguishes this group of carers from other groups (Congreve and Watts, 2021; Totsika et al., 2017; Walker, 2015). This includes longer hours of care provided and longer duration of caring years in comparison to other groups of carers and an associated increased susceptibility to negative psychological outcomes.

As highlighted earlier, supporting an adult with learning disabilities involves a multitude of diverse experiences (Cluley et al., 2020). Evidence suggests the level of support needs of the person is associated with higher levels of family carer stress, although no other negative well-being factors (Grey et al., 2018). We do not read the evidence as situating responsibility for higher stress levels within the person with high support needs. Rather, we ask for a redirection of accountability to the socio-political structures and services that should be responsible for meeting these needs that consequently impact family carer stress.

Narrow ableist assumptions of life trajectories and familial roles across a predetermined life course become undone through a critical reading of the evidence. For sibling carers, the role of carer can expand to include the provision of emotional support for parent carers (Sibs, 2020). Parent caring roles also change throughout the life course. Sibling carers may become "compound carers" whereby they manage multiple different caring roles simultaneously (Hayden et al., 2022a). Grey et al. (2018) and Walker (2015, 43) report the often unacknowledged shifts in care dynamics between family carers and the person with learning disabilities in later life, transforming into "mutual caring" roles or toward a more radical shift.

Dementia requires specific attention in the lives of adults with learning disabilities and carer mental health (Herron et al., 2020). The skills acquired by family carers do not always align with advocated principles of caring for an adult with dementia, although the exact ways in which this misalignment occurs are unclear (Herron et al., 2020). We highlight here the perpetuation of hyper-individualised expectations upon family members to acquire yet further specific caring skills. Learning disabilities can also overshadow early signs of dementia thus delaying diagnosis and appropriate interventions and treatments (Herron et al. 2020).

Late diagnosis, conflicting care practices, and the advancing of dementia all have a negative psychological impact on family carers. Herron et al. (2020) assert the importance of diagnosing dementia as early as possible via ongoing tests and baselining before any signs of dementia present (Herron et al., 2020). Another point at the intersection of older age and caring is age-associated physical health deterioration and the challenges this adds to the caring role. This role is reported as continuing by older carers "regardless of whether or not their loved one lived at home or in supported living" (Forrester-Jones, 2021, 50), undoing normative constructions of a final life phase of retirement.

3.4 Theme: Economic Labours of Love

Economics is explored here as multifaceted and inextricable from family carer mental health. The support provided by family carers of adults with learning disabilities is a far greater labour than can be confined to economics (Congreve and Watts, 2021). However, given the oft ignored value of this labour to the taxpayer and the ways it impacts carer mental health, this theme demanded attention (Congreve and Watts, 2021).

3.4.1 Subtheme: The (Un)Valued Economics of Caring and Its Lifelong Shadows

Caring roles entangle with paid labour opportunities for family carers, increasing financial precarity throughout life, with repercussions echoing negatively in what non-carers term "retirement" (Congreve and Watts, 2021; Walker, 2015). Current constructs of economic impact upon carers assume normative constructs of "working" and "non-working" lives that do not resonate with the familial caring role. This is echoed in Walker's (2015) depiction of financial anxiety and poverty that is ill-accounted for by policies fit for normative working lives and the assumed retirements and pensions that follow.

This matters in the context of repeated associations made between socio-economic status and carer well-being. Lower socio-economic status and financial vulnerability is associated negatively with psychological outcomes for this group of carers (Grey et al. 2018; Hayden et al., 2022b). Totsika et al. (2017, 959) highlight an increased likelihood of family carers reporting "significantly more financial difficulties than other carers", suggesting heightened financial precarity risk and associated negative impact upon well-being, while filling "the gaps left by the care system" (Congreve and Watts, 2021).

