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## Ageing carers and intellectual disability: a scoping review of literature

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## Ageing carers and intellectual disability: a scoping review

**Purpose:** Individuals with intellectual disability(ies) are living longer contributing to an overall increase in the average age of caregivers. This study reviewed the literature on the physical, social and psychological needs of ageing carers of individuals with intellectual disability(ies) in the United Kingdom.

**Design:** A scoping review framework was used to identify literature from eleven databases, the grey literature and the references lists of relevant studies. Only primary research studies that discussed the needs of non-professional carers, aged 65+ years old, of individuals with intellectual disability(ies) in the United Kingdom were included. No date restrictions were applied. Thematic analysis was used to narratively synthesise findings.

**Findings:** Six studies were included. Five key themes were identified: Living with fear, lack of information, rebuilding trust, proactive professional involvement and being ignored. Housing and support information is not communicated well to carers. Professionals require more training on carer needs and trust must be rebuilt between carers and professionals. Proactive approaches would help identify carer needs, reduce marginalisation, help carers feel heard and reduce the risk of care crisis. Greater recognition of mutual caring relationships is needed.

**Value:** This review highlighted the needs of older caregivers for individuals with intellectual disability(ies) as well as the need for more high-quality research in this field. The information presented in this review may be considered by primary care providers and funding bodies when planning future support for this growing population of carers.

**Keywords:** Ageing, older, learning disability, intellectual disability, carers, caregiving, needs.

**Article classification:** General review.

## Introduction

The population of the United Kingdom (UK) is getting older (Office for National Statistics, 2018). It was reported that in 2016, 18% of the UK population was aged 65 and over, with 2.4% aged 85 and over (Office for National Statistics, 2017). It is projected that by 2036, over half of all local authorities in the UK will have 25% or more of their local population aged 65 and over (Office for National Statistics, 2017). Despite the ongoing health inequalities faced by people with intellectual disability(ies) in the UK - including growing evidence of premature deaths (Heslop *et al.*, 2013; 2015) - a significant number of people with intellectual disability(ies) are now living longer, mirroring general population trends (Emerson and Hatton, 2008; Walker and Ward, 2013). Whilst a general ageing population presents its own challenges including increased rates of cognitive decline such as dementia and Alzheimer's Disease and reduced physical health including a decline in immune system functions when fighting infections and increased musculoskeletal complications, ageing processes often occur at a younger age, approximately 40–50 years old, in adults with intellectual disability(ies) (e.g. Holland *et al.*, 1998). Despite age-related changes, most individuals with intellectual disability(ies) continue to be cared for by a family member, usually a parent. It is estimated that in the UK approximately 29,000 individuals with intellectual disability(ies) live with a family member over the age of 70 (Mencap, 2002). Furthermore, UK carers (all care populations) are estimated to save the state £132 billion per year (Buckner and Yeandle, 2011) with residential care for an adult with intellectual disability(ies) costing on average £64,417 per annum compared to £25,553 for those who reside with their family (Taggart and Hanna-Trainor, 2017).

While the UK government has focused on increasing the provision of care for a general ageing population, little research has been conducted on the needs of and/or support available for the increasing number of individuals aged 65 years and older who care for a family member with intellectual disability(ies). The government strategy '*Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own*' (Department of Health, 2008) stated that UK services had failed to meet the needs of individuals with intellectual disability(ies) and their carers. The document promoted the vision that by 2018 carers would be supported mentally, physically and financially to continue their caring role, alongside their own personal life goals and would be recognised as a respected care partner. The subsequent White Paper '*Caring for our Future: reforming care and support*' (Department of Health, 2012) again focused on ageing carers of individuals with intellectual disability(ies) and proposed a long-term vision that would improve both the lives of individuals with intellectual disability(ies) and their families. The paper included the aims of improved wellbeing, increased independence and reduced risk of crisis points. Crucially, it recognised that ageing carers required additional support and that their needs should be independently assessed from those they care for, with appropriate services developed to address those needs (Kersten *et al.*, 2001). The White Paper '*Valuing People: a new strategy for learning disability for the 21st Century*' (Department of Health, 2001) and the subsequent document '*Valuing People Now: A new three-year strategy for People with*

