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What skills do older self-funders in England need to arrange and manage social care?

Findings from a scoping review of the literature

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Abstract

Older people in England who pay for social care from their own funds ('self-funders') receive little help in seeking and arranging care compared to older people funded by their local council. This suggests an implicit assumption that people funded by local councils need help to manage their care whereas self-funders do not. This paper reports findings from a scoping review of published evidence from England, Scotland and Wales on the skills that older people need, and the help they get, to seek, arrange or manage use of social care, and how this help affects outcomes. Searches undertaken in October 2018 resulted in the inclusion of thirty-six empirical papers and seven reviews. Thematic analysis identified the importance of everyday life and specific business skills, and personal attributes including objectivity when evaluating options. The review identified two significant gaps in the evidence; first, how help in seeking and arranging care compensated for lack of, or complemented existing, skills; and second, how outcomes for people receiving help in arranging care compared with those not receiving help. The paper concludes that a tailored approach to supporting older people arrange and manage care, irrespective of funding, should be considered.

Keywords: Older people, Scoping review, Self-funders, Social capital, Social care

Introduction

Arranging social care in later life can be complicated, whether for oneself or a family member. It can involve assessing needs, thinking about care and support options, making relevant arrangements and managing budgets. People eligible for local council-funded care receive help with these activities, but people who pay for their care from their own resources, known as self-funders, typically manage all this themselves. This suggests an implicit assumption that people funded by local councils need help to manage their care whereas self-funders do not. But what do we actually know about the skills and abilities that older people and their families need to arrange and manage care?

This paper presents the findings from a scoping review that explored published evidence on the skills that older people need, and the help they get, to seek, arrange or manage use of social care, and how this help affects outcomes.

Background

Adult social care in England falls under the responsibility of local level governments known as local councils. It is means-tested with some people fully funded by their local council, some receiving a contribution from their council towards care costs and others paying all the costs themselves. People eligible for council funding are offered a ‘personal budget’ (PB) to spend on care and support. They can opt to take this budget as cash (known as a direct payment (DP)) and manage it themselves or to have the budget managed by the local council (usually referred to as a managed PB). Most older people who are funded by their local council choose the latter, often because they do not want the perceived hassle of holding a budget (Glendinning *et al.*, 2008) or feel they do not have the relevant knowledge for arranging care (Baxter *et al.*, 2017). People who pay for their social care and support from their own resources are known as self-funders. People typically self-fund because they are not eligible for council-funded care. This can be because their needs have been assessed as below the required eligibility threshold or their assets or savings are over the eligible financial limit of £23,250. Self-funders are usually, but not exclusively, older people.

Data on the number of self-funders and their characteristics is limited; there are no national datasets on self-funders and local councils often have limited knowledge about self-funders in their localities. Estimates suggest the number of self-funding care home residents to be in the region of 120,000 to

180,000 (Baxter and Glendinning, 2015; Henwood *et al.*, 2019) and that they may account for around 41% of care home residents in the United Kingdom (UK) (Competition and Markets Authority, 2017). For home (domiciliary) care, Henwood *et al*. (2019) estimate the number of self-funders in England to be around 230,000, with a further 150,000 in the rest of the UK. Earlier evidence cited in Baxter and Glendinning (2015) suggested that between 170,000 and 290,000 people self-funded home care in England.

Despite the prevalence of self-funders, we know little about their needs and pathways to care, including how many have formal assessments of need. Qualitative evidence suggests self-funders can be reluctant to pay for the amount of care family or professionals suggest they should have (Baxter *et al.*, 2019) and many arrange care without a formal needs assessment (Baxter *et al.*, 2017). As a result, people may be left with unmet need which has the potential to adversely affect future well-being and care costs.

Irrespective of a needs assessment, self-funders receive little help in seeking and arranging social care compared to older people funded by their local council. This perhaps stems from the introduction of personal budgets as part of the mainstream offer. At the time, self-funders were considered to have more freedoms and choices around care than people who were council funded; PBs were seen as a chance to offer these opportunities more widely (HM Government, 2007). Since then, a range of support services have developed to assist PB users, especially those taking their budgets as DPs, with care and support planning. As a result, PB and DP users now appear to receive more help with arranging and managing care than self-funders (Baxter *et al.*, 2017).

