



Putting **People First**  
Transforming Adult Social Care

# People who fund their own care and support

A review of the literature

and

Research into the existing provision of  
information and advice



## FOREWORD

We have become increasingly aware of the growing numbers of (primarily older) people who make their own arrangements for care and support services without the direct involvement of their local council. Figures suggest that at any given moment no more than around one in five people aged 75 or over in a particular council area make contact with the council and only around one in six receive council funded support. These figures are lower still for areas with above average wealth/health.

Both the "Putting People First" (PPF) programme and the Government's Green Paper on the future funding of social care stress the importance of supporting the whole population to stay healthy and active, and also to be assisted in making the right choices regarding ways of meeting their care and support needs. This is a crucial aspect of the transformation process and the so called 'universal offer' is a key aspect of both the PPF programme and the proposed National Care Service.

Yet despite this, relatively little is known about those who fund their own care and support. In pursuit of a better understanding of the 'self-funding' population, the PPF local government Consortium (ADASS/LGA/IDeA) has joined with SCIE and the Joseph Rowntree Foundation to commission work from Melanie Henwood Associates to explore this area in more detail.. The attached reports set out their findings.

This work is intended as the first of a two-part study, with more detailed follow-up work intended to draw its direction from these initial findings. We hope you find the reports useful and informative.



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# **A Parallel Universe?**

## **People who fund their own care and support: A review of the literature**

**Bob Hudson and Melanie Henwood**

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**A Parallel Universe?  
People who fund their own care and support:  
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## **Executive Summary**

1. This report was commissioned from independent consultants Bob Hudson and Melanie Henwood by the Association of Directors of Adult Social Services (ADASS), the Social Care Institute for Excellence (SCIE) and the Joseph Rowntree Foundation (JRF). It reviews a range of literature across policy, research and development, focusing on or relevant to people who fund their own care and support ('self-funders') who often appear to exist in a parallel universe to that occupied by people who meet eligibility criteria for council funded social care.
2. The review is the first part of a wider study, and a companion report investigates the approach of (mainly third sector) organisations involved in the provision of information, advice and advocacy (IAA). Both components need to be read together as they provide a platform for conclusions and recommendations for more detailed research.
3. There are shortcomings in the information, advice and support available to people seeking help as self-funders. For the vision of a 'national Care Service' envisaged by the Green Paper to be achieved, much will need to change. Some key findings can be highlighted.
4. **The issue of self-funders is growing in urgency but the concept is not watertight:** the combination of demographic change, wealth distribution and a broader conceptualisation of social care away from the Poor Law safety net are all contributing to a change of focus, but defining a 'self-funder' is not straightforward and misconceptions abound.
5. **The evidence base on people who are self-funding is limited:** it is dated, biased towards those people already in care homes and fails to capture the longer care journey that people undertake.
6. **Numbers:** again data is poor, but there has been a steady rise and self-funders account for as much as 40% of the social care market. There are considerable local variations; some councils have undertaken studies to understand their situation more fully but there are untested possibilities around some figures in Joint Strategic Need Assessments (JSNAs).
7. **Policy exhortation is already in place:** The original FACS Guidance, and the latest consultative draft revised guidance, impose a duty to assess needs separately from means, and to actively encourage people to seek out information and advice.

8. **There is a policy-implementation gap:** attitudes and approaches are highly variable, there is a continuum ranging from service denial through to minimal support and (rarely) a robust strategy.
9. **Access to information:** there is some evidence of improvement in recent years but persistent problems remain including limited information, highly variable responses, poor web sites, information written for professional rather than lay audiences; and people have specific needs that require more than just an information bank.
10. **Assessment of needs and means:** there is only limited access to need assessment for self-funders which is highly variable often depending upon the attitudes of care managers; care home admissions of people who are self-funding frequently occur without a needs assessment; and there is inadequate forward financial planning or consideration of what happens when personal resources are exhausted.
11. **Access to ongoing support:** a failure to support 'contract-making' for self-funders; signposting often occurs with little or no follow-up; and there are limited channels for redress of grievance.
12. **The universal offer:** of access to information and advice about care and support that should be available to everyone is central to the future position of self-funders. It is also central to the Green Paper – a 'care and support information brand' and there needs to be a robust IAA strategy addressing all three of these dimensions in all councils.
13. **A robust evidence base:** there is an urgent need to underpin policy and practice with proper research and both quantitative and qualitative evidence.

## **A Parallel Universe? People who fund their own care and support: Key findings from the literature**

### **1 Introduction and context**

1.1 This review has been jointly commissioned by the Department of Health, the Association of Directors of Adult Social Services, the LGA and SCIE. It draws together a range of literatures across policy, research and development which focus upon, or are highly relevant to, the situation of people who fund their own care. Specifically it seeks to:

- clarify the concept of 'self-funder'
- estimate the numbers and characteristics of self-funders
- highlight official expectations of support for self-funders
- identify the key dilemmas in supporting self-funders
- outline the features of good practice

1.2 The review is part of a wider study to explore what is known about people who are funding their own care and support and how they are signposted to relevant information and services. It is envisaged that the study will provide a platform for a further stage of work which will explore in greater detail the pathways taken by people who fund their own care and support and how they make the decisions they do.

### **The Growing Importance of Self-Funding**

1.3 The situation of people who fund their own care is growing in significance. There are three main reasons for this:

- demographic changes and their financial consequences for public services;;
- the increase in real terms in the savings and wealth held by older people;
- the changing conceptualisation of the nature of social care.

1.4 In the case of demographic change, rising public resources for social care are not keeping pace with demographic pressures on the system, and this has seen an increasing shift of responsibilities to find and fund care (especially residential care) being placed upon people and their families. In some of the more affluent parts of the country, where more than 70%



of people aged over 65 own their own homes, the numbers of people who are potentially self-funding can be very high indeed. Despite this, it is still relatively unusual to find robust local council strategies in place to ensure these people are supported with appropriate advice and information. However, there is increasing recognition that if more people are to be expected to fund or part-fund their own support, then there should be a clear and explicit commitment to help them do so effectively and safely.

- 1.5 The re-conceptualisation of social care such that it reaches beyond traditional notions of a means-tested safety net towards some form of 'universal offer' is increasingly evident. The 1948 National Assistance Act made it plain that councils were only obliged to provide care and support to people in circumstances where it was not 'otherwise available to them' – a safety net rather than a universal entitlement. However, there are now broader expectations being laid upon councils – to promote health and wellbeing, for example, or ensuring people receive support to live independently at home, as expected under National Indicator 139. At the same time, however, there are countervailing forces which have seen the redefinition of what would historically have been regarded as health care, but which is now deemed social care. Large elements of residential and nursing home provision, for example have moved from the health arena to social care, and have accordingly moved from a service free at the point of need, to one which is means-tested and charged for.
- 1.6 In recent years there has been a raft of policies and programmes that have resulted in a conceptualisation of social care that goes well beyond that of a 'safety net'. These include:
- *Opportunity Age* (DWP, 2005), which sets out a strategy for older people that recognises the contribution they make to their community and economy as citizens.
  - *Linkage Plus*, a three-year DWP funded programme (from 2005) to develop accessible preventive services that are designed with older people themselves.
  - *A Sure Start in Later Life* (Social Exclusion Unit 2006) aimed at stimulating communities to reshape services in ways that are accessible, flexible and 'upstream'.
  - *Partnerships for Older People Project (POPP)* funded by DH to deliver and evaluate local innovative schemes for older people that promote independence and wellbeing.
  - *Putting People First* with its four key themes of facilitating access to universal services, building social capital within communities, making a strategic shift to prevention, and ensuring people have greater choice and control over meeting their needs.

- *Building a Society for All Ages* (Department for Work and Pensions, 2009) develops *Opportunity Age* and sets out a vision for a society where people should no longer be defined by their age, but where their skills and experiences are harnessed for the benefit of society as a whole.
- The Green Paper, *Shaping the Future of Care Together* (2009) set out “six things that everyone in the country should be able to expect” from the proposed new ‘National Care Service’ – prevention services, national assessment, a joined-up service, information and advice, personalized care and support, and fair funding.
- New guidance on eligibility criteria for social care issued for consultation in July 2009 similarly emphasised that delivery of the transformation agenda of *Putting People First* is contingent on a strong focus on ‘place shaping’ and promotion of well-being through universal services.<sup>1</sup>

1.7 This all adds up to a significant move away from the paternalistic models inherent in the safety-net era, towards a model rooted in control, choice, flexibility and citizenship. This in turn raises a debate about what is increasingly being called the ‘*universal offer*’ – that irreducible level of social care support that *all* citizens can be entitled to expect regardless of whether they fund their own care or are publicly funded. As Glendinning and Bell observe<sup>2</sup> such a model can be underpinned by notions of entitlement that are more usually associated with individual claims on social security benefits.

1.8 The concept of a ‘universal offer’ has fast been gaining currency but it has been less clear what this offer constitutes, especially for people who fund their own care. The Green Paper<sup>3</sup>, however, does now begin to give more shape to the components of this offer by proposing a National Care Service as outlined above. It states that:

*“We believe that the new National Care Service must be a system for everyone. It must help everybody to find and obtain the good-quality care and support they need so that they can live their lives the way they want to.”* (p65)

*“Everyone should get support to stay independent and well. Everyone should be able to have access to information and advice about care and support. If their needs qualify for*

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<sup>1</sup> Department of Health (2009), *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, England 2009 (consultation stage)*

<sup>2</sup> Glendinning, C and Bell, D (2008), *Rethinking social care and support: What can England learn from other countries?* (York: Joseph Rowntree Foundation).

<sup>3</sup> HM Government (2009), *Shaping the Future of Care Together*, Cm 7673, London: The Stationery Office.

*further assistance, everyone should get financial help in meeting the cost of care and support.” (p47).*

- 1.9 The Green Paper has also gone further in indicating that a new national model would mean that wherever they live in England, people would get a consistent service, by the introduction of national eligibility criteria, and would get some help with their high-level care costs – the state, it is said, should have a role in helping *everyone* to meet the costs of their care and support.<sup>4</sup> This all ties in with the various options for funding long-term care that are reviewed in the Green Paper. Under the favoured ‘partnership model’ the state would provide *everyone* with at least *some* help with their care costs, and this could radically alter the situation of people who self-fund. At the time of writing the Green Paper is out for consultation and all these matters remain unresolved. With a General Election on the horizon by Spring 2010 it is also evident that all parties are grappling with the thorny issues of paying for long term care and how to address the situation of people with modest assets and savings which put them beyond local authority funding.

#### **Who Are the Self-Funders?**

- 1.10 Self-funders are often defined negatively (those people whose care is *not* arranged or provided by a local authority) rather than neutrally as those people who arrange and fund their own care and support. This can include support to live independently at home or in a care home. However, this bald distinction is far from watertight for several reasons:
- people ineligible for council *funding* may still be helped with *arranging* their care;
  - people may be part-funded by the council and pay the balance themselves;
  - people may be eligible for council funding but fail to apply for it;
  - people whose care is council-funded may still make a substantial cost contribution from an old age pension, pension credit and private pension;
  - where people qualify for attendance allowance/disability living allowance, these sources are generally used by a self-funder to contribute to the cost of support;
  - people using personal budgets could be *arranging* their own care but not *funding* it;
  - and finally, the definition of self-funders is in many ways subjective and describes a continuum of arrangements rather than a single state. Many people who are arranging a

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<sup>4</sup> HM Government (2009), *Shaping the Future of Care Together*, London: The Stationery Office, P.47.