*Learning Disabilities*' (Department of Health, 2009) also discussed the need to support carers and encouraged the identification and enhancement of support networks for older carers. In response to the *Valuing People* White Paper the '*Good practice guidelines in supporting older family carers of people with learning disabilities*' document was published (Department of Health, 2003). However, despite a policy focus on the issues facing ageing carers of individuals with intellectual disability(ies) in the wake of *Valuing People*, the thirteen funded Learning Disability Research Initiative (LDRI) follow-up projects (which were developed to directly address recommendations made by the White Paper), did not include research on ageing or family care (Walker, 2015). Furthermore, the early policy emphasis on older families of people with intellectual disability(ies) has since waned, with this group becoming increasingly neglected following the loss of Department of Health funding for the National Valuing Families Forum in 2017. It remains unclear exactly what support ageing carers of individuals with intellectual disability(ies) need and what interventions, if any, are currently available to meet those needs across the UK. This question remains imperative as the number of older UK carers is set to rise, resulting in an inevitable increase in the number of households that contain not one but two or more vulnerable people i.e. ageing caregivers and ageing individuals with intellectual disability(ies) (Hubert and Hollins, 2000).

A preliminary search for existing scoping reviews and/or systematic reviews found that while the needs of carers are discussed as a general population, to-date there are limited primary research papers and research syntheses available on the topic ageing carers of individuals with intellectual disability(ies) within the UK (for an overview see Hogg and Lambe, 1998; Walker and Ward, 2013; Walker, 2015). Of the research available, both in the UK and internationally, the findings are inconclusive. McGrath and Grant (1993) for example examined support networks for Welsh families of children with intellectual disability(ies). While the study did not present carer age it did compare support systems across four different life stages of individuals with intellectual disability(ies). Through this comparison they identified that ageing carers were particularly vulnerable. The study highlighted that siblings and relatives outside the family offered carers the most support. However, due to ill-health and death, these informal support systems decrease over time. The reduction in support networks, both formal and informal, negatively impacted ageing carers at a time when they require this support the most, as replicated in other research (e.g. Prosser and Moss, 1996; Walker and Walker, 1998). Similarly, Dillenburg and McKerr (2011) interviewed 29 older parents/caregivers in Northern Ireland, aged 47 – 84 years old, and reported a severe lack of support, respite care and future planning, all of which can lead to increased levels of caregiver stress. While these studies, and others, report negative physical and/or mental health associations with caring for a child with intellectual disability(ies) into older age (e.g., Cairns *et al.*, 2013; 2014; Dillenburg and McKerr, 2009; McConkey *et al.*, 2006; Murphy *et al.*, 2007; Walker and Walker, 1998) others have reported little or no difference in the physical and/or social wellbeing of parents and parent caregivers of children with intellectual disability(ies) compared to

parents who do not have a child with intellectual disability(ies) (e.g. Chen *et al.*, 2001; Kersten *et al.*, 2001; Krauss *et al.*, 1993; Llewellyn *et al.* 2010). When comparing research on this topic it is important to consider a number of factors. For example, studies have reported that carers' physical and mental health may be impacted by a number of different factors including cultural differences, the age of the caregiver (e.g., McCullagh *et al.*, 2005; Schulz and Sherwood, 2008), the gender of the caregiver (e.g., McDonnell and Ryan 2011; 2014), the specific intellectual disability(ies) diagnosis of the individual that is being cared for, whether the carer has a partner or not, the size and the perceived level of support offered to them (e.g. Grey *et al.*, 2018), the type of care-load (low or heavy) including physical caregiving (e.g. Grey *et al.*, 2018), employment status (e.g., Berecki-Gisolf *et al.*, 2008; Juratovac and Zauszniewski, 2014) remoteness of housing (Doebler *et al.*, 2017) and the amount of respite care they receive.