3.4.2: Subtheme: The Love of a Skilled Care-Force

A powerful construction of love is woven throughout this subtheme, one that transcends private spaces, sustaining a care-force that plugs economical and service gaps (Congreve and Watts, 2021). Love sustains intensive, skilled, and long hours of family caring in a context of austerity-related diminishing support and short-term breaks (Forrester-Jones, 2021) and demands recognition as a political force. This love drives family carers to continue their intense provisions of support and care (Sibs, 2020). Carers report deep joy in their caring relationship and the importance of mutual well-being: "as long as he's happy, then we are satisfied" (Pryce et al., 2017, 90).

This love constructs a blurring of culturally conceptualised normative boundaries of caring, parenting, and professional roles (Turnpenny et al., 2020). Through the complex and stressful management of personal budgets and paid personal assistants, financial management becomes an endeavour of love (Forrester-Jones, 2021; Turnpenny et al., 2020). Positive outcomes of providing long-term care were associated with satisfaction with support and more robust coping strategies of carers, although the mechanism of this buffer remains unclear (Grey et al., 2018). The acquisition of skills and development of caring competence are often shared as a source of pride (Pryce et al., 2017).

The invisibility of this work disrupts normative perceptions of lockdown and isolation as being solely associated with the COVID-19 pandemic. Carers report experiencing challenging periods of isolation and self-imposed “lockdowns” before the pandemic, either during periods of crisis or as a normal part of their pre-pandemic life (Patel et al., 2021). This is an important yet overlooked perspective when considering the *additional* negative impact of lockdowns and isolation on family carer mental health (Willner et al., 2020).

3.5 Theme: Services and Communities for Carer Mental Health

The mental health of family carers does not exist in isolation, intersecting with varied factors that cause, perpetuate, and/or sustain positive and negative carer mental health experiences. These are explored throughout this theme of communities of support that are responsible (or not) to the heterogenous lives of family carers (Congreve and Watts, 2021).

3.5.1 Subtheme: The Responsibilities of Service Provision

There is little recognition or appreciation within service provision and professional support of the skilled and often demanding care provided by family carers (Forrester-Jones, 2021). Forrester-Jones (2021, 52) reports a perceived unstable foundation of service provision whereby family carers feel that they must remain alert and “‘on call’ to mitigate problems”.

Where satisfaction with services are high, positive mental health gains are reported (Grey et al., 2018; Pryce et al., 2017). Perception of services as inadequate are associated with poorer psychological outcomes (Grey et al., 2018) alongside a negative impact on the lives of people with learning disabilities (Davys et al., 2016). A disconnect between the quality and personalisation of support provided by family members in comparison to that provided by paid carers is also reported (Davys et al., 2016). Given the interconnectedness of family carer well-being with the perceived well-being of the person they support, this is often directly implicated with carer well-being (Forrester-Jones, 2021). Services can perpetuate negative emotions when perceived as inadequate (Sibs, 2020), inflexible to needs (Pryce et al., 2017), or a disengaged battlefront (Congreve and Watts, 2021). Secondary trauma is further reported in sibling carer evidence when disabled adult siblings have experienced institutional abuses (Sibs, 2020; Sibs, n.d.).

There are moments where normative experiences associated with bringing joy or short breaks that are understood to support well-being are absent due to inadequate support. These include holidays, time with other family members, days out, and celebrations (Forrester-Jones, 2021; Totsika et al., 2017). These restrictions on many taken-for-granted joys in normative constructs of living are important and for this care-force, restrictions and their potential impact upon mental health demand attention (Forrester-Jones, 2021).

3.5.2 Subtheme: Communities for Care

Evidence suggests individual coping strategies are associated with better psychological outcomes for carers (Grey et al., 2018) and bolstered by positive perceptions of the quality and appropriateness of support (Pryce et al., 2017). We implore caution in the evaluations of individualised and internalised coping mechanisms as discrete from wider contexts due to concerns that this narrow gaze misses that which constructs or deconstructs carers' coping abilities. For socio-economic policies to appeal in an ever-heightened neoliberal society, individualised responsibilities are too easy a distraction from state responsibilities.

