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Baxter, Catherine Rachel orcid.org/0000-0002-3094-9546, Heavey, Emily Elizabeth Louise orcid.org/0000-0003-0920-7705 and Birks, Yvonne Frances orcid.org/0000-0002-4235-5307 (2017) *Older self-funders and their information needs*. Report. National Institute for Health Research: School for Social Care Research

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Older self-funders and their information needs

Information about social care and support needs to be available in one place to help self-funders

Self-funders currently feel lost and confused when searching for care information

Clearer guidance is needed for self-funders to know that practitioners are available to discuss their needs and recommend appropriate types of support that are available to them, even though they cannot recommend named providers

Local councils and social workers need more time to provide information on care and care options to self-funders

Increasing public awareness of adult social care is a key priority

BACKGROUND

Research evidence about people who pay for their social care – self-funders – is limited. Estimates of the number of self-funders in England vary, but there is agreement that numbers are increasing as a result of population ageing and rising eligibility thresholds for local authority-funded care.

The importance of self-funders to local authorities is also increasing, in part due to the Care Act 2014 which stipulated, amongst other things, that local authorities must establish and maintain services to provide information and advice on care and support to all residents, however they are funded.

ABOUT THE STUDY

This study focussed on self-funders (people who use their own funds to pay for social care).

It explored the experiences of self-funders in seeking information about care and support, and of practitioners in providing information.

It also created a leaflet and short film as resources to assist self-funders and others starting to search for care for the first time.

Methods

Forty interviews with self-funders or their relatives between 2015 and 2016 explored their experiences of seeking information about care at home or in a care home, and 19 practitioners (including local council social workers and 'first contact' advisors, voluntary organisation advisors, care providers and GPs) were interviewed about their experiences of being asked for and providing information.

In addition, senior managers from five local authorities gave a strategic perspective.

Study participants attended workshops (one for self-funders/their relatives and one for practitioners) to help design the short film and leaflet.

FINDINGS

SELF-FUNDERS' EXPERIENCES OF FINDING INFORMATION ABOUT CARE AND SUPPORT

Self-funders and their relatives discussed in some detail their experiences of looking for information about care, and using that information to get appropriate care.

The routes they took varied from start to finish, although there were some recurring themes. Some respondents were prompted to seek care by an acute incident, including medical crises like a fall or a stroke; others experienced gradually increasing needs, and were able to seek information over a longer period of time.

The length of time between deciding to look for information about care and getting the appropriate care also varied; some respondents got the care they needed within days of starting to look – often because a crisis or sudden change in circumstances necessitated it. Others found the process of deciding to look for care, searching for information, choosing a care option, and having that option implemented took months or even years.

In the course of looking for care, self-funders and relatives sought information from various sources including local authorities, GPs and where relevant other health care practitioners and voluntary organisations. Many also relied on advice from family and friends, prior knowledge about the care system, or online searches. A few sought advice from solicitors or financial advisers. No respondents discussed using a support broker or care navigator/planner. This range of sources illustrates the lack of a clear route for self-funders or their relatives in seeking information about care.

Despite some differences between their experiences of looking for information, self-funders and their relatives faced many of the same challenges.

Information seeking and daily life

Respondents reported that seeking information was a time-consuming and exhausting process, exacerbated by their own circumstances or, if seeking information for someone else, the demands of a job or caring role. They reported financial concerns, not only related to paying for care but to the fear of spending all their money and leaving no inheritance.

The experience of seeking information was characterised as stressful and upsetting, and for some this was linked to a sense of unfairness about paying for care while others were funded by local authorities. Escalating care needs intensified many of these challenges.

FINDINGS

Dealing with different organisations

Specific organisations presented a challenge for some respondents.

Adult social care departments were challenging for many; people felt they were dealt with in a perfunctory manner and not offered help once it became clear they were self-funders. The experience could be frustrating due to long waits, repetitive processes or being passed around different departments. This was not always the case; there were examples of smooth processes in which councils helped find and arrange care, especially if fast-tracked in a crisis.

Voluntary organisations were reported to be efficient, solving queries in a single call. Not all respondents knew voluntary organisations could provide information on finding care.