‘little bit of help’ for themselves would not necessarily perceive themselves as ‘self-funding.’

- 1.11 Perhaps the most commonly used definition is in relation to the national financial ceilings used to determine eligibility for council support in paying for a place in a care home. Here, self-funders are those individuals who fund their care home placement using their income, savings and capital. Currently (April 2009) this means individuals with savings above £23,000 (or an income that covers the cost of their support) are required to meet the full costs of care, though people with capital between £14,000 and £23,000 are expected to make a contribution from capital as well as income. In the case of support to live independently at home, councils are free to levy their own charges (within a framework of fairer charging policies) and these can vary from council to council, though most mirror the £23,000 national care home threshold regarding savings. The value of a person’s home is counted as capital for people entering a residential or nursing home, but not for those people being supported in the community.

## **2 Self-funders: numbers, characteristics and evidence base**

- 2.1 Any estimate of the needs, numbers and circumstances of people who fund their own care has to be treated with caution. This is because of:
- the difficulties of definition outlined above;
  - the lack of data on people who by definition do not come to the attention of councils;
  - the lack of data on people who *do* come to the attention of councils but who are then ‘signposted’ elsewhere;
  - the lack of research and data on people who wholly or partly fund their own support in the community;
  - the difficulty of accessing people who self-fund for research and data collection purposes.
- 2.2 Most of the official data and research is therefore focused on people who fund their own care home place, and even here the evidence is dated and partial. Moreover, the bulk of data is quantitative, with relatively little known about the minutiae of people’s ‘care journey’ as they face choices and options in arranging and funding their own support. This is

especially so in the case of alternatives to a care home placement. The intention is that this gap in the evidence will begin to be addressed in the next phase of this study.

2.3 Despite these reservations and qualifications, there *is* a literature to be analysed on the issue, and there is a fairly consistent narrative that emerges from it. This literature is a mix of academic research, policy-related research, 'grey' literature and official publications, especially by regulatory bodies. This review will include (but not be limited to) the following key sources:

- Netten, A, Darton, R and Curtis, L (2002), *Self-Funded Admission to Care Homes* (Personal Social Services Research Unit, 2002)
- Office of Fair Trading (2005), *Care Homes for Older People in the UK: A Market Study* (London: OFT)
- Swain, D et al (2006), *Accessing Information about Health and Social Care Services* (Picker Institute, 2007)
- *Which?* (2007), *Care Essentials* (June pp 19-23)
- Commission for Social Care Inspection (2007), *Hello, how can I help? An analysis of mystery shoppers' experiences of local council social care information services.*
- Commission for Social Care Inspection (2008), *A Fair Contract with Older People?*
- Henwood, M and Hudson, B (2008), *Lost to the System? The Impact of Fair Access to Care* (London: CSCI)
- Commission for Social Care Inspection (2008), *Cutting the Cake Fairly.*
- Hudson, B and Henwood, M (2008), *Analysis of Evidence Submitted to the CSCI Review of Eligibility Criteria* (London: CSCI).
- Sykes, W. et al (2008), *Opportunity Age Information Indicators Feasibility Study* (Department for Work and Pensions).
- Dalley, G. with Mandelstam, M (2008), *Assessment Denied? Council responsibilities towards self-funders moving into care* (Relatives and Residents Association)
- Williams, C et al (2009), *Transforming Social Care: access to information, advice and advocacy* (I&DeA).

- Commission for Social Care Inspection (2009), *CSCI Quality Ratings Market Research Report*.

### **Numbers: Estimates and Trends**

- 2.4 For all the reasons outlined above, it is not possible to put an accurate figure on the number of people who currently fund their own care. The Wanless Report <sup>5</sup> points out that the data on self-funded care is much less complete than that on state-funded care, especially in the case of home care support where it is difficult to distinguish between private care and private domestic help, and much of this occurs through informal and 'grey' economies rather than necessarily through transactions with agencies and staff. The Department of Health estimates that people arranging and funding their own adult social care now comprises about 35% of users<sup>6</sup> - a figure that can be expected to rise. In the case of care home places, it is estimated that around 115,000 people (27% of independent sector residents) fully fund their own fees.<sup>7</sup>
- 2.5 The poor quality of basic data constitutes a major omission that will hinder any attempt to shape a new strategy, and it is vital that more detailed work is undertaken. Some localities will have undertaken their own surveys, but there has been no attempt to gauge the extent of such work or to aggregate the findings. Rotherham Council, for example, has identified 320 people in care homes in their area who fund their own care, of whom two-thirds made arrangements without any needs assessment. Similarly, Norfolk County Council has estimated that in 2008, 15,350 people aged 65+ were funding their own care (covering care homes, domiciliary care and day care), 30% of whom are thought to have 'high care needs'. and again, LB Richmond in its Older People Needs Analysis identified that 50% of care home places were occupied by self funders, and that only one in two of all residents aged 85 or over were in contact with/received any council support. Richmond also identified that a high proportion of people in their 60s intended to move out of the borough in the next five years.
- 2.6 It is possible that local JSNAs will shed further detail on the numbers, and it should be feasible to aggregate all such local estimates – a task that needs to be undertaken urgently. The importance of understanding the size and characteristics of the self-funding population is two-fold. Councils need to ensure information, advice and support are available and

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<sup>5</sup> Wanless Social Care Review (2006), *Securing Good Care for Older People*. London: King's Fund.

<sup>6</sup> Department of Health (2008), *Impact Assessment of Independent Consideration of Complaints About Non-Local Authority Adult Social Care*.

<sup>7</sup> Age Concern (2008), *Parliamentary Briefing: A note on self-funders in care homes*

suitably targeted, but secondly because the self-funding and state-funded populations intersect at critical points and the first many councils know about the existence of self-funders is when they have exhausted their resources and need urgent support. A better understanding of the self-funding population will assist in addressing such eventualities.

2.7 Data on the features and characteristics of people who self-fund again tends to be confined to care home residents. Even here, the main national study by PSSRU (cited earlier) is very dated, having been undertaken in 1999/2000, and – surprisingly – included no qualitative fieldwork with the residents themselves. This major study is therefore both dated and of limited value. The research aimed to:

- establish whether self-funded people in care homes differed in terms of financial assets and informal support from elderly people in private households;
- establish the extent to which self-financed residents are admitted at levels of dependency that might have been maintained in the community;
- explore the admission process and whether the least dependent people are admitted through choice or lack of appropriate alternatives;
- investigate factors associated with the choice of home;
- identify the level of receipt of non-means tested benefits; and
- estimate expected length of stay of self-funded residents.

2.8 The headline findings of the study were:

- Compared with publicly-funded residents, self-funded people tended to be older and less likely to be married.
- A significantly higher proportion of self-funded people were identified as needing at least some type of nursing care (76 per cent compared with 43 per cent among publicly-funded residents).
- The type of informal support people were receiving prior to admission was associated with the types of care they received. Those receiving supervision, physical help, personal care, and/or help with taking medicine prior to admission were significantly more dependent on admission.
- Self-funders appeared less likely to have local authority arranged home care services prior to admission, and those that did received fewer hours per week.

- Over 90 per cent of friends/relatives of the older people perceived there to be at least one unmet need prior to admission in relation to food/nutrition, personal care, the relative's concern for their safety, social participation and involvement and control over daily life.
- There was some evidence indicating a link between low levels of dependency and unmet needs for social participation, suggesting that some of the motivation for entering a home would be for the company it would provide rather than the need for care or support *per se*.

### **3 Policy and practice issues in relation to people who self-fund**

#### **Official Expectation and Exhortation**

- 3.1 There is already some obligation to support people who fund their own care. Councils have a legal duty to assess a person's needs where their circumstances come to the attention of the council, and it is thought they may be in need of community care services that the council has the power to arrange. This duty applies regardless of the person's entitlement to services or their financial circumstances, and guidance makes clear that the assessment of need should be separate from, and should precede assessment of financial means. Guidance on Fair Access to Care services states:

*"An individual's financial circumstances should have no bearing on whether a council carries out a community care assessment or not. Neither should the individual's finances affect the level or detail of the assessment process."*<sup>8</sup>

- 3.2 The consultation guidance on eligibility criteria for adult social care issued in July 2009 is similarly clear that:

*"An assessment of the person's ability to pay for services should therefore only take place after they have been assessed as having eligible needs."*<sup>9</sup>

- 3.3 Although councils will obviously have difficulties where people do *not* come to their attention, there is still a need to consider what steps they have may have taken to encourage people to seek out council advice. Overall, the duties of councils comprise an

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<sup>8</sup> Department of Health, LAC 2002(13), *Fair Access to Care Services: guidance on eligibility criteria for adult social care*, para 70.

<sup>9</sup> Department of Health (2009), *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on eligibility criteria for adult social care, England 2009 (Consultation stage)*. Para 55.



assessment of needs and circumstances, a decision about eligibility (i.e. what will be provided under the council's eligibility criteria), and a financial assessment of what the person will be expected to contribute to the costs of support and care provided.

3.4 The purpose of the **needs assessment** is to get a full understanding of a person's needs and circumstances in order to support decisions about what help or care might be required and how it might best be provided. As part of this process, councils are obliged to involve housing or health partners when it appears that other support or care might be required. This should include people with significant health needs who may be entitled to fully funded NHS Continuing Care, or who require regular nursing support. Guidance<sup>10</sup> also makes it clear that the process should ensure that people are actively involved in the assessment and that it should be carried out in so far as possible in a way that supports people to:-

- gain a better understanding of their situation;
- identify the options that are available for managing their own lives;
- identify the outcomes required from any help that is provided;
- understand the basis on which decisions are reached.

3.5 The **decision about eligibility** – entitlement to support – is taken following assessment of needs. Councils are required to set and make available local eligibility criteria that comply with national guidance – Fair Access to Care Services (FACS) – based on the degree of risk to independence in four 'bands': critical, substantial, moderate and low. People who fund their own care may well have needs which are eligible for support under the eligibility criteria, but they are then found to be financially ineligible following a **financial assessment**. What is important here is that the obligation to undertake an assessment of *need* is not conflated and confused with the assessment of *eligibility* or the assessment of *means*. The 2009 consultation guidance on eligibility criteria addresses eligibility in the context of investment in prevention and well-being, and the wider personalisation agenda. It proposes retaining current eligibility criteria (at least in the short to medium term while wider resource allocation issues are being decided following the Green Paper), but emphasises the need for 'fairer and more transparent implementation.'

3.6 The move towards some form of 'universal offer' (noted earlier) has resulted in further expectations from the Government on the support local councils should be offering to all relevant people, including those who self-fund.

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<sup>10</sup> Department of Health (2002), Op Cit.