We argue for a shift away from hyper-individualisation towards an insistence on communities of caring whereby the responsibilities are always shared, never rested solely on an individual (Runswick-Cole and Goodley, 2018). The agency of carers is thus *always* situated and valued as part of the wider community (Bollier and Helfrich, 2012). Within the evidence carers share experiences and advice through research interviews (Davys et al., 2016) and more directly their stories of caring (Action for Carers, n.d.; Sibs, 2020). These shared narratives do more than retell the lives of family carers; they offer connectivity, an activism of community shaking the cloak of invisibility that so often falls over this caring labour (Action for Carers, n.d.; Sibs, n.d.).

Where community retreats, loneliness and isolation are reported (Congreve and Watts, 2021). Whilst these issues brought to the forefront during the COVID-19 pandemic, we saw above how isolation and loneliness predate the pandemic (Congreve and Watts, 2021; Patel et al., 2021). Evidence suggests, however, a contraction of support during periods of national lockdown and enforced isolation (Patel et al., 2021), with reported feelings of service "abandonment" impacting carer mental health (Congreve and Watts, 2021, 18). Of particular concern is evidence that pre-pandemic professional support levels are not returning, nor is there plan for their return across UK nations (Congreve and Watts, 2021).

3.6 Theme: Confronting Inhumanity

This review of "evidence" means nothing without centralising and valuing the lives of people with learning disabilities and family carers in engagement with it. We remain critically attuned to the terminologies and politics of the evidence reviewed (Cluley, 2018). There are inconsistencies in terminology, moments of disconnection from equitably valued diverse human lives and ongoing problematic moments of deficit and hyper-individualising discourse to which we attend.

3.6.1 Disrupting Ableism for Mental Health

Negative judgments of adults with learning disabilities persist, as do fixed and predetermined normative socio-economic and developmental expectations Mitter et al. (2018, 332) report on the negative impact of affiliate stigma on the well-being of family carers which is described in a way that makes us recoil: "conceptualised as a mark of social disgrace". Affiliate stigma in this context refers to the stigma experienced by family carers by virtue of their association with the person stigmatised.

Whilst it is important to pay attention to the ways in which affiliate stigma is experienced, we look beyond individuals and focus our attention on the ableism and hostile social reactions to differences that construct these concepts. If carer well-being is shaped by the communities in which they live and it is these communities that produce experiences of stigma, then addressing ableism is paramount.

3.6.2 Subtheme: Language Matters: (Re)Constructing (All) Lives for Justice

The words we choose matter. Language and identity labels are steeped with political, social and cultural assumptions and consequences yet the complexities and implications of terminological choices are rarely acknowledged. The terms *unpaid carer* (Congreve and Watts, 2021) and *family carers* (Grey et al., 2018; Herron et al., 2020; Forrester-Jones, 2021; Patel et al., 2021) or *older carers* (Forrester-Jones, 2021) are used interchangeably. Informal carers (Totsika et al. 2017, Willner et al., 2020) is used in relation to unpaid status which we consider problematic given family carers may be employed and/or in receipt of state benefits, although it is important to point out that carers allowance as a standalone benefit does not constitute a liveable wage. We feel further discomfort that the perspectives of people with learning disabilities are completely absent or are included in such a limited way as to be tokenistic.

Learning disabilities (Congreve and Watts, 2021; Davys et al, 2014; Forrester-Jones, 2021; Turnpenny et al., 2020; Walker, 2015), intellectual disabilities (Davys et al., 2016; Grey et al., 2018; Herron et al., 2020; Patel et al, 2021; Pryce et al., 2017; Totsika et al., 2017; Willner et al., 2020) and intellectual and developmental disabilities (IDD) (Hayden et al., 2022a and 2022b; Mitter et al., 2018) were used interchangeably with specific diagnostic labels and the term complex needs was also evidenced. Forrester-Jones (2021, 55) engages with the term "loved one", which was agreed by the participants in this study. This reads with a humanness that more closely represents the lives of family carers than the biological term "offspring" used elsewhere (Patel et al., 2021). We applaud this inclusion of family love that permeates throughout this literature yet is rarely acknowledged.