But how equitable is this system? Do self-funders have the capacity to judge their need for care, navigate the care system and arrange care, all without professional support? And how do these different levels of help in arranging and managing care affect outcomes? Usually it is people from the most deprived socio-economic groups who are disadvantaged compared with people from the least deprived, for example in utilisation of health and social care (Dixon *et al.*, 2015; Cookson *et al.*, 2016). For people navigating the system and arranging social care, this inequality is reversed; those who are self-funders (and likely to be in the least deprived socio-economic groups) are disadvantaged in terms of help to access social care. As demand for care increases with an ageing population and providers adjust to market conditions, the task for people without expert support to navigate the system can only become more challenging.

The issues discussed above suggest it may be important for local council (or other) practitioners to understand older people's skills and capacity to arrange care, and tailor the level of support they give to people accordingly, rather than basing help on people's means of paying for care. Tailoring support could have important implications for preventing, reducing and delaying people's need for both social and health care. Unsupported decisions may result in people engaging care sooner than necessary or at a higher intensity; for example, Netten and Darton (2003) found self-funders entering a care home with lower levels of need than council-funded peers. Such decisions may not only affect quality of life outcomes, through compromising independence and potential adverse effects on mental well-being, but also the length of time that self-funders are able to continue funding their care before their resources are depleted. This impacts individuals' finances and those of their families but also spend by local councils that have to cover subsequent care costs.

This scoping review aimed to determine the current research evidence-base examining the skills older people need to effectively seek, arrange and manage on-going use of social care. In essence, it answered the question: What do we expect self-funders to be capable of doing for themselves?

Methods

This was a rapid scoping review (Arksey and O'Malley 2005) which aimed to map research evidence including grey literature across the following groups of older people:

- not eligible for local council funded care;

- eligible for local council funded care, including those using managed personal budgets or direct payments;
- with continuing healthcare funding.

We searched for evidence on:

- the skills and capabilities needed to arrange care, and how these impact on use of support services;
- the support provided in arranging care and how it complements or compensates for skills;
- evaluations comparing short or long-term outcomes for people who have received help with arranging/monitoring care and those who have not.

Search Strategy

The following databases were searched: ASSIA (Applied Social Science Index and Abstracts); Scopus; Social Care Online; Social Policy and Practice; and Social Services Abstracts.

The search strategy was broad ranging to include as many relevant documents as possible. First, we searched each database for evidence about older people who were (1) self-funders, (2) council funded clients, including direct payment or personal budget users, and (3) funded through continuing healthcare. We then restricted groups (2) and (3) to papers describing information, advice or support services. For group (1) (self-funders), Scopus identified over 3000 references so the restriction was applied. For the other databases, the number of papers identified about self-funders ranged from 57 (Social Policy and Practice) to 320 (ASSIA), so the information, advice or support services restriction was not applied.

Where databases allowed, we restricted searches to the year 2000 or after, when older people became entitled to use direct payments. Box 1 provides a summary of search terms. A sample search strategy is available upon request. Searches were undertaken on 23rd October 2018.

Searches identified 1645 references that were uploaded to Endnote reference software. 264 duplicates and 93 pre-2000 publications were removed electronically, leaving 1288 references for title and abstract screening.

Inclusion and exclusion criteria

Table 1 gives inclusion and exclusion criteria.

Screening

KB and MW independently screened all 345 titles and abstracts about DP/PB users identified through searching Social Care Online and met to review decisions. There was a high level of agreement. Disagreements were resolved with reference to the inclusion criteria.

The remaining references were screened by either KB or MW. All exclusions were checked by the second researcher.

This process resulted in 127 references eligible for a review of the full text.