Literature does exist detailing best practice and guidelines relating to caring into older age and intellectual disability(ies) (e.g. Bigby, 2000; Cowen and Hanson, 2013; Magrill, 2007; Magrill and Walker, 2002) however a gap still remains regarding empirical research on the experiences and needs of ageing carers of individuals with intellectual disability(ies). This population present as a unique caring group and as such their needs must be assessed separately from a general carer population, and the individuals they care for. Compared to other carer populations, older carers of individuals with intellectual disability(ies) have generally provided care for longer and/or throughout their lifetime and are most commonly sole females (Walker and Walker, 1998). There is an urgent need for the design, delivery and resourcing of more proactive services and support systems that assist individuals with intellectual disability(ies) and their ageing carers to 'age in place' (McConkey *et al.*, 2004). Ageing 'in place' refers to the ability to continue living in one's own home, regardless of age, until it is no longer feasible, with additional support being provided before alternative residential options are accepted (McConkey *et al.*, 2004).

Despite the focus on supporting families and individuals with intellectual disability(ies), including the recent NHS Long Term Plan (2019), a UK-specific systematic review regarding the needs of ageing carers of individuals with intellectual disability(ies) has, to-date, been incomplete. The barriers and facilitators faced by UK-based ageing carers may be unique compared to international cohorts, specifically due to the cultural dynamics of the general population, the structure of national healthcare model (NHS – e.g. personal budgets) and the availability of community-based services. The limited availability of UK-based primary research, and consequential gap in existing knowledge, resulted in the current scoping review. The aim of the current review was to collect and synthesise current knowledge on the physical and mental wellbeing needs of ageing carers (65 years old and over) for individuals with intellectual disability(ies) in the UK. Specifically, it aimed to: i) identify gaps in the literature, ii) provide recommendations for future research and iii) identify any interventions currently available to address carer needs. Within this review a 'need' was defined as any service, resource or support system that would result in a physical, social and/or psychological wellbeing gain

and/or that would allow for the continued provision of care, if this was deemed the most appropriate option. The term ‘carer’ included any individual who provided primary support regardless of whether or not the person being cared for lived in residential care or at home (Bigby, 2004; Heller and Factor, 2004; Heller *et al.*, 2005; Seltzer *et al.*, 2005; Vagg, 1998). Caring responsibilities may include, but were not limited to, physical and/or emotional support, organising care and/or planning personal budgets. While the *Valuing People* (Department of Health, 2001) White Paper defined “older” carers as aged 70 years or over, “ageing” carers in our review are defined as individuals aged 65 year or over. This age matches the state retirement age and is used in official state data and to access services for older individuals (Magrill, 2007).

## **Methods**

### **Study design**

A scoping review methodology, adhering to the PRISMA checklist, was used. The review followed the methodological framework proposed by Arksey and O’Malley (2005) as well as the amendments proposed by Levac, Colquhoun and O’Brien (2010), Peters *et al.*, (2015) and the guidelines for best practices provided by Colquhoun *et al.*, (2014). The Arksey and O’Malley’s scoping review framework consists of five stages: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, (5) collating, summarising and reporting results. Each stage is discussed in further detail. The last optional stage, consultation, was not included in the current scoping review.

#### *Stage 1: Identifying the research question*

The review aimed to address the following questions:

- What are the physical and mental wellbeing needs of (unpaid) ageing carers (65+) for people with intellectual disability(ies) in the UK?
- What interventions are available in the UK to address the identified physical and mental wellbeing needs of (unpaid) ageing carers for people with intellectual disability(ies)?
- What outcomes, if any, are provided by interventions that are available in the UK to address the identified physical and mental wellbeing needs of (unpaid) ageing carers for people with intellectual disability(ies)?
- What are the key barriers and facilitators affecting (unpaid) ageing carers for people with intellectual disability(ies) in accessing interventions in the UK?