4. Discussion

This rapid scoping review offers a critical exploration of a diverse body of evidence surrounding the mental health needs and experiences of family carers of adults with learning disabilities in the UK. Findings have been reviewed by a public involvement group of self-advocates with learning disabilities and family carers. Our findings indicate a complex interplay of factors constructing family carer mental health experiences. The review highlights how, within the UK context post-2014, there is limited evidence surrounding the specifics or perceived effectiveness of types of services, interventions, and support systems that support family carer mental health and well-being. No evidence included offered insight into family carer use or engagement with any particular medical, pharmaceutical, psychological or complementary therapies.

Throughout this review, we highlight the need to undo ableist life-course assumptions in care and planning. We argue for the sensitive and kind embedding of future planning as an ongoing fixture in the present. There is a need to remain responsive to the heterogeneity of adults with learning disabilities and those who provide the support they need to live well. The contributions of a highly skilled family care-force are of profound economic and social value to the UK, yet this value is not widely recognised in policy or the wider population, nor afforded the support required to protect the mental health of this group. This is despite the fact that recent research has calculated the economic value of the contributions made by carers in England and Wales as £162 billion per year, rising 11% since 2011 (Petrillo and Bennett, 2021).

Future planning exists in the evidence as a source of worry, stress, and ambiguity for family carers and the perspectives of people with learning disabilities are overlooked. The ways in which it is allowed to manifest, unplanned and either ignored or resisted, needs to be urgently addressed in health and social care research, policy, and practice. This is not only to avert the already identified potentially catastrophic consequences of preventable situations for the adult with learning disabilities when a family carer dies (Forrester-Jones, 2021; Pryce et al., 2017), but to also alleviate the persisting fears of unplanned futures for adults with learning disabilities and their family carers (Ryan et al. 2024). One self-advocate in their 20s in our public involvement group shared they worry about the future and find it difficult to think about. We argue this must be attended to much earlier in life.

Attention must be paid to how family carers can be reassured that their loved one will be supported to live a good and flourishing life in a future without them in a country with an inconsistent record of high-quality social care and provision (Ryan, 2021). There is a lack of future planning perspectives from adults with learning disabilities, and we argue that research, policy, and practices need to make space to centralise these perspectives. Previous research has identified significant barriers to planning for the future (Bibby, 2013). It seems that despite the changes under the Care Act, and perhaps because of a sustained period of austerity, there has been little progress in supporting families to plan for the future. The public involvement group commented on the intensity of caring in the present and how this makes future planning difficult. The challenge here lies in supporting family carers through the entirety of robust futures planning, including the initiation of this process (Ryan et al., 2024)). Such a process requires sensitive consideration of review increments as it is not appropriate to leave future planning solely at the point of older age; unforeseen crises can occur at any point (Ryan et al., 2024).

This review highlights ways in which the life courses of adults with learning disabilities and family carers can disrupt normative life-stage and family role assumptions. This includes assumptions of the length of parental responsibility, sibling roles, and relationships and notions of independence as a marker of adulthood (Smith, 2021). The caring role can ebb and flow, with periods of "compound caring" experienced by siblings supporting both their disabled sibling and the parent (Hayden et al., 2022a) and "mutual caring" where the adult with learning disabilities also cares for their family carer (Grey et al., 2018; Walker, 2015).

We offer as provocation a need to tend to how these ongoing dynamic shifts in life might be better reflected in research and practices through which caring and cared for roles are often demarcated as bounded and static identities. We also highlight, particularly in sibling research, that the sibling relationship is not assumed as synonymous with a caring role; siblings are not legally required to undertake a caring role and the decision to support a sibling with learning disabilities is individual and often complex (Sibs, 2020). Again, we highlight the absence of the perspectives of siblings with learning disabilities (Hayden et al., 2022a) while staying attuned to how the terminology used here can cause discomfort for people living their lives together, compelled to adopt identity labels to access services and resources (Smith et al., 2023). We also note the lack of research involvement with adults with learning disabilities and argue that all perspectives must be considered in future research into the lives of family carers of people with learning disabilities.