A sample of 12 full texts was screened for inclusion to ensure consistency across the team. Each of the three authors screened eight full texts. Disagreement on two texts was resolved through discussion. Both texts were included. The remaining 115 texts were divided equally between the three authors and screened for inclusion. Eighty-four texts were excluded, leaving 43 for data extraction.

Data extraction

The three authors independently extracted data from the included texts they had screened using the following headings: author and date; aims; methods; whether the data were specific to older people or included other groups; evidence on the skills and capabilities needed to arrange care, and any impact on use of support services; evidence on support provided in arranging care, and how this complements or compensates for skills; evidence of outcomes for people receiving/not receiving help in arranging and managing care; and other relevant data. Only data relevant to older people were extracted.

Figure 1 presents information on the numbers of references identified, included and excluded.

Findings

Description of the evidence base

Thirty-six documents included empirical research data; seven were literature reviews.

We did not undertake a formal assessment of quality, however, 14 papers (including one review) were published in academic peer-reviewed journals; four in practice-focussed magazines or journals that were not peer reviewed; and the remaining 24 were research reports where peer review was unclear. Half the documents (18) reported qualitative research only and 13 included multiple methods. One paper reported only quantitative data (Davey *et al.,* 2007), one was based on analysis of practice examples (Ayling and Marsh, 2014) and the methods in three were not clear (Clark, 2001; Lovell, 2007; Carr-West and Thraves, 2013).

Fifteen of the 36 empirical documents reported data on older people only. None focused specifically on people with dementia. The remaining 21 provided data about older people but also included other groups (typically carers, people with mental health issues or people with learning disabilities); only those data specific to older people were extracted.

The seven reviews were described as scoping reviews, literature reviews and syntheses of evidence. They encompassed self-funders (Hudson and Henwood, 2009; Baxter, 2016), person-centred planning (Dowling *et al.,* 2006), self-directed support (Manthorpe and Hindes, 2010), employment relationships for disabled people employing their own care workers/PAs (Manthorpe *et al.,* 2011), improving choice and control for older people using DPs/PBs (Social Care Institute For Excellence and

Carr, 2013), and non-statutory care co-ordination services (Challis *et al.,* 2016). To avoid double counting findings due to multiple citations, data extracted from the literature reviews are presented only where they add value to, rather than duplicate, the empirical research data.

Evidence of the skills and capabilities needed to arrange care

Extraction of data about the skills and capabilities that older people need to identify, arrange and manage social care was challenging. None of the papers identified addressed this specific issue. The evidence was usually presented as the types of tasks people found difficult or that they expressed the need for help with. We have inferred from the evidence of these difficulties that people need relevant skills to undertake these tasks.

The findings are presented under two main themes - practical skills and personal attributes. Table 2 summarises these themes.

Theme 1 - Practical skills

1(a): Everyday life skills

The evidence suggests *information searching and management* are key skills. Older people want clear, tailored information in multiple formats and bite-sized chunks (Newbronner *et al.,* 2011), but the ability to access information through online sources, local councils and social networks, and to navigate information about a range of service options is also crucial (Scourfield, 2005; Carr-West and Thraves, 2013; Greenhalgh and Ogunye, 2016; Mangano, 2016; Audit Scotland, 2017). Difficulties in finding information on websites (Ayling and Marsh, 2014), suggests understanding potential search terms is important.

The ability to manage and navigate several sources of information in large volumes is fundamental (Baxter and Glendinning, 2011) but time-consuming (Competition and Markets Authority, 2017). Williams, Porter, and Marriott (2014) noted older council-funded clients and their families valued help from support planners in managing such streams of information. For self-funders, failing to find information may result in sub-optimal choices, such as premature admission to a care home (Netten and Darton, 2003).

For self-funders and people using DPs, six primary research studies (Clark *et al.,* 2004; Glendinning *et al.,* 2008; Priestley *et al.,* 2010; Williams and Porter, 2011; Baxter *et al.,* 2013; Greenhalgh and Ogunye, 2016) and two reviews (Manthorpe and Hindes, 2010; Social Care Institute For Excellence and Carr, 2013) established that the *ability to manage money and a budget* is vital. Knowing an indicative budget before planning care and support packages through PBs has also been shown to be important (Williams and Porter, 2011) which suggests a vital attribute for self-funders is the ability to set a budget for care.