#### *Stage 2: Identifying relevant studies*

An initial exploratory online search using the electronic databases MEDLINE (PubMed) and CINAHL identified articles and evaluation reports related to the topic of ageing carers of individuals with intellectual disability(ies). Text words and index terms from relevant retrieved papers were then

analysed to develop a rigorous search strategy that was undertaken across all included databases. Databases were searched from their start dates to October 2018. Databases included the CINAHL, British Nursing Index, Web of Science, Cochrane library, PsychInfo, SocIndex, University of York Centre for Reviews and Dissemination, JBI Database of Systematic Reviews and Implementation Reports, PubMed, EPPI, Epistemonikos, grey literature and the references of the included studies. The search strategy can be found in Appendix 1. Reference lists of identified reports and articles were searched for additional studies. A list of inclusion and exclusion criteria are detailed in Table 1. No date restrictions were applied.

Table 1. Inclusion and exclusion criteria for the review.

| <b>Inclusion criteria</b>   | <b>Exclusion criteria</b>  |
|---|--|
| Carers aged 65+ for individuals (adults; aged 18+) with intellectual disability(ies).   | Carers < 65 years old.<br>Carers for individuals who do not have intellectual disability(ies).   |
| The primary care giver must not provide said care as part of their professional vocation i.e. unpaid parent(s), family member(s) etc. | Professional or paid carers.   |
| Studies based in the United Kingdom written in English.   | Studies based outside the United Kingdom or not written in English.  |
| Literature must relate to the physical and/or mental wellbeing of ageing carers of individuals with intellectual disability(ies).     | Literature that does not relate to the physical and/or mental wellbeing of ageing carers of individuals with intellectual disability(ies). |

### *Stage 3: study selection*

After eliminating duplicates, an initial screening of titles, abstracts, and summaries was undertaken. The full text was obtained for articles that may meet the inclusion criteria and then screened against these criteria. Any excluded studies were listed with the reason for their exclusion. Study selection (both at title/abstract screening and full text screening) was performed by two reviewers, independently. Any discrepancies were solved by the decision of a third reviewer, where necessary. A total of six studies met our inclusion criteria and were included in the review, see Appendix 2.

### *Stage 4: charting the data*

Data for analysis were extracted from the included studies and managed in an Excel spread sheet. Extracted data included authors, year of study, aim/purpose, type of record (e.g. journal article), geographical area, study population (e.g., age of participants and intellectual disability(ies) diagnosed), sample size, study design, mental wellbeing needs identified (psychological and social), physical

wellbeing needs identified, description of the interventions/support for mental wellbeing needs, description of the interventions/support for physical wellbeing needs, duration of interventions, factors that facilitate and/or hinder access to interventions/support, outcomes reported by carers accessing/not accessing interventions (and how measured), key findings that relate to the needs of ageing carers of individuals with intellectual disability(ies) in the United Kingdom.

#### *Stage 5: collating, summarising and reporting the results*

A narrative synthesis approach was adopted, in accordance with the ‘Guidance on the Conduct of Narrative Synthesis in Systematic Reviews’. Preliminary synthesis allowed for an initial description of the findings and to identify patterns across included documents. Thematic analysis, following Braun and Clarke’s (2006) six-phase thematic analysis framework, was then used to analyse the findings. The analysis included the following six stages: 1. Familiarisation with the extracted data, 2. Generation of initial codes, 3. Searching for themes, 4. Reviewing themes, 5. Defining and naming themes and 6. Write-up.

## **Results**

A total of 3021 records were screened (title and abstract). This was shortlisted to 244 records that were assessed in full text (see Appendix 2). The final review included 6 research papers that met the inclusion criteria (see Appendix 3). The majority of these papers focused on the general theme ‘future care needs and planning’. Their aim therefore was not to identify carer needs in general or how to support caring ‘in place’ but to examine carers’ perceptions of the future and any support that is needed to plan for the end of caring. This highlights the gap in research regarding ageing carers of individuals with intellectual disability(ies) in the UK and their daily needs. Following Braun and Clarke’s (2006) thematic analysis method we analysed any findings that directly related to ageing carer needs across all six articles, identifying five main reoccurring themes.