Temporality across the life course is disrupted, with normative notions of agency and experience in regard to "working" and "retirement" life stages undone (Congreve and Watts, 2021; Walker, 2015). For some family carers, there is no distinct point of retirement as long-term caring produces significant financial consequences throughout life and impacts on pension security (Congreve and Watts, 2021). This is important given the evidence indicating interplay between lower socio-economic status and poorer carer mental health (Kivimäki et al., 2020). The impact of care as a cumulative experience through which acquired skills and expertise may offer a buffer that protects carer mental health is evidenced (Grey et al., 2018), yet the mechanisms of this buffer need clarification. We are cautious to not synonymise a naturalisation of poorer mental health over time with *better* mental health; as an older carer in the public involvement group reminded us: "I have been doing this for so long I am not even sure what normal feels like" (personal correspondence between Martina Smith and a Tea and Cake group member, 2023).

The acquisition of skills is evidenced though not referenced in detail or reflected in policy. Challenges in systems such as direct payments are identified alongside the ways in which these hyper-bureaucratic systems demand the development of skills. However, there is a failure to acknowledge the pitfalls in making these demands such as a risk of negatively impacting carer mental health or indeed alienating those who should benefit from these services altogether (Turnpenny et al., 2020). Families must be at the heart of service design, interfaces and processes without unnecessary expectations of additional skill acquisition amongst carers who already care for long hours (Turnpenny et al., 2020).

The impact of the COVID-19 pandemic is evidenced (Flynn et al., 2022) and warrants robust future pandemic planning. Brexit has also featured in discussions with our public involvement group but is absent from this review. We acknowledge the difficulties in disentangling the consequences of Brexit upon social care from the pandemic and other global issues during this period, but this should be given attention, and any impact of Brexit upon health and social care warrants addressing in terms of impact upon family carer mental health. It should be noted that much of the research included in this review was conducted pre the Brexit referendum and the UK leaving the EU.

Evidence surrounding recreational activities and self-directed coping strategies carers engage with to support their own mental health is unclear. Engaging with mindfulness as a tool for supporting mental well-being is raised in the context of coping during the pandemic but is contextualised as an impossible tool to engage with as it demands time and space which are often scarce when consumed with caring duties and worry about the person cared for (Patel et al., 2021). This inability to switch off is echoed in relation to inadequate time away from caring. Strategies for supporting carer well-being and short break provision need to be critically considered in terms of how they work to alleviate persistent rumblings of worry and caring that continue beyond the physical presence and acts of care (Patel et al., 2021).

Whilst our review acknowledges the skills and expertise of family carers, further exploration is needed as to how these skills might inform service delivery and the professional development of health and social care professionals. A carer member of our public involvement group reminds us that “yes, carers have lots of skills but councils and professionals often miss opportunities to learn from families” (personal correspondence between Martina Smith and a Tea and Cake group member, 2023). Research, policy, and practice need to consider how to address this ongoing power imbalance and the ways in which valuable skills and expertise are often ignored, a process through which carers are further made invisible and undervalued. It is also important to recognise the consequences of austerity politics here. Reduced access to services negatively impacts on relationships between social care service systems and family carers and people with learning disabilities (Gant, 2010; Mitchell et al., 2015).