Finally, there was some evidence that *contingency planning* was important (Glendinning *et al.,* 2008; Sanderson, 2010), specifically, older people were concerned about getting help at home should DP arrangements break down (Lucas *et al.,* 2009; Hasler and Marshall, 2013).

1(b): Business-related skills

There was an abundance of evidence that people need *administrative skills* in order to arrange and manage care and support. Project management skills were also vital (Clark and Spafford, 2001). Older people and their carers experienced stress from, or were concerned about, the paperwork involved with various forms of personal budget (Scourfield, 2005; Glendinning *et al.,* 2008; Priestley *et al.,* 2010; Campbell *et al.,* 2011; Williams and Porter, 2011). Stress diminished over time and with experience (Glendinning *et al.,* 2009).

Key *employment-related skills* centred on advertising for and recruiting PAs or other non-agency care workers (Clark and Spafford, 2001; Clark *et al.,* 2004; Ekosgen, 2013; Tanner *et al.,* 2018) and being an employer (Scourfield, 2005; Glendinning *et al.,* 2008; Ekosgen, 2013). Specific issues around recruitment included people wanting help writing adverts and contracts (Clark *et al.,* 2004), particularly in translating their understanding of their needs into a job description (Clark and Spafford, 2001). Other perceived onerous tasks included putting employment contracts in place, organising employers' liability insurance and dealing with salary payments and national insurance contributions, sickness cover, and legal issues (Scourfield, 2005; Glendinning *et al.,* 2008; Ekosgen, 2013).

Negotiation skills are also important and often facilitated by a care manager or broker for people receiving council funding; specific issues included agreeing care tasks, times and rates (Clark, 2001; Baxter and Rabiee, 2013), and negotiating with providers when under time pressure (Mangano, 2016).

The capacity to interpret *legal issues and rules* is also essential, including legal and financial issues relating to care, and charges and billing practices (Greenhalgh and Ogunye, 2016). In particular, older people need the skills to understand the relationship between paying for care, wealth management and the status of a Last Will and Testament (Wright, 2003).

Theme 2 – Personal attributes

2(a): Interpersonal skills

The evidence suggests the importance of *'people management' skills* including the ability to manage PAs or other care workers, such as managing boundaries between formal and informal relationships (Clark, 2001; Clark and Spafford, 2001; Clark *et al.,* 2004; Glendinning *et al.,* 2008; Tanner *et al.,* 2018). These boundaries can be complex, with self-funders finding the balance difficult when perceiving their care needs to conflict with their care workers' preferences (Tanner *et al.,* 2018). Previous experience from managerial or supervisory careers can be helpful (Clark *et al.,* 2004). A number of reviews also stressed the importance of managing relationship boundaries where family or friends were involved in care planning or provision (Dowling *et al.,* 2006; Manthorpe and Hindes, 2010; Manthorpe *et al.,* 2011).

Having *wide-ranging social and other networks* can help people in seeking information and arranging care. Clark and Spafford (2001), Clark *et al*. (2004), Sanderson (2010) and Baxter and Glendinning (2011) reported the value of being well networked, including facilitating access to good information through word of mouth and community groups, particularly helpful for people whose first language was not English. Furthermore, both Clark studies found that older people preferred personal recommendations when sourcing a PA and typically preferred to employ someone they already knew. Social networks are also important for sharing experiences with peers (Scourfield, 2005; Newbronner *et al.,* 2011).

Two reviews offered additional insights. Dowling *et al*. (2006) confirmed the importance of circles of support but added that developing such networks may be difficult for people who are severely disabled or who spend most of their time with people paid to work with them. Finally, Manthorpe *et al*.'s (2011) review of employment relations reported evidence that people with stronger social networks were less reliant on 'unproven' PAs and achieved better value for money.