- The Concordat *Putting People First*<sup>11</sup> stated that councils should ensure the provision of “a universal information, advice and advocacy service for people needing services and their carers irrespective of their eligibility for public funding.”
- The subsequent local authority circular, *Transforming Social Care*<sup>12</sup> published in January 2008, made it clear that information should be available and accessible to everyone to “support decision-making and access to care services, irrespective of people’s social circumstances and eligibility for statutory services.”
- The latest circular, issued in March 2009<sup>13</sup> similarly emphasises that significant system redesign of processes, practice and culture, is necessary “to ensure people have access to high quality information and advice, appropriate early interventions and can exercise choice and control over the services and support they need.” The Social Care Reform Grant (half a billion pounds ring-fenced over three years) has been introduced specifically to support such systems investment and transformation.
- The consultation guidance on eligibility criteria (2009) reiterated that all people, whether or not they are funding their own care, “can benefit from effective information, signposting and support planning. Individual financial means should have no bearing on this offer.” Councils must consider “how they can work to support high quality outcomes for all their citizens, including those funding their own care and support.”<sup>14</sup>
- The consultation guidance also hypothesised that if councils are successful in developing strategies to support a broader base of citizens through investment in universal services and prevention, “there may be an argument for discontinuing the use of the fourth eligibility criteria band (low).”<sup>15</sup>

## **Responding to Policy and Guidance**

3.7 The evidence on how far these various injunctions are being observed is not extensive, but what *is* clear is that attitudes and approaches towards self-funders can vary widely across

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<sup>11</sup> HM Government (2007) *Putting People First. A shared vision and commitment to the transformation of adult social care*, London: The Stationery Office.

<sup>12</sup> Department of Health (2008), *Transforming Social Care*, LAC (DH) (2008) 1.

<sup>13</sup> Department of Health (2009), *Transforming Social Care*, LAC (DH) (2009) 1.

<sup>14</sup> Department of Health (2009), Op Cit, para 81.

<sup>15</sup> Department of Health (2009), *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Consultation on the revision of the Fair Access to Care Services guidance to support councils to determine eligibility for social care services*, para 55.

the country. In the CSCI *Lost to the System* study<sup>16</sup>, Henwood and Hudson report that self-funders constitute “a large and often very vulnerable part of the care sector, but seem to be invisible to politicians, managers and practitioners alike” (p37). They identify three broad responses on the part of local authorities to people who self-fund:

### *Service Denial*

- 3.8 The most common response of councils to the issue of support for self-funders was that of service denial – indeed, some of the council respondents in this study appeared to be puzzled that the issue was even being raised with them. Respondents at all levels in most of the councils in the study felt unable to identify any way whatsoever in which their council might support self-funders, as the following comments illustrate:

*“I can’t think of any offhand, no.”*

*“I’m not quite sure how to become proactive.”*

*“I personally think they are in a different system and off our radar. I don’t think they should be on it. If people want to do their own thing then why do they need to come to us?”*

*“Lots of people buy their own care and never knock on our door. We wouldn’t want to interfere in that.”*

*“You have got to be careful not to sort of impose yourself on people that don’t need us and don’t want us. I really don’t know that there is anything we can do.”*

*“Obviously the local authorities have a threshold that is a set of financial means. So if you have £70,000 in the bank and a property that is worth £400,000 (...) why would you need to have somebody come in and interfere in your life?”*

- 3.9 These sorts of observations (of which there were many in the study) raise issues of problem *conceptualisation* rather than issues of implementation – many people in key positions had simply not considered the matter of self-funders. Ignorance can breed its own solution as summed up in the observation by a social worker that “*unless we know them, we don’t know them*”.

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<sup>16</sup> Henwood M and Hudson B (2008), *Lost to the System? The impact of Fair Access to Care*, A report commissioned by the Commission for Social Care Inspection for the production of ‘The State of Social Care in England 2006-07’, London: CSCI.

- 3.10 Similar findings were reported by the Hampshire County Council Commission of Inquiry which reported difficulties faced by people making decisions about their own care or that of people they know, highlighting:

*“the lack of information and help with exploring care options and options for paying for care, Many of these respondents were self-funders or relatives of people self-funding disadvantaged by the unwillingness of statutory services to offer them any kind of help.”<sup>17</sup>*

### ***Minimalist Support***

- 3.11 Where service was not totally denied, councils generally conceded that self-funders, along with others, were entitled to an assessment of their needs.

*“I’ve always been clear that when someone comes to us and they may require an assessment, then they should get that assessment irrespective of their financial status.”*

*“Our responsibility is that anyone who knocks on our door is entitled to an assessment.”*

- 3.12 The drawback to this position is that it normally relies upon self-funders being proactive and approaching the council for advice and assessment – an unlikely occurrence given that many people are unaware that councils may provide this service. The authors found very little evidence that councils are actively inviting people to take advantage of an assessment, and indeed one care manager felt that any such action would be discouraged:

*“We have a duty to assess but it is not encouraged. If you go to your manager and say this person has asked for an assessment you would be discouraged. The general consensus is that they don’t need us.”*

- 3.13 This finding was reinforced by the CSCI *Fair Contract*<sup>18</sup> study undertaken at around the same time which reported:

- In 2 out of the 10 councils in the study, both commissioners and care managers identified that the process of assessment was the same for older people funding their own care as it was for other older people paid for by the council or NHS.

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<sup>17</sup> Hampshire County Council (2008), *Getting Personal: A fair deal for better care and support, The report of Hampshire County Council’s Commission of Inquiry into Personalisation and the Future of Adult Social Care.*

<sup>18</sup> Commission for Social Care Inspection (2008), *A Fair Contract with Older People?*

- In 4 out of the 10 councils, commissioners specifically identified that the level of support for assessment was lower for people paying for their own care than for other older people.
- 4 of the councils' websites made clear that people who funded their own care would be entitled to an assessment and possibly some further support. In the remaining 6, there was either no mention of support for self-funders or very little information.

### *Structured Strategy*

- 3.14 Only one of the 6 councils in Henwood and Hudson's study – one with a high proportion of self-funders – had developed a strategy for supporting people who self-fund, though even here the strategy had yet to be implemented at the time of the fieldwork. In this council some respondents took a different view of the situation:

*"Self-funders are our business. I don't really think there should be a distinction."*

- 3.15 The plan in this council consisted of eight action points for improving information and support for self-funders:

- remind independent care homes under contract with the council of their obligations to provide information to self-funders;
- promote access to council information for people considering residential care options;
- promote access to independent information and advice;
- identify the number of self-funders;
- share information about self-funders with neighbouring councils;
- provide information and advice direct to self-funders;
- ensure independent homes are equipped to support self funders on issues such as adult protection and dignity in care;
- improve access to information for self funders and their carers.

- 3.16 Underneath these broad differences in approach, it is possible to identify three key points in the 'care journey' of self-funders that will shape the effectiveness (or otherwise) of their care outcomes – access to information; access to assessment; and access to ongoing

support. Moreover, as Dunning<sup>19</sup> points out, these are inter-dependent factors, best conceived as interrelated circles rather than different points along the same continuum.

### **Access to information**

- 3.17 Williams et al in the I&DeA<sup>20</sup> study define ‘information’ as “*the open and accessible supply of material deemed to be of interest to a particular population (which) can be either passively available or actively distributed*”. Certainly, adequate information is essential to one of the key aims of Government policy – the promotion of choice and the empowerment of service users. CSCI, in its *Fair Contract* report, sees three key dimensions – reliable and timely information about what is available, how it might help, and what it might cost.
- 3.18 This interest is far from new. As far back as 1998 the Department of Health and the (then) Social Services Inspectorate published a guide to better information<sup>21</sup> which said:
- “Providing good information about social services is more than just advertising. It helps people to understand what is available so that they can make informed choices...The range and complexity of public services can be bewildering for potential service users. Information is the signpost that helps them to understand what is available and where it can be obtained.”*
- 3.19 In the more mixed economy of social care that exists today, and with the growing numbers of people who self-fund, the role of information is even more vital. It is now seen as imperative that councils ensure that robust arrangements to provide coherent information and guidance are in place for their residents to help them make informed choices, regardless of whether or not they end up paying for their own care. Moreover, there is a need for this to be available *before* the onset of a crisis, so that people are better placed to plan ahead.

### **Information giving: the evidence base**

- 3.20 Although the evidence base is still not strong or up-to-date, it is probably right to say that in recent years councils have made improvements in the quality and accessibility of

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<sup>19</sup> Dunning, A. (2005), *Information, advice and advocacy for older people*. Joseph Rowntree Foundation: York.

<sup>20</sup> Williams C., Harris J., Hind T & Uppal S (2009), *Transforming adult social care: access to information, advice and advocacy*, London: I&DeA.

<sup>21</sup> Department of Health/Social Services Inspectorate (1998), *Signposts to Services*.

information about adult social care in their areas. The 2007 CSCI 'mystery shopper' investigation involved a team of eighteen 'shoppers' who telephoned all 150 councils in England twice, indicating that they were calling on behalf of a spouse/partner who had an elderly parent experiencing problems coping at home. The study reported councils' social care advisors to be easy to access, friendly and helpful – indeed, most shoppers were impressed by the knowledge of the person to whom they spoke. The need for an assessment was mentioned in most of the conversations, though it tended to be assumed that callers knew what this entailed, and some shoppers also felt they were being pushed towards the private sector. Nearly 9 out of 10 council advisors talked about funding and sometimes asked immediately about the savings of the elderly relative – an appropriate topic if handled correctly.

3.21 However, it is evident from the wider picture that significant problems persist, especially for self-funders. CSCIs *Fair Contract* survey of 2008 included an on-line survey of 188 people about their experience of written information. It found:

- 79% of survey respondents said the information did not explain clearly what rights they had;
- 76% would have liked more or better information;
- 73% felt the information did not explain the process fully;
- 68% thought it did not help them to make informed decisions about which care options were most suitable;
- 64% thought it did not explain clearly about costs and how they would be paid for.

3.22 Although it is wrong to see councils as the sole repository of information for prospective service users, councils should reasonably be expected to either provide robust information themselves or ensure people are guided to the best information sources available elsewhere. The evidence suggests variable achievements in this respect.

- The *Fair Contract* study reported that (with two exceptions) the council care home directories examined only comprised lists of names and addresses of care homes, with little information on fee levels, top-ups and levels of council funding. Similarly council websites contained only limited basic information.
- The '*mystery shopping*' survey found that nearly a quarter of councils did not send any written information out to shoppers, and of those that did, 25% were either 'poor' or

'very poor' in terms of accessibility. This was contrasted with the experience of information provided over the telephone and "*potentially an older person or their relatives and friends might get good spoken information but receive poor written information as a follow up.*" The study also noted the absence of any pattern to the conversations – while the shoppers asked the same questions of each council, the answers varied widely both between and within councils.