For some, the variety of organisations available presented its own challenge, with respondents reporting difficulty in knowing which organisation was most appropriate, and others feeling they were always being 'signposted' elsewhere, or to another person in the same organisation.

People found speaking to a named individual rather than a team was helpful. The immediacy of the self-funder's needs meant they were sometimes unable to contact many organisations.

Accessing and understanding information

Many respondents struggled to find appropriate information, and especially advice, about care.

People wanted personalised advice, not generic information. In particular, they expressed frustration at not receiving recommendations about care providers from local authorities, GPs, or voluntary organisations.

The information that was received was reported by some to be confusing or otherwise inadequate; for example, lists of care providers could be unclear on what services a particular agency offered, and letters or advice sheets contained unfamiliar terms. Exceptions were factsheets or other information offered by some voluntary organisations.

In some cases, the quantity of information provided by practitioners could make people feel burdened and overwhelmed, rather than enabling them to make more informed choices.

While some respondents benefited from prior knowledge or advice from friends and families, some were misinformed or confused by such information, for example in expecting particular benefits because a friend had received them.

LOCAL COUNCIL AND OTHER PRACTITIONERS' EXPERIENCES OF PROVIDING INFORMATION

Practitioners were asked explicitly about the purposes of providing information about care and support to self-funders.

A common response was to empower self-funders and help maintain independence by increasing their awareness of care options. Some practitioners emphasised to self-funders the greater choice and the flexibility they were afforded through paying for their own care, compared with people funded by local councils.

A more general aim of local council practitioners specifically was to change people's perceptions of adult social care; there was a sense that some people feared local councils/social workers would insist on them receiving care that they did not want or moving into a care home against their will. Local council practitioners were also aware of their Care Act duty to provide information about care and support to all their resident population.

Some also felt clearly that part of their role was to signpost people with low level needs or who could pay for their care themselves to voluntary and community organisations, and thus reduce the demand on busy adult social care teams.

Practitioners discussed challenges but also effective ways of providing information. Providing information face to face, or looking at information together online while on the phone, were felt to enhance understanding.

Many practitioners, particularly those with a health or social work background, felt uncomfortable discussing finances or the costs of care. On the other hand, local council advisors who were trained to be the first point of contact for people enquiring about adult social care felt relaxed about ascertaining basic information about people's financial



FINDINGS



circumstances. Discussing the costs of care upfront was seen as enabling an open discussion. The rules about financial eligibility thresholds were known by local council and other specialist care advisers, but non-specialists were less clear. Some advisers felt uncomfortable in not being able to give people concrete or reassuring information about the financial assessment process and what they may have to pay towards care.

Advisors from all types of organisation felt constrained by the amount of time they had available to spend helping people seek and understand information. Time pressures were alleviated by reablement services which gave self-funders more time to think about levels of long-term care and its cost. Many also reported a sense of guilt that they passed people 'pillar to post'.

Practitioners sometimes felt uncomfortable being unable to recommend particular providers when it was clear that people wanted help in making choices. Advisors were allowed to give information and advice about, for example, appropriate types of care homes, but not recommendations about which one to choose.

THE STRATEGIC PERSPECTIVE FROM LOCAL COUNCILS

The strategic perspective from senior managers was limited by the very small numbers interviewed but suggested

that self-funders were moving up or already high on councils' adult social care agendas.

A priority was to raise the awareness and visibility of adult social care. Managers confirmed that the public have little understanding of social care. Confusion arises around which organisations provide what care, especially between health and social care, and in parts of the country where there are two tiers of local government. There is further confusion about the term 'care' as it can refer, for example, to health care, social care, long-term care and intermediate care.

Although councils wanted to raise the visibility of adult social care, for example, by moving offices to 'shop front' locations, this was matched by concerns about having sufficient capacity, or appropriate information technology, to cope with the potential increase in numbers of self-funders who may approach councils for information or assessments. Similarly, whilst prevention, self-management and reablement were seen as key to helping people remain independent, there were worries that people may get 'sucked into the system' unnecessarily.