2(b): Objectivity in decision-making

After accumulating information, people need the ability to *evaluate alternatives* in a systematic and objective way to compare options and make relevant choices. Older people often struggled with this (Glendinning *et al.,* 2008), especially with specific issues such as comparing and contrasting providers (Clark, 2001; Greenhalgh and Ogunye, 2016) or feeling able to adequately digest information (Clark *et al.,* 2004). Older people also found processing conflicting advice and information difficult (Baxter and Glendinning, 2013), but professionals can be an important source of help in thinking through options and working to help people achieve their goals (Abbott *et al.,* 2001). However, while some older self-funders act systematically in looking for solutions to their needs and are wary of making hasty decisions, they can often be unsupported and choose a higher level of care than needed (Putting People First Consortium, 2011).

Objectivity is particularly challenging where discussions are emotive (Baxter and Glendinning, 2013); with findings suggesting that older people under-recognise their needs during assessment processes, perhaps due to concerns over revealing vulnerability (Williams and Porter, 2011; Hasler and Marshall, 2013). Furthermore, even after recognising need, self-funders' and carers' can be reluctant to ask local councils for help (Mangano, 2016). One of the important issues affecting abilities to arrange care is that it is often undertaken at a time of crisis when people are already emotionally drained and may not be taking on board information as effectively as usual (Clark, 2001; Competition and Markets Authority, 2017).

2(c): Other personal attributes

Creativity and innovative thinking were highlighted as key attributes for support planners and other practitioners helping older people plan care (Campbell *et al.,* 2011; Williams *et al.,* 2013; Audit Scotland, 2017), with especially good support planners encouraging service users to widen their horizons when thinking about what they wanted (Williams and Porter, 2011; Rabiee *et al.,* 2016).

Further central attributes were shown to be the *confidence and willingness* to take control or to voice opinions (Abbott *et al.,* 2001; Greenhalgh and Ogunye, 2016; Ettelt *et al.,* 2018), including the ability to robustly raise complaints (Williams *et al.,* 2013). Glendinning *et al*. (2009) in their report on PBs and unpaid carers found that half of carers were not prepared to manage PB accounts as they felt it would be too daunting. Similarly, Hasler and Marshall (2013) reported that councils were less likely to promote DPs to older than younger people as they assumed they did not have the capacity or willingness to manage them, whereas Abbott *et al*. (2001) found that continuing healthcare recipients, including older people, had both the confidence and competence to monitor services.

Evidence on how the support provided compensated for or complemented skills

In general, the evidence showed that older people with council funding received help with support planning from professionals or peers/user-led organisations (for example, Davey *et al.,* 2007; Glendinning *et al.,* 2008; Hasler and Marshall, 2013; Ayling and Marsh, 2014) whereas self-funders received more limited, if any, help (for example, Hudson and Henwood, 2009; Putting People First Consortium, 2011). The type of help offered was not always well described but typically centred on provision of information, support planning and employment support.

While there is an assumption that increasing the quantity of information is beneficial and older people will be able to navigate what is offered (Hudson and Henwood, 2009), support can also be tailored to people's individual needs (Lucas *et al.,* 2009; Newbronner *et al.,* 2011; Williams *et al.,* 2013), including proactive support planning for people newly disabled (Williams *et al.,* 2014) and offering support in a "hand in hand", "hand over" and "hands off" way (Campbell *et al.,* 2011, paragraph 3.60).

Although no papers explicitly sought information on or discussed whether support complemented people's existing skills, many described the support offered in a way which suggests it may be complementary, for example, as helping people to make the best choices (Sanderson, 2010), assisting people rather than doing things for them (Ayling and Marsh, 2014), raising the skill levels of people needing support and their families (Hasler and Marshall, 2013) and widening people's knowledge of potential options (Greenhalgh and Ogunye, 2016; Rabiee *et al.,* 2016).

Evidence comparing outcomes for people receiving help in arranging care with those not receiving help

None of the seven review papers reported any published evaluations comparing well-being or quality of life for people who had received help with arranging and monitoring care with those who had not received help.