### *Living with fear*

Carers were aware that they could not care indefinitely. Despite this, many had not made plans for their future or the future of the individual they cared for. This inevitably increased the risk of care crises and the level of stress, anxiety and fear experienced by older carers. Taggart *et al.*, (2012) identified the core theme “unremitting apprehension” that underpinned most of the carer experience.

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

While carers felt fear about caring for their child throughout their life, this was enhanced in older age particularly due to deteriorating personal health and smaller support networks. Interviews conducted



with people with intellectual disability(ies) by Pryce *et al.*, (2012) revealed that while parent carers often wanted to continue caring at home, those being cared for may wish to choose alternative care options. The reoccurring theme ‘lack of information’, which will be discussed separately, emerged from the majority of papers and underpinned much of carers fears. In short, while limited information regarding care alternatives, as well as support to continuing caring at home, was available in some instances, this information was not reaching older carers who are often socially isolated and do not have access to digitised resources such as the internet.

### *Lack of information*

As mentioned previously, it was consistently reported that older carers do not have sufficient information regarding available services and support, especially regarding future and/or alternative care options. The studies included in the review reported that a high percentage of older carers do not make future care plans, and of those that did, the majority viewed family caring (i.e. sibling(s) or family member that could take over their role) or residential care as their only options. Shifting caring responsibility onto other family members was often associated with guilt as parent carers did not want to burden that individual, while residential care received mixed-opinions (Bowey and McGlaughlin 2006). Many of the carers interviewed by Bowey and McGlaughlin (2006) stated that residential care was their preference (possibly due to lack of information regarding alternative care options), however in general, older carers reported feeling apprehensive towards residential care. Carers often felt that this option did not provide the appropriate level of support for their child (Gilbert *et al.*, 2008), especially if their child had limited verbal communication skills (Bowey and McGlaughlin, 2006). Bowey and McGlaughlin (2006) reported carer fears about the standard of care provided by residential homes which often developed from a lack of information, reports of abuse and historical personal bad experiences with health and social care professionals including short-term breaks. This caring population is unique in the prolonged length of time they spend caring, therefore historical negative experiences over the lifetime of their child could lead to carers losing trust in professional services (this will be discussed in more detail by the theme “Rebuilding Trust”).

A lack of housing and care support information prohibited carers’ ability to plan not only their future and the future of the individual they cared for but it also often exacerbated feelings of anxiety, stress, isolation and fear. While some carers wanted to continue caring into older age, others felt that it was an accepted role rather than a chosen one. This was mainly due to no suitable alternatives being made available to them to discontinue their caregiving role (Gilbert *et al.*, 2008).

In summary, the included papers made the following recommendations,: i) greater communication needed between social services, housing agencies and older families, ii) information to be written for, and distributed to, older carers on a proactive and regular basis iii) those delivering the information to be trained and made aware of the needs of older carers and their concerns and iv) support to be explained and provided to carers that will assist them in continuing to care within their own home

(particularly due to increasing rates of mutually reciprocal caring relationships i.e. where the person with intellectual disability(ies) also provides care to their ageing parent(s)). The included papers identified that older carers need more information about care options for their adult child including community-based care, residential care, and support for their child to be cared for at home by professionals in the event of their death.

### *Rebuilding Trust*

As mentioned previously, older caregivers reported low levels of trust in professionals and social services. Many of these caregivers have provided care for most of their lifetime and did not expect to care into older age. Professional services that were made available when their child was younger may not have been appropriate for their child's needs, with historical negative experiences increasing caregiver mistrust.

*“With me being one of the older ones, you’ve seen things from years ago, how it used to be and it sticks with you. The stigma is hard to forget (Margaret, lone carer).”* (Bowey and McGlaughlin, 2006, p. 50)

Some caregivers did report good experiences with individual social workers and those that did generally felt more supported and positive about their role (Gilbert *et al.*, 2008). Overall, trust must be rebuilt between carers and professional services. In order to achieve this aim, professionals, including health and social care staff, require more training about how to support ageing carers. The role of ageing cares must be fully recognised by health and social services. As identified by Bowey and McGlaughlin (2006), proactive and regular contact with carers could help to improve professional relationships, as well as avoid care crisis that occur when carers disengage from services due to lack of trust.