No items included for review were primarily focused upon the positive aspects of caring; however joy and pride are woven through as threads of love, friendship, and humanity. Caring can entail reciprocal fun in these moments (Davys et al., 2014), and we are left determined to critically engage with how to simultaneously harness the positives and explore what needs to be done to sustain these periods of joy and pride whilst not eroding the need for professional health and social care services, support, and resources. We need to find a workable public/political concept of love for our communities to deploy in policy documentation that matters yet in which we don’t traditionally associate love. We need love and kinder worlds to tend to the well-being of those who work so hard caring yet remain unvalued and invisible in policy and general social gaze. Kinder worlds cannot be forged from practices shaped by documentation, regulations, and practices that exist disconnected from the lives of people with learning disabilities and family carers.

4.2 Limitations

We acknowledge that through our use of a rapid scoping review methodology, we have constrained the body of evidence included for review. We have however committed to the inclusion of sources of evidence that may have otherwise been ignored via traditional academic exclusion criteria and searches. In limiting the publication date inclusion criterion, we may also have missed relevant evidence items but consider this justified given the project timescales and need for streamlining (Tricco et al., 2020). This allows us to contextualise the evidence in such a way that aligns with the rapid political landscape changes in the UK in the past decade and in response to post-2014 policy shifts. As is commonplace at the intersection of rapid and scoping review methodologies (Tricco et al., 2017), no risk of bias assessment has been undertaken and as such, we are unable to comment on the quality of evidence included.

5. Conclusion

We have centralised and remained attuned to the diverse lives of adults with learning disabilities and their family carers throughout this review. This attunement demands we stay vigilant to our responsibilities for the ways in which everything we write, research, and practise is deeply implicated in the ongoing constructions of caring and mental health experiences. We understand this group of carers not as Other or invisible but as an immensely valued relational part of our communities with whom we belong in an expansive commons. We have explored the often-ignored value of family caring as a vital labour of love not only in the context of the lives immediately implicated, but to UK society. Despite this value and the essential caring provided in our communities by family carers, there remains much to do and much still to find out in order to address and improve the mental health and well-being experiences family carers deserve. These factors have been explored through the themes identified in this review, with considerable gaps in knowledge highlighted. We will continue to work together with adults with learning disabilities and family carers to fill the knowledge gaps exposed here and further explore the confounding factors identified. The caring continues, it matters, and we feel our responsibilities deeply and daily in our continued drive to do this work.

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Appendix for Tired of Spinning Plates: A Rapid Scoping Review of the Mental Health Needs and Mental Health Support of Carers of Adults with Learning Disabilities in the United Kingdom

Tired of Spinning Plates

Things we have found out about the mental health of family carers from our reading.

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easy read

Theme 1.
Caring and mental health through time

Caring and mental health can change a lot over time.

This looks different for different people.

Carers worry a lot about the future.

Planning for the future can be difficult.

We do not know enough about what people with learning disabilities think about the future.

Caring for a long time may mean that people learn better ways of managing their mental health.

We need to find out more about this.

Theme 2.
Money, caring and love

Family carers make a big difference to society.

People don’t know how hard carers work or the long hours they care for.

This can make carers feel invisible.

Family carers have a lot of skills and know about the person they care for. Carers can’t always do paid work so a lack of money and pensions can be stressful.

Many carers work hard at caring because they love the person they care for.
When the person they care for is happy, this makes carers happy.

Theme 3. Services and Support

Professional services like day centres and paid carers can help family carers to care and feel better.
This works well when carers have choice and control.

Services don’t always understand different people need different support..

Sometimes carers have to fight for help.
This is hard work.

Without good support carers don’t get rest and time for things that make them happy.

Carers like to support other carers.

Friends, families and neighbours can all help carers feel cared for too.

Theme 4.
We all count and the words we use matter

There is not much from people with learning disabilities in the things we read.

We think this must change.

Sometimes people forget they are talking about lots of different people when they talk about learning disabilities and caring.

Sometimes people can be negative about the person with a learning disability or say something or act in a way that is hurtful.

This makes some carers feel sad or uncomfortable.

Your thoughts matter

Was there anything in this booklet that jumped out at you?

What is missing?

What else could we find out about family carer mental health?