Only one of the 36 primary research papers from which data were extracted reported outcomes for people receiving help in arranging and managing care and those not (Paine Ellis *et al.,* 2014). However, this evaluation of an information and advice intervention compared to brokerage and befriending reported outcomes for the two groups combined, making findings that older people felt more involved, in control and aware of options hard to interpret.

Discussion

This scoping review investigated the published evidence on the skills that older people need, and the help they get, to seek, arrange or manage use of social care, and how this help affects outcomes. It found some evidence on these skills and capabilities, but none specifically on how support compensates for lack of or complements existing skills, or affects well-being outcomes.

The review has a number of limitations. Fewer than half the papers reported evidence exclusively on older people; where other groups were included, findings were not always clearly reported according to these groups. Quality of papers was not formally assessed. However, only a third were published in peer-reviewed journals and studies addressing outcomes were typically poorly designed or reported. Although our search terms were deliberately broad, searches were limited to England, Wales and Scotland to ensure the evidence was relevant for self-funders in England. Evidence from other long-term care systems which may have offered additional insights is therefore not included.

None of the 36 empirical papers included in the review reported explicitly on the skills and capabilities that older people need to arrange and manage care themselves; instead they presented evidence about the support that is provided to older people using social care. From this support we have inferred the skills and capabilities that are implicitly identified as needed. Some of these are more obvious than others. For example, it is not surprising that people need skills in searching for information and managing budgets. However, this review has also highlighted less obvious skills and also some personal attributes that might benefit self-funders and be of interest to social care practitioners in targeting support to people most in need.

One of these attributes is the ability to step back from the emotional responses associated with needing care. This can be as important for family members as it is for the person needing care. Older people tend to make decisions about social care at a time of crisis and emotional vulnerability, perhaps at discharge from hospital, following a sudden life changing event such as a stroke or diagnosis with a more slowly developing condition such as dementia. While emotional responses can play a positive role through sharpening the senses, they can also alter people's perceptions of risk and lead to regret about decisions (Beresford and Sloper, 2008). Support planners play a key role for people funded by their council by detaching themselves from the emotional aspects of a person's situation and focussing on what care and support would best suit the older person in meeting their short and long-term goals. Offering similar support to self-funders could enhance sustainability and potentially cost-effectiveness of solutions.

The evidence also suggested having wide social networks can be beneficial in seeking information and arranging care. But not everyone has such networks. Support planners or other community-based workers might usefully target support according to the networks people have available rather than their means of paying for care. One particular group who might be affected by diminishing social networks is people living with dementia. A diagnosis of dementia can place existing relationships and networks under strain, but 'facilitated friendships' (Ward *et al.*, 2011) may help rebuild social capital. Given the size of the self-funding population, it is reasonable to assume that a significant proportion will be living with dementia. Wittenberg *et al*. (2019) estimate that 70% of care home residents and 25% of older people who used social care in the community were living with dementia in England in 2015. Building or maintaining networks in the early stages of the disease could be beneficial in the long term. However, people are, in general, reluctant to plan for care. Reasons include fear of looking to a future of dependency and reluctance to plan for something that may never happen; for self-funders, there is also uncertainty about how best to invest for care or how much it will cost (Heavey *et al.*, 2019; Dixon *et al.*, 2019). A challenge for social care practice is to identify and engage people, self-funders or not, who might benefit from interventions to assist with building networks and early care planning.