There were concerns about the development of a two-tier market. Providers were believed to prioritise self-funders (who pay higher fees) making it hard in some localities to source care for people funded by the council. There were also worries about self-funders moving into care homes sooner than councils felt necessary, potentially reducing independence and funds. Councils felt they had little influence on the quality of care if a provider dealt only with self-funders with whom the council had no relationship.

Pressures on hospital beds presented a challenge and highlighted differences between health and social care, with

hospitals focussing on speeding up the discharge process and social care focussing on enabling people to have sufficient time to plan their post-discharge living arrangements. These pressures were thought to be particularly difficult for self-funders who might be offered (or want) limited discharge support from councils.

CO-PRODUCTION WORKSHOPS TO DESIGN A LEAFLET AND FILM

The interview findings suggested that self-funders and their relatives struggled with the very first steps in finding information, in particular, not knowing what organisations to approach or what questions to ask. Both self-funders and practitioners felt that a simple leaflet would help people get off the starting blocks.

Around 20 self-funders or their relatives attended a workshop to discuss emerging findings and the creation of a leaflet and film to facilitate finding information about care and support for older people. A similar number of practitioners attended a separate workshop. Workshops participants discussed various scenarios and used their own experiences to suggest types of organisations and people to approach for information. They also discussed styles and formats for the leaflet and short film, and potential distribution strategies.

The suggestions developed in the workshops and subsequent discussions with the project advisory group and selected individuals were brought together to create a leaflet entitled *Getting informed, getting prepared: first steps to finding care and support for older people* and a short film called *Finding care and support for older people*. Both can be viewed at www.gettinginformed.net.

CONCLUSIONS & RECOMENDATIONS

- The overarching finding from this research is that self-funders and their relatives felt lost and confused when searching for information about social care and support. Raising the level of awareness and understanding of adult social care is a long-term challenge that councils are already tackling.
- Self-funders could also benefit from councils and voluntary organisations making it clear what they can offer to people who are not eligible for financial support.
- Self-funders wanted personalised information and advice. They appreciated discussing their requirements with a named individual rather than having to repeat their stories at each step of the way. Some organisations achieved this, but there are opportunities for others to improve.
- Although practitioners are not able to recommend particular providers, they are able to recommend types of providers that are able to meet an individual's needs, for example care homes that offer nursing or dementia care. It should be made clear to self-funders that these types of discussions and recommendations are available to them.
- A particularly frustrating issue for self-funders was the use of jargon in both written and verbal communication. Practitioners from all organisations should take care to use terms that are meaningful to members of the public and to check that they have been understood.
- Some practitioners were reluctant to discuss personal finances or the costs of care, whereas others found it helpful to do so upfront. Finances were one of the most confusing issues for self-funders. When approached sensitively, discussing financial eligibility and care costs can help set the scene for informed decisions.

Getting informed, getting prepared

First steps to finding care and support for older people



GETTING INFORMED ABOUT CARE AND SUPPORT FOR OLDER PEOPLE

The outputs from this research include a leaflet and short film to help people looking for information about care:

Getting informed, getting prepared: first steps to finding care and support for older people is a leaflet aimed at people starting to look for information about care and support for older people.

Finding care and support for older people is a short film in which a study participant talks about her experiences of finding information about care for her husband. The film indicates steps that others might take to find the information they need.

The www.gettinginformed.net website contains the leaflet (also in text only, large print and audio versions), and the film (with and without subtitles).

School for Social Care Research

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

NIHR School for Social Care Research
London School of Economics and Political Science
Houghton Street
WC2A 2AE

Tel: 020 7955 6238

Email: sscr@lse.ac.uk

sscr.nihr.ac.uk

THE UNIVERSITY *of York*

This research was undertaken by Kate Baxter (kate.baxter@york.ac.uk), Emily Heavey (emily.heavey@york.ac.uk) and Yvonne Birks (yvonne.birks@york.ac.uk) at the Social Policy Research Unit at the University of York.

Social Policy Research Unit
Alcuin Block B
University of York
Heslington
York
YO10 5DD

Tel: 01904 321950

Email: spru@york.ac.uk

Twitter: [SPRUYork](https://twitter.com/SPRUYork)

www.york.ac.uk/spru/

www.gettinginformed.net

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