- The *Relatives and Residents Association 2008 study*<sup>22</sup> reviewed the web sites of fourteen local authorities in England. Some councils were praised for their achievements, but some major failings were also identified including: poor website navigation; incomplete or inaccurate (and out of date) information; information written for professionals rather than the public; and an emphasis on charging for services rather than information about needs assessment as a process separate from financial assessment.
- The I&DeA study published this year included an on-line survey of directors of adult services undertaken via the Association of Directors of Adult Social Services, which produced 82 returns (approx 55 per cent). A parallel investigation was undertaken of the websites of 50 councils with social services responsibilities. Considerable variation was identified between websites in terms of content, accessibility and quality, and the survey concluded that access to information and services was "*considerably less well developed in adult social care than in some other services sectors.*"
- A recent study funded by the Joseph Rowntree Foundation<sup>23</sup> emphasises the need for information to be up-to-date and accurate, otherwise the source will soon lose credibility. It suggests that if capacity is limited, it is better to have a small, quality website that can be maintained.

3.23 What this can result in is a cleavage between those who understand information sources and are capable of navigation and assimilation (the 'information rich') and those who are less able to do this (the 'information poor'). This is precisely the conclusion of the Picker Institute study<sup>24</sup> of how service users and carers find out about locally available health and social care services and how to access them. The research noted that the lack of routinely provided information provision had led many users to become "*expert information seekers*",

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<sup>22</sup> Dalley G with Mandelstam M (2008), *Assessment Denied? Council responsibilities towards self-funders moving into care*, London: The Relatives and Residents Association.

<sup>23</sup> Horton, C. (2009), *Creating a stronger information, advice and advocacy system for older people*. Joseph Rowntree Foundation: York.

<sup>24</sup> Swain, D et al (2006), *Accessing Information about Health and Social Care Services* (Picker Institute, 2007)



but these were generally highly motivated, articulate and assertive individuals. The report concludes that “*those without these characteristics are much less likely to fare well in the quest for information, raising serious concerns about equity of access to local services*” (p62).

3.24 For those in this latter position, information will still be vital, but they will tend to seek it from other – possibly less reliable - sources. The ‘mystery shopper’ report, for example, concludes that while council commissioners of care services rely on internal and external reports, people who actually use services rely much more heavily on what their friends and relatives say, and prioritise practical considerations such as the location of a care home.

3.25 This is in line with the wider study for the DWP by Sykes et al (2008) on the ways in which older people access and use information. The researchers found that councils and other agencies often developed quite sophisticated banks of information predicated upon the assumption that service users will then systematically collect information to meet their needs. Older people, however, did not generally seek information directly from primary sources or instigate direct contact with public services agencies with a view to gaining information; rather they drew on knowledge they *already* had, or on intuitive perceptions of the way they thought things work. Rather than say ‘*I have a problem, what should I find out?*’ they say ‘*I have a problem what shall I do?*’ Moreover, if they *do* decide they need to find out more, they will tend to use informal sources (the ‘grapevine’) rather than consult formal sources, which tend to be seen as a last, rather than a first, resort.

3.26 The study found that raw information is seldom perceived as sufficient to give people a clear idea of their options for several reasons:

- the systems people need to know about are often very complex;
- many people seemed doubtful that they would be able to interpret whatever facts they discovered;
- factual information is often general, with unclear implications for individuals in particular situations;
- facts may tell you how things are *supposed* to work, but things often don’t seem to happen as they should – in which case people need support or advocacy.

3.27 The DWP research therefore reports a general perception amongst people aged over 50 that there is a great deal of information ‘out there’, but this does not necessarily make them

feel better served – indeed a glut of information can be just as problematic as a dearth. The key challenge for people remains being able to lay their hands quickly and easily on what they need, when they need it, and then be able to make practical use of it. Individuals were found to be turning to formal organisations for help only when really important issues were reaching a point of great difficulty. When they did so, the authors found:

- local councils were most frequently mentioned, but infrequently contacted; few people saw them as broad repositories of information about community services, or as potential signposters to other providers;
- the Citizen's Advice Bureaux was the most frequently mentioned advice agency – few respondents mentioned organisations specifically targeted at older people or people with disabilities;
- libraries are sometimes used as sources of leaflets and other literature, but in general people are not 'tuned in' to acquiring leaflets;
- call-centres and press-button menu systems are viewed as remote and impenetrable.

3.28 The guidance on eligibility criteria issued for consultation recognizes that people who are found to be ineligible may still benefit from effective support planning and signposting to more universal sources of support. It is also acknowledged that this may need to be proactive and *"if individuals need other services, councils should help them to find the right person to talk to in the relevant agency or organisation, and make contact on their behalf"* (para 85).

### **Access to assessment**

3.29 As we have described above, there should be two sequential assessments – of needs and of means – which should shape the support available to people who self-fund. As already noted there are two potential obstacles here: that self-funders are denied an assessment of needs, and that an assessment of needs and means is too often conflated in practice.

### **Assessment of Need**

3.30 There is a considerable body of evidence to suggest that people who self-fund do not generally receive a proper assessment of their needs, whether this is at the point of referral or post-referral. The CSCI *Fair Contract* study, for example, found that half of the ninety

people who funded their own care said they did not have a needs assessment. The shortcomings described by survey respondents included:

*“We were very confused whether to choose residential or nursing and two years later the staff nurse said Dad shouldn’t be in a nursing home. Why didn’t we know how to get an assessment?”*

*“My father at 89 was very frail, blind, almost unable to walk with very poor balance. He was to be discharged from hospital following a chest infection. My mother at 88 was no longer able to care for him at home. We were just given a list of homes and told to find one. It was very lucky that I was living locally and could help my aged and not very mobile mother trawl around the homes and find something suitable. We had no advice or direction, as it was assumed my father would be self-funding. In the end we found a less than perfect place that he could afford.”*

3.31 In *Lost to the System*, Henwood and Hudson note the concern that in their *initial* contact with a local authority, people’s needs and circumstances may be insufficiently explored. Traditionally the gatekeeping role of determining access to council funded care (or at least to an assessment of need) has fallen to professionally qualified social workers based in duty teams on a rota basis or as a specialist intake team. Henwood and Hudson report that this role is now often undertaken by reception staff without a professional background in social work, or is being done on the basis of a telephone conversation. This will affect council-funded and self-funded applicants alike. Whilst some see this as a desirable trend, others (such as the Residents and Relatives Association) have expressed concern that it may fail to uncover real levels of need.

3.32 This finding was further reflected in some of the written evidence submitted to the CSCI review of the FACS eligibility criteria<sup>25</sup>, especially from groups representing people who use services and their carers:

*“We are concerned that local authorities are relying more and more on telephone assessments to make a judgement about eligibility...We are worried that applicants’ needs can easily be taken at face value when downplayed by an individual (as is often the case with older people who find it hard to ask for help) and therefore can go unrecognised.”*

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<sup>25</sup> Hudson, B and Henwood, M (2008), *Analysis of Evidence Submitted to the CSCI Review of Eligibility Criteria* (CSCI)

*“We meet service users on a regular basis who appear to have been screened out because a brief initial phone call elicited the ‘wrong’ responses in social services eyes. The needs that a person mentions at the beginning of a phone call may not be their primary needs.”*

*“Before the referral reaches the duty officer, sometimes it appears it has been pre-assessed by reception staff who are asking what the person needs or wants, rather than referring directly to the duty officer for an assessment.”*

3.33 Help and support from a social worker or care manager is a crucial part of making the process of choosing the right support a manageable process, but there is evidence that even where individuals do have contact with a care manager, the relationship is variable. The CSCI *Fair Contract* study reported significant differences between care managers as to their involvement in providing advice and help with financial matters - this was true both within *and* between councils. Three quarters of the care managers interviewed said they sign-posted people towards voluntary organisations as a source of information on the care homes available, whilst the research from the *Residents and Relatives Association* reported that the social work role was typically experienced as filtering people *out* of support rather than guiding them through it.

3.34 All of this can mean that the first proper assessment of need is undertaken by the new service provider - far too late to determine the best course of action, and effectively setting people on an irrevocable trajectory of care. The issue here is the range of policy and organisational imperatives that give priority to care home admission over independent living and community support. Evidence of direct care home admission without an assessment of need is substantial. In her 2003 study of self-funding residents in care homes, Fay Wright<sup>26</sup> concluded that it was a common policy to encourage older people to admit themselves directly to care homes without a needs assessment. This picture was confirmed in the later CSCI *Fair Contract* study and indeed in the *Lost to the System* research which found that people described deciding to enter a care home because they didn't know what else to do and were fearful of not being able to cope:

*“Well, when I was on my own, I began to think – what’s going to happen to me? So I started this business of having respite [and then moved in permanently].”*

*“I had a relapse. I couldn’t even make my bed, it was too much (...) and the doctor came and he said I would have to go into a home, so that was that.”!*

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<sup>26</sup> Wright, F (2003), Discrimination against self-funding residents in long-term residential care in England. *Ageing and Society*, 23: 603-24.

3.35 A crucial factor here is that organisational imperatives can receive a higher priority than individual needs. In the case of councils this can be the need to fill up care home beds purchased through block contracts – the *Fair Contract* study found that older people in two out of the ten councils visited felt that care managers influenced people to choose council-run care homes, or care homes where the council had agreements to purchase beds:

*“It seemed as though the social worker wanted my friend to go into a council run care home even though it was supposed to be my friend’s choice where she ended up.”*

3.36 The other organisational imperative is the NHS priority to ‘unblock’ beds in acute settings, combined with the ‘delayed discharge fee’ introduced under the *Community Care (Delayed Discharge) Act 2003* whereby councils must pay hospitals if they fail to provide a care home place for patients moving into a care home within three days. These patients will still need a great deal of care and support, and in principle they should be able to access funded intermediate care for a limited period of rehabilitation where this is necessary.

3.37 In practice, direct and non-assessed admission to a care home can – from an organisational perspective - seem a simpler solution. The *Fair Contract* study reported that the process of moving into a care home can be rushed, most often because there is pressure for the older person to vacate a hospital bed. One in three of the people interviewed in this study had been in hospital immediately before moving to a care home and felt that the process might have been different if they had had more time. This echoes the key finding of the Office of Fair Trading report and CSCI studies on hospital discharge.<sup>27 28</sup> It also goes against established good practice that where possible people should not move directly from a hospital to a care home for the first time, but should have a period of time to make personal arrangements and adjust.<sup>29</sup>

3.38 Two relatives in the *Fair Contract* study said:

*“When my mum was in hospital I felt I was put under pressure by social workers and hospital staff to quickly find a home for her. I was told that if I didn’t find somewhere soon they would find a home for her and that might not be the home I would pick.”*

*“I think being given 7 days to select a home when a relative is in hospital and needs to go into a care home after treatment very unfair on both the patient and the relatives”*

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<sup>27</sup> Commission for Social Care Inspection (2004) *Leaving Hospital- the price of delays* London: CSCI

<sup>28</sup> Commission for Social Care Inspection (2005) *Leaving Hospital-revisited A follow-up study of a group of older people who were discharged from hospital in March 2004* London: CSCI

<sup>29</sup> HSC 2003/009:LAC(2003)21 *The Community Care (Delayed Discharge etc.,) Act 2003 Guidance for Implementation*

3.39 The key issues here seem to be convenience and complexity – the most convenient solution for the organisations is a quick care home admission, whilst the most complex (though arguably the best) solution is a home care package. The latter will take time to arrange and cost – it may involve a range of different people coming in at different times of day, each having a vital role to play. In the case of people who self-fund, any service failure could be left to the user or relatives to sort out, since the council's care management infrastructure will probably not be available. The complexity, potential risk and high cost can result in an in-built default position that favours care home admission.