There was limited evidence that help to navigate the system and arrange care was tailored to people's knowledge and skills; a 'one size fits all' approach appeared to be the norm. This is likely to mean that some people want more help while others feel the help they are getting is duplicating their own efforts. This lack of personalised help is not unique to self-funders or social care; Bickerdike *et al.*'s (2017) systematic review of the effectiveness of social prescribing found no evidence that interventions by link workers were tailored to individual needs. The 'one size fits all' approach also echoes the healthcare utilisation literature which explores the point at which patients meet the professional healthcare system, and factors that enable patients to engage (Babitsch *et al.*, 2012). Of particular relevance is candidacy theory (Dixon-Woods *et al.*, 2005) which has been used to explore how a person seeks and navigates health care services (Mackenzie *et al.*, 2013). As Dixon-Woods *et al.* state, '*Health care organisations often rely implicitly on an 'ideal user', who is able to match the precise set of competencies and resources to the way in which the service is intended to be used'* (2005, p5). The social care system is no different but, in reality, people need to deploy a range of skills and resources to engage with and access care, and, as we have seen, there is no evidence to suggest that self-funders are any better equipped than people receiving council funding.

Finally, a major gap is any evidence to show what effect, if any, help to arrange and manage care has on outcomes such as quality of life, quality of care and sustainability of funding, or how these differ in relation to people's characteristics, skills and attributes. It is crucial that future research evaluates such outcomes if professional help is to be targeted effectively and efficiently across older populations, regardless of means of paying for care. The DETERMIND project (http://determind.org.uk/), a five year, mixed methods programme of work will begin to fill this gap by investigating inequalities in dementia care, measuring a range of health and well-being outcomes over time, for self-funded and council-funded older people with dementia as well as for people receiving no formal care, and exploring self-funders' experiences, including the support they receive in planning for and arranging social care.

Conclusion

A blanket approach to supporting older PB users to arrange and manage care while offering no or very little support to self-funders is the norm, but there is no evidence that this is an effective use of resources. A more tailored approach irrespective of funding may be more suitable. But this is not without challenge; social care practitioners will need to consider ways of engaging with self-funders as well as determining how best to tailor support.

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Box 1: Summary of search terms

Searches included the following key terms and their relevant derivatives, adapted for each database as appropriate:

- Self-funder terms - Self-fund, private purchase, private spend, personal fund, private fund, private pay, private expenditure, pay for care, self-finance, paid for, top up
- Council-funded client terms – direct payments, personal budgets, individual budgets
- Continuing healthcare terms – continuing healthcare, continuing care
- Information, advice and support service terms – support services, support schemes, support systems, support programmes, support planning, support planners, person-centred planning, brokers/brokerage, advisers/advice services, information services, strengths-based, peer support, user-led support, care management/managers/assessment, needs assessment