### *Proactive professional involvement*

It is known that many people with intellectual disabilities living with older carers are not known to services until there is a crisis. The *Valuing People* White Paper suggested that up to 25% of people with intellectual disabilities living with older carers are not known to services until there is a crisis (Department of Health, 2001). Support, if any, is most commonly provided by informal networks such as a spouse, family member or neighbour. Worryingly, as these carers age their support networks diminish, with sole female carers the most commonly represented demographic within this population. The non-proactive approach taken by the majority of social services and health care professionals increases the perception of being ignored, forgotten about or being “left in the dark” (Cairns *et al.*, 2013). These feelings were exacerbated by reduced services over time, lack of information and a general perception that their own needs are not being identified or assessed. A proactive approach to identifying and addressing carer needs may reduce the occurrence of care crisis, help carers plan future care for both the individual they care for and for themselves, as well as improving the experience of carers who

care in place. Some suggested approaches include systemic therapy, regular monitoring, improved professional training, and increased support from social services and health professionals who may be aware of the risk of crisis occurring but do not have the capacity to proactively prevent this.

*“I really think that seventy is too late to start, because with us it’s going to be two years before it happens. It’s taking a long time, but at least it’s given us time to think about it, because it’s very scary. We want choice as well, as well as people with learning disabilities who should have choice without doubt (Emily, dual carer).”* (Bowey and McGlaughlin, 2006, p. 48)

### *Being ignored*

Carers often felt ignored and that their own health needs were neglected. Their lives often revolved around the individual they cared for which included following daily routines. This left them with little or no time for their own personal life. Cairns *et al.*, (2013) reported a startling difference in self-reported quality of life for carers who were supported compared to those that sole care. The feeling of being ignored stems, in part, from the lack of available information, poor training of health and social services regarding carer needs, limited professional support and the experience that their role as a caregiver was not always appropriately recognised. While some carers reported support from individual social services staff, the closure or reduction of some services such as respite care as well as the inflexible approach of some services further increased carers’ feelings of marginalisation and isolation. Carers often developed their own coping strategies that included accepting their parenting/caregiving role and finding meaning in their care relationship. Experiences of mutual caring relationships develop more into older age and require more support to be maintained.

*“You just have to get on with it by yourself because there’s not really anybody else to help and it’s not fair to put onto others (female carer)”* (Pryce *et al.*, 2017, p. 7).

### **Discussion**

The review highlighted the limited research available on the needs of ageing carers of individuals with intellectual disability(ies) in the UK, particularly needs that support continued caring ‘in place’. While the six studies included in the review primarily focused on future care plans, some reoccurring themes were identified regarding ageing carer needs in general. Overall, it was reported that ageing carers did not receive enough support or information from professional services regarding care alternatives, at-home support, respite care or information about government or local legislation. A lack of information resulted in carers feeling isolated, anxious and fearful about their future. While carers wanted to continue their caring role, some felt like they had accepted the role of carer as no suitable alternatives were available to them. Carers had little trust in social services or the quality of care professional

services could offer their child. Mistrust was built over a prolonged period of time and was often confounded by poor-quality short stay experiences, reduced or limited services, long waiting lists and poor communication between professionals. Trust must be rebuilt with this carer population in order to identify and best support their physical, social and psychological needs. Better support networks could also help identify “hidden” carers that are not made aware to services until a time of crisis (e.g., Horne, 1989). A survey of UK Learning Disability Partnership Boards reported that only 21 per cent of respondent boards collected any information about older families and their plans for the future (Haley and Perkins, 2004). Despite an estimated 29,000 adults with intellectual disabilities being cared for by a parent aged 70 year or over, where caregivers often struggle to continue their role due to frailty and age-related decline, local authority directed alternative housing was organised for only 1 in 4 cases (Care Quality Commission, 2012).