### *Assessment of Means*

3.40 Access to publicly funded social care has always been dependent upon a test of means as well as an assessment of need, and – by definition – people who self-fund their own care are normally deemed to be insufficiently poor to qualify for fully publicly funded support. The whole question of how social care should be funded, and the respective roles of the state, the individual and the family, are the subjects of the Green Paper<sup>30</sup>. Clearly the content of the Green Paper may change the entire policy context within which the needs of self-funders are located, but under the existing system the evidence highlights two areas of difficulty – insufficient cost transparency and inadequate forward planning.

### *Insufficient Cost Transparency*

3.41 Of the 36 people interviewed for the *Fair Contract* study, over half said they had experienced difficulty in understanding how their needs assessment related to the financial assessment – an understandable situation where councils themselves confuse the two processes. In the case of care homes, people did not understand the financial implications of some homes charging more than the council would pay. There were also some cases where the outcome of the financial assessment took between three and five months to come through, leaving residents and relatives anxious as arrears built up.

3.42 Again, in the case of care homes, the *Fair Contract* study reported a lack of transparency of costs in relation to the differential fees charged to self-funding and council supported residents respectively. Council-funded block purchases to achieve economies of scale are commissioned at lower rates than those paid by people funding their own care who are essentially spot purchasing their places. Councils acknowledge differential charging occurs

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<sup>30</sup> HM Government (2009), Op Cit.

because council rates are set low, but the study found that people who pay for their own care have too little information at an early stage when deciding to move into a care home, and do not know why care homes are charging top-ups and what they will be charged. This complexity and lack of transparency may be one of the reasons why people tend to have unrealistically optimistic expectations of the level of free care they think they will receive.<sup>31</sup>

### *Inadequate Forward Planning*

- 3.43 The *Lost to the System* study reported that the issue of redirection of self-funders *back* into council funded care when they have exhausted their savings is a growing concern for local authorities. Councils in this study were well aware of the danger of resource depletion – the situation in which the resources of self funders fall to the level at which councils have funding responsibility - but none of them appeared to have a developed strategy in place for dealing with it.

*“It’s a significant problem. We are looking at setting up a mechanism to try to identify who is coming to the end of their savings so that we can be better prepared.”*

- 3.44 Any such strategy involves close liaison with private care home owners. Although a stronger relationship would be in the interests of both parties, the *Lost to the System* study found this was not an easy task to accomplish. This can result in people continuing to pay for their own care beyond the point when they become eligible for state funding. One private home owner summed up the reluctance to inquire about the savings of residents:

*“When self funders come to us I will say to them ‘I don’t want to know what your resources are, but when you think they are coming to a close, say a year away, it is in your interest to talk to the local authority’. But they may not remember to do it. I have had two or three cases where someone finishes on Friday and they have no money.”*

- 3.45 Councils, in turn, expressed frustration at not being able to engage with service providers:

*“We try very hard but they say they don’t know themselves, so they are clearly not asking.”*

*“People slip through. I’ve found referrals coming through when the person’s money is at a ridiculous level, and the home will only be aware if the money has run out.”*

- 3.46 In these situations where people have ‘spent down’ their savings they may be told by councils to move to a cheaper home or could even be assessed as not needing residential

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<sup>31</sup> Knapp, M et al, Care Costs: the public’s view. *Community Care*, May 21<sup>st</sup> 2009, p24/5.

care. In some cases they may not even qualify for *any* council support because they fall outside of the FACS criteria being operated by their council – another consequence of entering the residential sector without having first undergone an assessment of need by the council.

- 3.47 A study by the Institute of Public Care was commissioned by Buckinghamshire County Council to look at the number of people paying for their own residential or nursing home care in the county, and to estimate the likely costs to social services of former self-funders now requiring financial support.<sup>32</sup> The study shed light on some factors that are likely to be of wider relevance, particularly in localities which have a larger than average proportion of self-funders. For example, it was evident among the population of ‘ex-self funders’ subsequently picked up by the authority that one third of those in residential care and more than one fifth of those in nursing care had come from outside the county, representing additional calls on the council’s budget. In addition, only around one third of the group had previously received services or were known to social services; the remaining two thirds had only contacted social services when they needed support to remain in their care home. On average the self-funders were living in care homes that were more expensive than the fees paid by the council.
- 3.48 While the study found that although ex-self-funders represented just under 12 per cent of all those the council was paying for, they were a disproportionately costly group. Over a year it was estimated that ex-self funders cost the council £1.3 million, with at least £417,000 of this paid for people who originated from outside the county.
- 3.49 Understanding the reasons why people become self-funding residents is clearly important, particularly for councils wishing to avoid inappropriate admissions and costly placements.

### **Access to ongoing support**

- 3.50 Given the problems with access to information and access to assessment, it is only to be expected that the third dimension – access to ongoing support – is rarely in place for people who self-fund. This dimension itself has three aspects – a failure to support contract-making; a failure to maintain contact; and a failure to support redress of grievance.

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<sup>32</sup> Cairncross L (2008), ‘Predicting the impact of self-funded care home residents on current and future demand for local authority services’, CSCIP Commissioning Ebook, chapter 5.23, <http://www.dhcarenetworks.org.uk/BetterCommissioning/Commissioning-book/>



### **Failure to Support Contract-Making**

- 3.51 National Minimum Standard 2<sup>33</sup> relating to contracts requires that each care home resident should have a written contract (if they fund their own care) or a statement of terms and conditions (if the council funds their care) with the home, and this should be available at the point of moving into the home. Most of the evidence on this issue comes from the studies by Wright (op cit) and the CSCI *Fair Contract* report. Both find that people do not always have the contracts or statements of terms and conditions they should expect, whether they directly fund their own care or not. Even when contracts were provided, “*large numbers were potentially unfair, too complex or unclear, giving scope for unfair fee increases*” (p15).
- 3.52 Another common failing was people paying for their own care not having a contract to sign until *after* moving into a home. However, even the eventual drawing up of a contract is no guarantee that its provisions are understood and respected. The *Fair Contract* study undertook case study interviews with care home staff which revealed only limited understanding and exposure to residents’ contracts and terms and conditions - some managers said they had no dealings with contracts as ‘*everything is dealt with at head office*’.
- 3.53 A parallel weakness is evident in the case of *entry* into a care home. A review of the research and evidence base relating to advocacy services and older people’s entry into care homes in England<sup>34</sup> found a noticeable absence of evidence. It concludes that where care homes and advocacy are considered together at all, this is in relation to instances where the older person is already at the home. Advocacy in these cases may address issues such as breakdown in the relationship between the resident and care home staff or complaints about the standard of care, but not about the actual decision to enter the home.
- 3.54 This paucity of evidence is reflected, too, in the findings of a Cochrane review of interventions in this area.<sup>35</sup> Here, the objective of the review was to assess the effects of various decision-support interventions delivered by health or social care providers on the outcomes of older people facing the possibility of entering long-term residential care. The reviewers found no studies (in a field that could have included examinations of advocacy)

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<sup>33</sup> Appendix 1 provides details on National Minimum Standard 2

<sup>34</sup> Manthorpe, J and Martineau, S (2009). Scoping review of the research and evidence base relating to advocacy services and older people’s entry into care homes in England. Social Care Workforce research Unit.

<sup>35</sup> Gravolin, M, Rowell, K and de Groot, J (2007), Cochrane Database of Systematic Reviews (3)

that met their relatively stringent inclusion criteria. This all points to an urgent need for new research to address this major gap in our knowledge and understanding.

### **Failure to Maintain Contact**

- 3.55 For those people deemed to be ineligible for council support following either an assessment of need or means (or both), it is common practice for councils to ‘signpost’ people to other sources of support. ‘Signposting’ is essentially what the word suggests – people who approach their council for advice or support may be advised, and perhaps supported, to seek help elsewhere. In Henwood and Hudson’s *Lost to the System* study, the growing importance and acceptability of signposting was commonly recognised across their sites and the term itself was in widespread use.

*“It doesn’t have to be the responsibility of the council to respond to every need. We have to ask whether it might be a health responsibility or whether somebody else could help.”*

*“In the past we wouldn’t have thought about signposting, we would just have gone ahead, arranged and delivered. We haven’t been good at finding out what really exists out there, and the number of resources we have identified are quite astonishing.”*

- 3.56 Although the reasons for developing a signposting strategy are essentially economic, it is also seen as having other virtues such as responding to user preference (“*lots of people in the early stages would rather not go to a statutory organisation*”) and strengthening a sense of individual responsibility:

*“It’s taking paternalism away, taking that nanny state bit away from folk and saying ‘no, in some instances we think it’s reasonable that you start doing some of this yourself’.”*

- 3.57 The councils in this study had different positions on dealing with those people not considered eligible for council support, some more sophisticated than others. Some stuck to a firm ‘information only’ line. In one such council the local FACS guidance stated that:

*“People not eligible for social care services from statutory organisations must be given information and advice about private and voluntary organisations that may be able to help meet their needs. Beyond this initial assistance there will be no follow-up or monitoring of individual cases.”*

- 3.58 Not only does the lack of on-going contact with people who are self-funding mean they are potentially disadvantaged, lacking support and someone acting in their interests, but it also leaves councils vulnerable to unplanned demands from people who have run out of money, as we have previously described.
- 3.59 The on-line survey undertaken for the CSCI review of eligibility criteria specifically addressed the question of signposting and the consequences for people who did not meet council eligibility criteria for social care. It found:
- more than 60% of respondents stated that they were not given any information about other help that might be available;
  - around one third (29% people who could benefit from social care and 34% carers) indicated that they *had* been given information but this *did not lead to them getting any help*;
  - only five per cent of all those responding said that they had both been given information *and* that it had positive outcomes in leading to them getting help.
- 3.60 *Lost to the System* concludes that “*the reality seems to be that most councils actually make no attempt to ensure that vulnerable individuals who are signposted out of their own system are receiving some support*” (p67). In this circumstance, much seemed to depend upon the whims, skills and personal commitment of individual social workers and care managers, with some confining themselves to delivering a list of addresses and telephone numbers, and others attempting to support individuals along the signposting journey.

### **Failure to Support Redress of Grievance**

- 3.61 The *Fair Contract* study revealed that procedures in care homes for making complaints are generally good – 82% of the homes inspected met or exceeded the National Minimum Standard on complaints. Much less is known about the situation in non-residential support, and even less about any differences between those who self-fund and those who are publicly supported. Formal complaints are best regarded as the ‘long stop’ of any dissatisfaction with services and support – when all else fails an individual may feel that there is no alternative other than to activate formal complaints procedures.
- 3.62 Many people at vulnerable points in their lives will lack the skill, energy and motivation to go down this route. The *Fair Contract* study contrasted the existence of complaints procedures with their actual use, and said it was “*less evident that people actually feel confident about*

*complaining*". Three in four of the relatives interviewed said they were wary of complaining "in case of repercussions" for their relative, and self-funders "indicated their feelings of being powerless, having no-one to go to and no rights of redress" (p62).