Figure 1: Flow chart of screening process

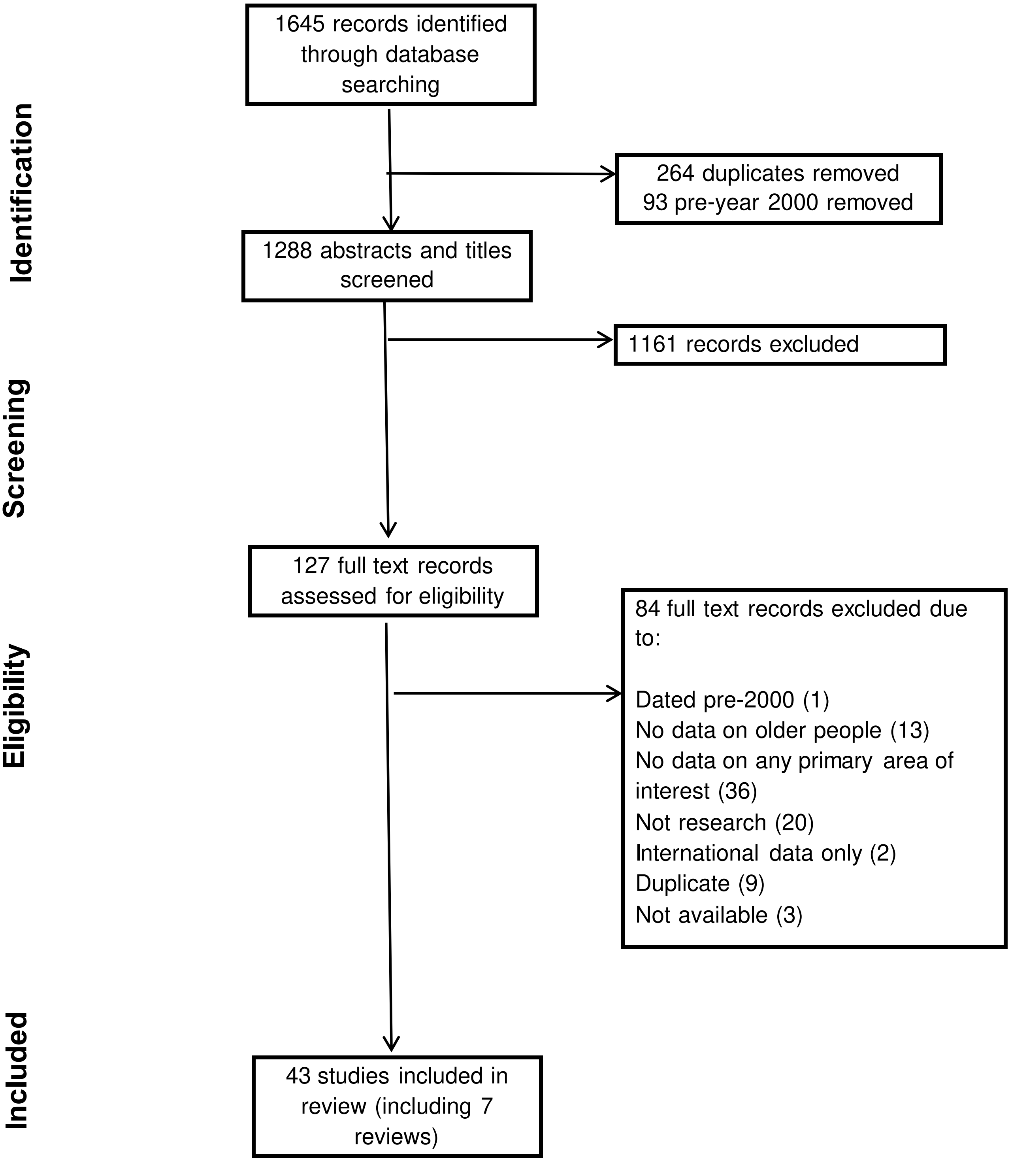

Table 1: Inclusion and exclusion criteria

Criteria	**Include if…**	**Exclude if…**
Publication year	2000 to 2018	Pre-2000
Publication type	Peer reviewed Research reports from academic units, independent researchers and voluntary organisations	Other grey literature (e.g. theses, conference proceedings)
Article type	Empirical data • research findings • reviews of empirical research	Policy papers and opinion pieces
Location	Data from one or more of England, Wales or Scotland*	International data only (including Northern Ireland*)
Population group	Older people (aged 65 or over but flexible down to age 60)	No data on older people
Subject of evidence	At least one of the following broad areas: • skills and capabilities needed to arrange care	Focus on mental health issues only (dementia should be included)

	• support provided in arranging care • evaluations comparing outcomes for people who have/have not received help with arranging/ monitoring care

* Although the funding systems are different in these three UK countries, there are similarities, for example health and social care are (usually) the responsibility of separate organisations and each country comprises self-funded individuals who manage at least some of their care with no/limited professional support. In the fourth UK country, Northern Ireland, health and social care are integrated and although a self-funder pays for their care, that care is arranged and managed by a health and social care trust. Therefore, evidence from Northern Ireland was excluded.

Table 2: Summary of key skills and capabilities needed to arrange care

Theme 1 - Practical skills	**Theme 2 – Personal attributes**
1(a) Everyday life skills • Information searching and management • Ability to manage money and a budget • Contingency planning 1(b) Business-related skills • Administrative skills • Employment-related skills • Negotiation skills • Understanding legal issues	2(a) Interpersonal skills • 'People management' skills • Utilising social and other networks 2(b) Objectivity in decision-making • Ability to evaluate alternatives • Role of emotions 2(c) Other personal attributes • Creativity and innovative thinking • Confidence to take control