A proactive approach may be adopted by health and social services to identify and engage with ageing carers while carers must feel that they can communicate openly and honestly with professional services without fear of repercussions. Bowey and McGlaughlin (2006) found that carers often feared that making future care plans may result in immediate placement and needed reassurance that this would not occur. A Carers Week Survey (2008) found that 95% of respondents regularly disguised any negative health impacts of caring in order to continue their caregiving role. Poor support networks and a lack of communication with older carers have resulted in fewer carers making plans for the future, resulting in inevitable care crises. Support workers may be aware of impending crisis yet they often do not have the facilities to proactively intervene. Mencap (2002) described the “housing crisis” facing this ageing population and more recently NICE guidelines (2018) proposed that more work was needed by commissioners to plan and avoid care crisis situations. This further highlights the fear older carers have regarding formal support networks, communicating their needs and the need for formal proactive measures to engage with this population.

Identifying and assessing carer needs, separately to the individual they care for, can help increase trust, prevent care crises, support caring in place and improve carers’ quality of life. Cairns *et al.*, (2014) found that carers self-reported a negative impact of caring on their physical health, despite their physical health being similar to UK norms while carers’ mental health was significantly reduced compared to UK norms. Hirst (2004) also found a correlation with mental health problems and caring, as opposed to physical health. It must be noted that Cairns *et al.*, (2014) compared ageing carer scores (65 years +) to the general UK population (18 – 64 years) and as such mental health results may have been impacted by age associated cognitive decline (Deary *et al.*, 2009). Princess Royal Trust for Carers (2011) found that all older care populations were “overwhelmingly exhausted and worried” (p. 34) and frequently neglected their own personal wellbeing. While ageing carers face their own age-related physical, social and psychological challenges, due to the demands of their caregiving role they are often left with no time to address their own deteriorating health. The caregiving role is often viewed as “demanding” and “stressful” however it is worth noting that not all carers perceive themselves as being

‘stressed’ and can frequently perceive their role as satisfying and rewarding (e.g. Cairns *et al.*, 2014; Dillenburg and McKerr, 2011; Grant *et al.*, 1998; Hill and Rose, 2009; Rowbotham *et al.*, 2011; Yoong and Koritsas, 2012). As such, carers often choose to continue caring into older age, especially when instances of mutual caring exist. More support is needed for these carers so that they can continue to care in place and experience a good quality of life doing so.

Older carers often rely on informal support networks, such as family members or neighbours (e.g. Hill and Rose 2009; Prosser and Moss, 1996). Due to illness, death and other reasons, over time these support networks reduce in size. Families who have not needed support before, or minimal support, may find themselves facing a care crisis (Hubert and Hollins, 2000). Gilbert and colleagues (2008) found that dual-carers often felt that planning for the future was less important compared to sole-carers, which resulted in fewer future plans for these families, yet a high percentage of older carers are widowed mothers (Walker and Walker, 1998). When a spouse dies, carers may find themselves facing a care crisis and experiencing feelings of isolation and hopelessness. A proactive approach to dual-carers, who may not frequently be in contact with professional services, as well as sole-carers, is needed.

The papers included in this review did not disclose any diagnosis of dementia or age-related neurodegenerative decline in the carer sample or individuals with intellectual disability(ies). It is known that individuals with intellectual disability(ies) experience age-related cognitive and physical decline at a younger age compared to the general population (NICE, 2018). Caregiver stress can be negatively impacted by the challenging behaviour of the person with intellectual disability(ies) which can increase when an individual is diagnosed with a co-morbid neurodegenerative disease such as dementia (Grant and McGrath, 1990; Unwin and Deb, 2011). Further research is needed to identify the needs of carers in these complex care situations. Future research must also try to represent “hidden” carer populations, different ethnicities, and different intellectual disability(ies) populations. Greenwood and colleagues (2014) reported that ethnic minority carers, while increasing in number, do not access services and are less satisfied with services compared to ethnic majorities. While some culturally appropriate community services were established in Britain (Baxter *et al.*, 1990), more support is needed for ethnic minorities as they continue to suffer from a lack of specific policies, language barriers, little information and a poor understanding of their beliefs and customs by professional services (e.g. Baxter *et al.*, 1990; Foundation for People with Learning Disabilities, 2012; Greenwood *et al.*, 2014; Hogg, 1997; Hubert and Hollins, 2000; Poxton *et al.*, 2011; Zarb and Oliver, 1993).