- 3.63 Despite this, councils in the *Lost to the System* study often equated a low level of complaint with high satisfaction with their 'signposting' strategy:

*"The only evidence we have is the lack of complaints. There is a lack of comment which would lead me to believe that there isn't a huge unmet need."*

*"If there was a problem then incidents would raise their head and people would come back to us."*

- 3.64 The observation in the *Fair Contract* study that self-funders have 'no rights of redress' should they be dissatisfied with the outcome of their complaint relates to two further aspects of their legal position. Firstly, denial of access to *independent* consideration of their complaints. Currently, people whose care is commissioned or funded by local authorities have access to the statutory social services complaints procedure, and then to the Local Government Ombudsman if the local authority does not satisfy the complainant. However the current arrangements do not cover services provided under private arrangements made either entirely independently or with the advice of the local authority. Nor do they cover services provided to people using a direct payment or personal budget from a local authority to pay for their own care, if the local authority is not involved in arranging this care. The Government is committed to reviewing this anomaly.

- 3.65 The second aspect is the exclusion of people who fund their own care from the Human Rights Act (HRA). At present, everyone who lives in a local authority care home is protected by the HRA, including those who pay the local authority for the full cost of their care. However, those people who arrange and pay for their own non-local authority care (both residential and non-residential) are excluded. Although the Government intends to bring independent care homes within the scope of the Act when a local authority arranges a placement, it does *not* propose to include those who fund their own care and make their own arrangements. This leaves a two-tier level of protection in place that discriminates against those who fund their own care.

- 3.66 The three dimensions of policy and practice explored above – on information, assessment and ongoing support – do matter. The ways in which they are addressed will make the difference between appropriate and inappropriate interventions, and between good and poor outcomes. This includes inappropriate admission to a care home as opposed to

receiving support in the community, and admission to a care home with fees higher than those the council is prepared to meet in the event of resource depletion. The *Lost to the System* study concluded that:

*“Many of the people funding their own care were living a lonely existence. Many had a very low mood and the fieldwork interview clearly provided some with a rare and welcome opportunity to socialise and interact with a visitor. While some residents benefited from caring and attentive staff, or from a GP who took time to visit them regularly, others were less fortunate.”* (p110).

- 3.67 Generally, however, relatively little is known about the fate of people who fund their own care – the information they encounter, their capacity and support for using it, the assessment and other support (if any) they receive, the wisdom of their subsequent decisions and the quality of their life. Given the large (and growing) number of people funding their own care, this is a remarkable omission from the evidence base, and one which needs urgent rectification. Alongside this evidence base there is also a need for a clearer policy and practice framework for supporting self-funders. The next section proposes an outline for such a framework that could be tested out in the fieldwork anticipated for the later stage of this study.

## **4 Self-funding: a framework for support**

- 4.1 The long anticipated Green Paper on adult social care was widely expected to properly recognise the significant and growing proportion of people who fund their own care, and to develop the concept of the ‘universal offer’ of information, advice and advocacy. Indeed, the paper has addressed these issues by identifying information and advice as one of the six components that everyone should be able to expect of a National Care Service.
- 4.2 The need for information and advice applies to people who may be eligible for help from social care, as well as those making their own arrangements, and the Green Paper is adamant about the importance of this comprehensive approach. It is said that the intention is to build upon the commitment given in *Putting People First* that carers and people who need care and support should have access to a local information, advice and advocacy service, regardless of whether they are eligible for state funding or are paying for themselves. This will be especially important at two points:

- at times of transition such as from hospital to residential care or from home to residential care;
- where individuals are caught in complex inter-organisational interfaces, particularly between the LA, PCT and hospital.

4.3 Indeed, as we have already explored, the Green Paper anticipates a less dramatic cut off point between these two groups of people such that whether or not they meet eligibility criteria, people should still have information and advice, and support to find their way through the system to appropriate help.

4.4 The Green Paper proposes introducing a 'care and support information brand' that will be as well recognised as the NHS brand, and suggests that people will need information on:

- what care and support they are entitled to
- what is available in their area.<sup>36</sup>

4.5 Any framework of information might reasonably be expected to address the following issues:

- understanding the support that people are entitled to based on eligibility criteria;
- deciding on the best form of care and support;
- choosing support;
- getting information on costs and funding;
- ongoing contact and support;
- robust redress of grievance.
- Sound financial advice (re savings investments etc) in relation to paying for care and support over extended periods

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<sup>36</sup> HM Government (2009), Op Cit, pp 55-57.

We have already explored eligibility criteria and the importance of these being understood and located within a wider context of universal services focused on prevention and well-being. We turn now to explore the other dimensions that information might be expected to address.

### **Deciding on the Best Form of Care and Support**

4.6 It is clear that people need much better and easier access to information. The DWP study found that people are more likely to look for information if they:

- believe it will be available and accessible
- are confident about getting and using it
- think they will find it without undue effort or frustration
- feel positive about the source and have trust in it
- believe they will understand it
- expect it to be personally relevant to them
- assume it will help them, tell them something new or take them forward.

4.7 An 'expert panel' constituted as part of the CSCI 'mystery shopping' study offered the following recommendations for the information they would like to see in an 'ideal' information pack from local councils:

- clear information on who is eligible for care
- details about the assessment process
- information about funding and costs
- how to find and pay for your own care
- lists of available services

- information about the types of care available
- details of local voluntary services
- relevant commercial information
- relevant government information
- clear contact details

4.8 The 'mystery shopping' study emphasised the need for people to have some standard basic information to hand that guides them through what is a complicated system of social care assessments, thresholds, self-funding, part-funding, direct payments, individual budgets and other matters. The emerging and imminent response to this is the Department of Health Information Accreditation Scheme (now renamed the 'Information Standard') for health and social care information providers. This will award a kite mark to approved information providers who can demonstrate that they have robust systems in place to check the quality of the information they provide as being up to date, written in clear English, available in accessible formats if required and consistent with what other reputable information providers are saying.

4.9 The I&DeA study of social care information services included a study of fifty council and ten national websites to ascertain clarity, accessibility and content, based on searching for specific information for a range of needs. There were vast differences between sites identified by the researchers, with examples of good and poor practice. Very few were found to give complete information to enable choice and access without further investigation, and the table below profiles some of the features of good and poor practice.

<b>GOOD PRACTICE</b>	<b>POOR PRACTICE</b>
information held at a high level	information buried
clear page design	cluttered pages
well structured site	unclear navigation
helpful external links	links directing from site
information aimed at the public frequently asked questions	information written for professionals with too much jargon
practical information	Information contained in too many PDFs
comprehensive information	out of date information
information to aid choice	information lacking content no mention of choice, quality or cost



4.10 Whatever the means of information provision used, the evidence emphasises the need for information to be *personalised*. The DWP report makes it clear that people prefer to find things out through personal (and ideally face-to-face) contact with someone who:

- knows about the system concerned
- can explain it in a friendly and simple way
- is amenable to questions and open to direct personal interactions
- can interpret the information – tell them what it means for them.

4.11 The Picker Institute study likewise emphasises the importance of face-to-face discussion between service users and advisers:

*“They wanted help from professionals they had come to trust, to supplement the information they were able to find for themselves. Every health and social care professional should be encouraged to embrace their role as a key information provider.”* (p64)

4.12 And again, the *Fair Contract* study also found that information given face-to-face was seen as more personal and relevant than written information, and this could come from professional or non-professional sources:

*“The information I have gained is from other people in the same position as myself and that is the most powerful source you could ever have.”*

*“All the information we got was verbal, mainly from the social worker who was very knowledgeable.”*

4.13 Horton (2009, *op cit*) points to the introduction in Nottinghamshire of *First Contact* – a multi-agency signposting scheme which enables older people to access preventive services through a single point of contact. It is said that when a staff member from any one of the partner agencies visits someone at home, they complete a checklist to find out if the older person has any particular needs for services such as a fire safety check, advice on money entitlements, signposting to local groups or support to prevent falls. Responses are fed back to one central point of contact who coordinates referrals to partner organisations, after which a representative from one of those organisations contacts the older person direct. In effect, the information gathering and response functions are streamlined and coordinated.

4.14 The CSCI ‘mystery shopper’ study acknowledges that there is a cost attached to this but says that Government and councils need to respond to the demand from older people and

carers for high quality information and advice services ranging from good one-to-one advice over the phone to expert brokerage services available across the country. The study by the Relatives and Residents Association points out that councils “*may not be best placed to provide disinterested information*” and a crucial role is played by specialist advice services able to respond to the specific needs and concerns of individuals and their families.<sup>37</sup>

- 4.15 This observation ties in with the proposal from the Resolution Foundation<sup>38</sup> for a new independent IAA (information, advice and advocacy) service consisting of national and local ‘first stop shops’ which would serve as a single point of contact for a range of separate IAA services an individual might require. At national level, it is suggested, this could bring together adult social care, the new carers’ helpline and housing advice and information services, and could expand to include wider services such as the Money Guidance service being trialled by the Financial Services Authority. At local level there would be the facility for face-to-face support in local communities to meet the issue acknowledged in the Green Paper that “*people want the option of meeting someone face-to-face to discuss their care needs and how to get the services they want*” (p57).
- 4.16 Finally, before choosing one form of support over another there has to be some confidence in the assessed need, whether this has been professionally assessed, self-assessed or a combination of both. This in turn means that everyone in a locality should know they can have an assessment of their needs regardless of their financial circumstances. Councils will need to ensure all older people have opportunities during an assessment of their care needs to consider the range of available options for support, including the use of direct payments or individual budgets. This should apply whether people are at home or in hospital.
- 4.17 In this regard, the Resolution Foundation (*op cit*) proposes the creation of a new ‘care and wellbeing assessment’ which would be available as an entitlement to everyone over the age of 65 plus their carers. It sees this as “*a far more interactive and needs-led process*” that could encompass “*the entire spectrum of issues that might improve the quality of life*”. (p18). This would be especially valuable for self-funders who currently tend not to consider their wider needs (particularly prevention) or know what to buy.

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<sup>37</sup> Dalley & Mandelstam (2008), *Op Cit*, P.37.

<sup>38</sup> Resolution Foundation (2008), *Navigating the Way: the future care and wellbeing of older people*.