Get in touch

Martina Smith

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Tired of Spinning Plates: A Rapid Scoping Review of the Mental Health Needs and Mental Health Support of Carers of Adults with Learning Disabilities in the United Kingdom

Table 3 Themes, Sub-Themes and Supporting Evidence

Theme	Sub-theme	Evidence
The dis/temporalities of caring and mental health	Facing the (unfaceable) Future	Action for Carers, 2023; Congreve and Watts, 2021; Davys et al, 2015; Davys et al, 2016; Forrester-Jones, 2021; Hayden et al, 2022; Pryce et al, 2017; Sibs, 2020; Sibs, 2022-2023
	Dis/temporal Disruptions	Congreve and Watts, 2021; Forrester-Jones, 2021; Grey et al, 2018; Hayden et al, 2022; Herron et al, 2019; Sibs, 2020; Totsika et al, 2017; Walker, 2015
Economic labours of love	The dis/valued economics of caring and its life-long shadows	Congreve and Watts, 2021; Grey et al, 2018; Hayden et al, 2022; Totsika et al, 2017; Walker, 2015
	Invisible worlds of a skilled care-force	Congreve and Watts, 2021; Davys et al, 2015; Grey et al 2018; Forrester-Jones, 2021; Hayden et al, 2022; Patel et al, 2021; Pryce et al, 2017; Sibs, 2020; Turnpenny et al, 2020; Willner et al, 2020
Commoning and the multiplicities of carer mental health	The response-ability of service provision	Congreve and Watts, 2021; Davys et al, 2016; Grey et al 2018; Forrester-Jones, 2021; Pryce et al, 2017; Sibs, 2020; Totsika et al, 2017; Turnpenny et al, 2020; Sibs, 2020; Sibs 2022-2023
	Commoning for care	Action for Carers, 2022-2023; Congreve and Watts, 2021; Davys et al, 2016; Grey et al 2018; Patel et al 2021; Pryce et al 2017; Sibs 2020; Sibs 2022-2023
Confronting Dis/humanity	Disrupting ableism for mental health	Mitter et al, 2018; Pryce et al, 2017
	Language matters: (Re)constructing (all) lives for justice	Congreve and Watts, 2021; Davys et al, 2015; Grey et al 2018; Forrester-Jones, 2021; Hayden et al, 2022; Herron et al, 2019; Mitter et al 2018; Patel et al, 2021; Pryce et al, 2017; Sibs, 2020; Totsika et al, 2017; Turnpenny et al, 2020; Walker, 2015; Willner et al 2020

Tired of Spinning Plates Rapid Scoping Review
Search Strategy

Web of Science

Dates searched 2014-present
"learning disabilities" or "learning disability" or "intellectual disability" or "intellectual disabilities" or "profound and multiple disabilities" or "cognitive disability" or "cognitive disabilities" or "learning difficulties" or "developmental disabilities" or "developmental disability" (Topic) and "mental health" or "well-being" or "wellbeing" (Topic) and carer or caregiver or sibling* (Topic) not child* (Topic)

Scopus

(TITLE-ABS-KEY ("learning disability" OR "learning disabilities" OR "intellectual disability" OR "intellectual disabilities" OR "learning difficulties" OR "cognitive disability" OR "cognitive disabilities" OR "developmental disabilities" OR "developmental disability") AND TITLE-ABS-KEY ("mental health" OR "wellbeing" OR "well-being") AND TITLE-ABS-KEY (carer OR caregiver* OR sibling*) AND NOT TITLE-ABS-KEY (child*)) AND PUBYEAR > 2013 AND (LIMIT-TO (LANGUAGE , "English"))

PsychInfo

1 ((("learning disability" or "learning disabilities" or "intellectual disability" or "intellectual disabilities" or "cognitive disability" or "cognitive disabilities" or "learning difficulties" or "developmental disability" or "developmental disabilities") and "mental health" and carer*) not child*).af.
2 limit 1 to yr="2014 -Current"
3 limit 2 to english language