Lastly, the current review focused on UK-based studies. Research involving this unique carer population within the UK has been limited for a number of complex reasons, including difficulties in ‘counting’ how many people are in scope. Despite poor nationwide data capture, it is estimated that the number of older adults with intellectual disability(ies) accessing services aged 70 years old and above will more than double by 2030 (Emerson *et al.*, 2012), further indicating the increasing need for UK-based research on this topic. While UK governments have made some progress in highlighting the needs of older adults with intellectual disability(ies) and their ageing carers,

international research can provide a good stepping stone for improving possible future care models.

Innes and colleagues (2012) provided a comprehensive review of international literature regarding ageing among individuals with intellectual disability(ies). This included studies from the UK, Australia, Republic of Ireland, US, Israel, Canada, Taiwan and Belgium. Similar to the current review, studies lacked methodological detail, specifically participant age or included large age ranges. This made it difficult to identify papers specifically related to older carers. Again, this highlights the need for more focused research on the topic of older and ageing carers both in the UK and internationally. Innes *et al.*, (2012) identified fourteen studies that discussed ageing carers (mixed ages) with three key themes being identified i). fear of the future, ii). experience of older carers and iii). planning for the future. Our findings align with those reported by Innes and colleagues. Since Innes and colleagues' review, research continues on the topic of ageing carers and individuals with intellectual disabilities, yet similar results continue to be reported. Walker and Hutchinson (2018) for example, found that older parents (mean = 70 years) of children with intellectual disability in South Australia, continue to provide a high level of care for their children as they age, whether in supported living or at home, yet they do not have firm plans for their future, while Brennan *et al.*, (2018) reported that families of older individuals with intellectual disabilities in the Republic of Ireland, also have few future plans in place.

An international review by Heller and Arnold (2010) reported a number of interventions targeted at supporting ageing family carers and siblings of people with intellectual disability(ies) including advice and counselling regarding future care and financial planning as well as support groups and services for the entire family unit, based on the finding that interventions that include both the carer and the individual with intellectual disability(ies) are more beneficial than those that do not (Heller & Caldwell, 2006; Janicki *et al.*, 2003). Bigby (2000) highlighted the need for flexibility in future care plans and proposed that a key individual is identified to oversee the well-being of the person with an ID as opposed to rigid plans. Furthermore, studies have shown that an emphasis on 'active ageing' and community support may decrease anxieties felt by this care population and improve long-term outcomes (Bigby, 2005; Black & McKendrick, 2010; Caldwell, 2008; Heller & Caldwell, 2005; McConkey, 2006; Stainton & Boyce, 2004; Taggart *et al.*, 2012). This supports the inclusion of services such as day centres, respite care, domiciliary support services and befriending services in future UK-based care models. While previous international research has provided insights into specific services that may benefit service user outcomes, shared learning from the USA, Canada and Australia have also shown that, to increase the uptake of older informal carers and individuals with intellectual disability(ies) in accessing specialist services professionals must first address the fear and anxiety felt by these service users and reassure them that services do not aim to remove their son/daughter from their family home (Seltzer *et al.*, 2001; Slevin *et al.*, 2001). These international studies, in line with the current review, promote a proactive approach to engaging these ageing families, who in general, have limited support

or future care options available to them, as opposed to the reactive crisis care management approach currently in place in the UK (e.g. McConkey *et al.*, 2006).

## Conclusion

In conclusion, of the limited research available on the needs of ageing carers of individuals with intellectual disability(ies) in the UK, the general focus has been on future care needs and how to avoid care crises. More information is required to understand what needs carers have when they choose to care 'in place'. Furthermore, in response to the growing number of mutually reciprocal care relationships that exist within this carer population, future research must examine what care options, and support networks, are most suitable to meet the needs of these families.

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