## Choosing Support

4.18 Evidence has already been noted to suggest that social workers and care managers can vary in the amount of time they are prepared to allocate to support people who self-fund, and this helps to explain why 'lay' sources of help such as family, friends and neighbours are used so frequently. There are, however, other ways of supporting people to make better choices. In 2009 CSCI introduced a system of 'quality ratings' for all regulated services to give the public easily understandable information about the quality of care as judged by CSCI. An early evaluation of the ratings<sup>39</sup> suggests this has proved to be popular in helping people to make choices, though the impact was more strongly felt amongst council commissioners than users and carers themselves. The *Fair Contract* study noted other local innovations in use to offer extra support. These included:

- A 'service solutions team' to support care managers in finding the best care option following the care assessment. The team works across the council and the NHS. It has 'service finders' who work with older people to find the best care for them; and 'home finders' who help older people who are in hospital and need a care home to make their choice.
- A 'call centre signposting service' for people who may require residential care. Here, people able to fund their own care get the same access to assessment and support as those who are eligible for council and/or NHS funding. If the enquiry is from a person who funds their own care, the call will be referred to a designated 'self funder support' worker who offers advice, support and a care assessment.
- A 'Support to Access Care Service' specifically aimed at self-funders which offers care assessments and information on care home fee levels.

4.19 Finding better ways to coordinate information and support people to make informed choices would require someone to take responsibility for the task at a local level. The Picker Institute report, for example, calls for "a new cadre of information coordinators or brokers who understand the service user's perspective and have the necessary clout and diplomatic skills." (p63) This is not dissimilar to the 'care navigator' role raised in the 2005 Green Paper on adult social care<sup>40</sup> which talked about the introduction of 'a care navigator/broker model' where a 'care broker' is someone 'who might help the individual

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<sup>39</sup> Commission for Social Care Inspection (2009), *CSCI Quality Ratings Market Research Report*.

<sup>40</sup> Department of Health (2005), *Independence, Wellbeing and Choice: Our Vision for the Future of Social Care for Adults in England*.

*formulate the care plan, negotiate funding and help organise and monitor services'* (p36).  
Currently this sort of support is rarely available to people who self-fund.

### **Getting Information on Costs and Funding**

- 4.20 Information on costs and funding could involve several related components. First, a *clearer assessment of means* so that people understand at an early stage their entitlements and expectations. Direct advice from staff in finance departments has been found to be helpful here, as has the availability of a 'ready reckoner' to help people calculate what they might have to pay towards their own care. A welfare benefits check is also essential as self-funders may well be eligible for some benefits which they may not be claiming, and some councils operate a joint initiative with The Pension Service to offer self-funders in residential and nursing care a welfare benefits check.
- 4.21 Secondly, clarity on the cost and nature of the care being purchased. This will include clarity about who pays for what before entering an agreement, and providers making clear their prices and any rationale for charging self-funders more than local authority supported residents. Some councils say they already negotiate with care homes on behalf of people who fund their own care and have been able to agree a lower fee than would have been charged if people had acted without support. The aim here should be for all self-funders to have written contracts of their terms and conditions of support expressed in a personalised and understandable way.
- 4.22 Finally, greater clarity on the impact of *changes in personal circumstances* along with annual reviews to advise those whose savings are nearing the threshold of eligibility for public support. At a minimum, people have to be aware of the need to contact their council when their capital is diminishing, and should also be fully aware from the outset as to whether or not the council will be prepared to pay the fee level of the service they have chosen, or indeed whether their needs are such that they would be thought to require residential support.

### **Ongoing Contact and Support**

- 4.23 People may well need more than the provision of information, clarity on the nature of the support being purchased and help in choosing that support – they will also require ongoing contact and support. The minimum expectation here will be that everyone who is assessed

as meeting the eligibility criteria for social care services is offered advice and ongoing review and support irrespective of their financial status. Even people not meeting the eligibility criteria should receive active advice rather than perfunctory signposting. This need could partly be met by the proposed national and local first-stop shops proposed by the Resolution Foundation, as well as the 'care navigators' originally proposed in the *Independence, Wellbeing and Choice* Green Paper. The Resolution Foundation (2008, *op cit*) sees a navigation service as becoming "an interface between the individual and the range of statutory agencies, third sector and commercial organisations, and their separate application procedures and processes." (p24)

### **Robust Redress of Grievance**

- 4.24 If things go wrong, people should be able to access robust redress of grievance arrangements regardless of the service used or how the care has been funded. As noted earlier, people who fund their own care (where this has not been arranged by either a council or health authority) do not have any freestanding right to make use of statutory social services or NHS complaints procedures. This leaves a gap in the process – the only available avenue would be the Courts which is an expensive and impractical course.
- 4.25 The *Fair Contract* study requested the Government to consider the merits of a Care Services Ombudsman to provide independent consideration of complaints about regulated care services in those instances where resolution through either the provider's own statutory arrangements have failed, or where the existing scope and remit of other statutory procedures are limited to the actions of the public authorities and do not extend to private and independent providers.
- 4.26 In responding to this<sup>41</sup> the Government has considered three options – a new independent body to undertake investigations of self-funders' complaints; placing the task within the remit of the new Care Quality Commission; and extending the remit of the Local Government Ombudsman. The Government's preferred option is the latter, and it anticipates up to 1000 people per year having their complaints addressed by the Ombudsman. These arrangements are not yet in place, but concerns have already been expressed about the capacity of the Ombudsman to respond to this additional demand, and

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<sup>41</sup> Department of Health (2008), *Impact Assessment of Independent Consideration of Complaints about Non-Local Authority Adult Social Care*.

also as to whether an organisation whose primary role is to investigate public law duties has the expertise to consider contractual complaints.<sup>42</sup>

### **Sound Financial Advice**

- 4.27 For people who do not meet the means-test to qualify for financial support from councils in meeting their social care and support needs there are important questions about what sort of financial advice they might require. The provision of such advice is controlled by the Financial Services Authority (FSAs), and financial advice about such things as savings and investments, pensions, long term care funding, equity release etc should *only* be given to people by independent financial advisers (IFAs).
- 4.28 Long term care insurance has a short history in the UK and has not been widely taken up. New financial products are gradually emerging which, for some people, can offer the opportunity to ensure their support needs are paid for, while also safeguarding a proportion of their assets.
- 4.29 The literature repeatedly describes the situation of people who have assets above the £23K threshold effectively being let to make their own arrangements with care homes. As we have discussed above, there are implications for supporting people who are self-funding to choose appropriate care and support, but there are also implications for such support to include appropriate signposting to IFAs with expertise in this specialised area.

## **5 Conclusions**

- 5.1 In this paper we have reviewed a range of material relevant to people who are self-funding their care and support. It is evident that there are shortcomings in the information, advice and support that are made available to people seeking help or advice. The ambitions of the Green Paper for a new National Care Service present a vision of a fairer system in which all citizens are able to have their care and support needs assessed in the same way, have information and advice that enables them to find their way through the system easily, and have a right to have the same proportion of their care costs met, wherever they live in England.

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<sup>42</sup> Age Concern (2008), *Parliamentary Briefing: A note on self-funders in care homes.*

- 5.2 For this vision to be achieved, much will need to change. If the system is to deliver on these ambitious expectations there will have to be a clear understanding of the circumstances, behaviour and treatment of people who self-fund. What this review has clearly shown is that currently we know very little about this large and growing category of people, but that what little we do know all too often reveals a picture of policy neglect, practitioner indifference and poor individual outcomes. We urgently need to know more about how people who are self-funding currently find their way through the system and make the choices that they do.
- 5.3 By definition, self-funders are often hard to identify and not known to Councils, and this has contributed to the fact that research and other surveys have tended to exclude them. This cannot continue, and we recommend that additional work is undertaken in two phases. First, that there is a review of a number of agencies which operate helplines and provide information to the public to explore the nature of the demands they are handling and how this might be changing. Secondly, building on this work to identify a sample of people who have made choices as self-funders, and through in-depth qualitative investigation to understand the pathways they have chosen and the consequences of their decisions. It is only on the back of this more sophisticated understanding of the circumstances and motivations of people who self-fund that a more effective approach to support can be developed, and the aspirations of the Green Paper realised.





# **Navigating the Parallel Universe**

## **Information and Advice for People who Self-fund**

**Melanie Henwood and Bob Hudson**

**October 2009**

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# **Navigating the Parallel Universe: Information and Advice for People who Self- fund**

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## **Executive Summary**

1. In this paper we report on a preliminary piece of research exploring the approach of key national organisations and charities involved in the provision of information and advice across the area of social care and support. Specifically, we wished to examine whether and how such information addresses the needs of people who are self-funding. An on-line questionnaire was designed and invitations to submit returns were sent to 27 organisations in mid-August 2009. Reminders were also sent out and by the cut-off for completions in mid-September 16 returns had been received.
2. The exercise was not intended to provide a large scale representative survey so much as an opportunity for investigative development and to provide a platform for more detailed research of key themes. The questionnaire was followed by in-depth semi-structured interviews with 8 respondents; all interviewees were assured of anonymity and the quotations used in the report are not attributed to individuals unless such statements have been made in the public domain. We are very grateful to everyone who assisted us by completing the on-line questionnaire and in making themselves available for further discussion.
3. In this overview paper we examine the subject of information, advice and advocacy (IAA) and identify a number of key themes and messages. The following are of particular significance.
4. **'Information and Advice' is a simple phrase** which conceals the underlying complexity. This issue is multi-dimensional and covers both very general and highly specific needs and responses. There are also major differences in the particular information needs of various groups of people, for example older people will have different requirements from people with long term conditions, although there will also be some issues in common.
5. **Location:** the location of IAA can be local or on a wider basis, including national level. There is enormous potential for both duplication and inconsistency of messages. Some combination of centralised core information with signposting to local material of most direct relevance to a person's situation is probably the ideal arrangement, but there are significant challenges in ensuring such connectivity.
6. A **'care and support information brand'** for social care that might be as well recognised as the NHS is currently a long way from being a reality. Something like FirstStop may be a model for the way

forward but it will need major development. Not everyone is convinced this offers the best solution and the idea of a 'one-stop-shop' is not always appropriate.

7. **The pathway to information and advice is rarely smooth:** partly because of the complexity of IAA needs and the variety of organisations involved in providing different parts of the picture, people often struggle to get to the right information and may go through multiple steps before finding the right point of access. Clearly, the challenge is not simply about ensuring that IAA is comprehensive and relevant, but also that sources are appropriately publicised or 'marketed' to people at the right times in their lives (including in advance of crises developing).
8. **Quality Vs Quantity:** providing IAA to people in an appropriate and personalised way can take time. Because this is rarely about standard information a 'one size fits all' approach cannot work. People may need more than one contact and to be able to find support over a period of time; the quality of their experience will be crucial.
9. **Gatekeeping and information giving** are not good companions. There is a widespread view that councils have a conflict of interest and that too often they respond to people's preliminary inquiries by effectively undertaking a pre-assessment and diverting people from seeking support, or giving them the impression they are not entitled to support.
10. **Outcomes:** What happens to people as a result of receiving information or advice is an area where little is known. Follow-up monitoring or evaluation is rarely undertaken beyond customer-satisfaction surveys.
11. **Financial Advice:** The provision of financial advice is regulated by the Financial Services Authority and people giving IAA are aware of the need for financial advice to be provided by independent advisers. However, financial advice for long term care or for later life planning is highly specialised and many IFAs would not be able to address people's needs and people who are self-funding can struggle to find such expertise. It is important that financial advice is recognised as an integral component of IAA.
12. **The Information Standard Quality Mark** being introduced by the Department of Health appears to have achieved little profile or awareness at the present time. Its value will depend on sufficient organisations seeking accreditation and on that accreditation providing access to other

opportunities (for example, if it is a pre-condition for organisations able to respond to 'information prescriptions' issued for people with long term conditions).

13. **Understanding people's pathways:** the picture that is building up needs to be expanded and deepened by research which explores people's pathways and experiences. How people get the information and advice that they do; how they navigate their way through the system, and what they do subsequently are all areas where information is incomplete or anecdotal. In-depth qualitative research is needed to illuminate this experience and inform policy and practice development.
14. Building on the findings and conclusions both from this piece of work and from our companion literature review we make recommendations for a further phase of work that will allow in-depth investigation of a representative sample of self-funders to determine how decisions are made about their care and support, and with what outcomes.

## **1 Introduction**

1.1 In our review of the literature on people who self-fund we concluded that relatively little is currently known about this group of people or about how they access the system or make the choices they do. We recommended that two phases of additional work be undertaken:

- First to review a number of agencies which operate helplines and provide information to the public in the area of social care in order to explore the nature of the demands they are handling and whether this is changing in any way.
- Second, building on this work to identify a sample of people who have made choices as self-funders, and to understand the pathways they have chosen and the consequences of their decisions.

1.2 Here we report on the first of these elements. We approached a number of key national organisations and charities that operate helplines or make information available to the public (see Appendix 1). An electronic questionnaire was developed to encourage easy completion and participation. Invitations (and reminders) to complete the questionnaire were sent via email to 27 key organisations. These included groups concerned with a range of groups of people who may use social care services, as well as carer organisations and organisations involved in providing care services.

1.3 Access to information and advice is vital for people who may need social care support, whether or not this involves council organised social services. Key milestones developed jointly by ADASS and LGA with the Department of Health include targets for “universal access to information and advice” strategies and arrangements to be put in place during 2010.<sup>43</sup> We wanted to explore how people might access such information and what is available to them, as well as what data are collated and analysed by the surveyed national organisations. This can be particularly important for people who ‘self-fund’, as well as for people who are making use of personal budgets and Direct Payments. While councils have an important role to play, they reach only a small fraction of the population and many people will use a variety of other formal and informal sources of information and advice.

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<sup>43</sup> Department of Health, ADASS, and LGA (2009), *Putting People First. Transforming Adult Social Care. Progress measures for the delivery of transforming adult social care services.*

We wanted to develop a better understanding of some of these other routes that people choose and how they might find their way to them.

- 1.4 The questionnaire was therefore intended to explore the nature of information provided by organisations; reported changes in the volume and pattern of inquiries; the nature of monitoring of outcomes of information and advice giving, and deficits in provision.
- 1.5 Sixteen organisations completed the questionnaire (a response rate of almost 60%). Follow up telephone interviews were undertaken with 8 respondents. The people who agreed to be interviewed are not identified and material quoted in this report is not attributed to individuals.
- 1.6 We do not intend the questionnaire findings to be viewed as a nationally representative sample, or to allow quantitative analysis. Rather, this piece of work provided an opportunity for investigative development and enabled us to identify common themes and issues to inform a more detailed and in-depth level of investigation that we envisage as the next stage.
- 1.7 In this overview report we explore the key themes that are emerging. **Appendix 2** presents the detailed findings from the questionnaire analysis.

## **2 Information & Advice**

- 2.1 Six of the respondent bodies (37%) can be characterised as organisations representing people who use services (or may do so in the future) or are carers. Some of these were specific client group related organisations – such as Scope, or the MS Society – while others were more generic in focus – such as the Relatives & Residents Association, or Carers UK.
- 2.2 Seven of the responding bodies (44%) were organisations involved in the provision of information and advice to the public, while three (19%) were umbrella bodies primarily giving advice to service providers rather than to people using those services. **Figure 1** in Appendix 2 summarises the range of information types provided by responding organisations.
- 2.3 Three respondents indicated they were involved in providing advice in additional categories, as these comments illustrate:



*“General information and advice on all caring issues.”*

*“Information and advice on all aspects of cerebral palsy and disability related issues.”*

While another was not currently active in the sector but expected to be so in the near future:

*“We are currently building our proposition and anticipate offering all these services.”*

- 2.4 Some of the responding organisations were involved in the provision of independent financial advice or wider financial services, and would not necessarily have had direct contact with members of the public.

### **Complexity of Information & Advice**

- 2.5 The Green Paper states that in order to make its vision for the future a reality, people will need information on:

- What care and support they are entitled to
- What is available in their area

- 2.6 While these two dimensions *are* important, arguably they fail to convey the full complexity or multi-dimensional nature of the requirements around information, advice and advocacy (IAA). Just as people’s needs for IAA are complex, organisations responding to requests need to be highly skilled in understanding what people actually need and to recognise that IAA covers a broad continuum.

- 2.7 People who approach organisations (typically third sector organisations) for information, either on behalf of themselves or – more typically – for other family members, will often do so in a state of some confusion and frustration, as this interview comment indicates, for example:

*“It tends to be people who have struggled quite a lot through the system before they get to us, so we tend to pick up the pieces (...) and often they tend to be fairly complex cases rather than straightforward information requests. So it is often people who have been going around a local system, whether that’s dealing with a local authority or a local care provider or whatever, and they’ve hit some kind of brick wall and they get passed onto us.”*

2.8 In such circumstances people will often be experiencing a crisis because of changed circumstances, including finding themselves (or a relative) at the point of discharge from hospital and not knowing what to do next *“and people being forced into making instant big decisions.”* As another person remarked,

*“People don’t necessarily think it through and they don’t know how the system works well enough to think ‘if I do that then x,y,z will happen.”*

2.9 As a result, some of the approaches for information or advice occur *after* people have made decisions which have unforeseen consequences which put them into a deeper crisis. For example, if someone has made a poor choice over a particular financial product which later limits the options available to them to meet their increasing care needs.

2.10 When any issue relating to care is reported in the media it tends to trigger ‘a flurry’ of calls to relevant organisations including from people who may not have any immediate needs for care but just want to know what the situation might be if they did have. It is evident from some of the comments made that when people seek information not only may they be experiencing a crisis, but their lack of knowledge about how the system works can be the cause of huge concern and worry, for example:

*“Some of them are basic like ‘my husband needs to go into a care home; will I be made homeless?’ And you can absolutely reassure them that no, the house doesn’t count (...) but there are also people who live alone who are very surprised that they might have to sell their home to pay for care.”*

2.11 It is also evident that people do not always know what they need help or information about. The way in which information and advice is categorised is often from a professional perspective rather than one which is structured around people’s real lives. Whether people seek information in general or specific terms is also variable, as this person observed:

*“It ranges hugely (...) sometimes all that people want is a list of sheltered housing to buy in Woking or whatever (...) It ranges from those who know clearly what they want, they’ve had an assessment perhaps and they know they want nursing homes registered for dementia within a three mile radius, from that to people who don’t know where to start or have a very complex situation on their hands (...) and three different family members wanting three different things for Mum – who may not have been asked about any of them.”*

- 2.12 People who seek information about one area may subsequently reveal other needs, as these respondents commented:

*“Someone calls with the ‘headline reason’ for calling but once you start exploring it a bit there are quite a lot of other issues underlying it as well which are inter-related.”*

And

*“Some people are quite specific and they know what it is they want to find out, but I think that probably most of it is (...) they obviously have a trigger question which causes them to make the call, but there is a whole lot of other stuff there as well that then emerges when the conversation develops.”*

*“Other people want a definite piece of information but when you start to speak to them it is quite clear they may need something else or they don’t know what they want. Such as ‘Mum went into hospital with a stroke, and we need a list of nursing homes’, and you just have to wind things back a bit.”*

- 2.13 Clearly, with such complex and highly specific situations, people’s needs are not always easily dealt with simply by the provision of factsheets or advice leaflets, and may require a casework approach which continues over time for as long as necessary. This interviewee described the operation of a triage system structured to ensure that people get the best response for their situation:

*“People come to us and are dealt with on the front desk, and if it is straightforward – primarily an information request – they are dealt with there and then; if it is more complex, then an appointment is made with one of our caseworkers, and that’s normally within 24 hours.”*

- 2.14 In this situation the caseworkers brought a range of skills and experience, from social work, housing, and advocacy for example.

- 2.15 Some aspects of information and advice are more specialised than others. While large numbers of people who need care and support may want general information about how the system operates and what might be available, those specifically seeking information about residential care, for example, are a smaller group. This respondent commented:

*“There aren’t hundreds of thousands of people desperately trying to get into residential care every year. I think some of the advice-giving organisations make very ambitious claims for the coverage they are going to get. Obviously the generalist ones can expect to receive calls about all manner of things (...) but it [residential care] is a niche market.”*

### **3 A care and support information brand**

3.1 The Green Paper identified the need to make it easier for people to access information directly *“for example by introducing a care and support information brand that will be as well recognised as the NHS brand”* (p.57). It is not yet clear what this may mean in practice, or whether it is envisaged that a ‘one stop shop’ approach should become a single ‘brand’ that will replace the need for multiple points of access. We found people divided on the merits of such an approach with both strengths and weaknesses being identified.

3.2 The recently established FirstStop service brings together Counsel and Care, Elderly Accommodation Counsel, Age Concern and Help the Aged, and NHFA (formerly the Nursing Home Fees Agency), to provide information and advice for older people, their families and carers, about care and housing options in later life. The background to the establishment of FirstStop includes the publication of a report in 2005 by the Office of Fair Trading<sup>44</sup> that identified ‘an overarching issue that must be dealt with’. The report stated:

*“We have found that not only is there a lack of information, but there is confusion about where people should go to get information, help and advice. What is lacking is a single point of reference that tells them what to expect, where to go, and what questions they should be asking.”* (para 5.89)

3.3 Accordingly, the OFT recommended that government should establish a central information source or ‘one stop shop’ for information about care for older people. In the same report the OFT also highlighted the particular situation of self-funders, and the importance of people with an assessed need having:

*“..access to the same advice, guidance and assistance on choice as older people receiving public funding (...) and are guided during the whole process of getting their care needs met.”* (para 5.97)

3.4 The OFT recommended that councils should be monitored for their performance in this area and that either social services should be responsible for this support, or they might outsource the task of guiding self-funders.

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<sup>44</sup> Office of Fair Trading (2005), *Care homes for older people in the UK. A market study.*

3.5 In the wake of the OFT report, Age Concern, Counsel and Care, the Elderly Accommodation Counsel and NHFA Ltd put together a partnership which became FirstStop, subsequently joined by Help the Aged who provide the front line service, with the other partners providing a second tier where inquiries can be referred according to the nature of the request. The model of the partnership is that together the organisations are able to bring the range of expertise and specialist knowledge to meet people's needs in a way that might not be achieved by a single generic organisation.

3.6 The service operates almost exclusively through telephone and email contact. For many people the telephone will be the preferred method, as this person commented:

*"The client group we deal with is still very much into manual communication (...) [many] people still don't have access to a computer and the vast majority of those are probably over 60."*

3.7 NHFA Ltd is a commercial partner providing specialist financial advice for people who need to pay for long term care. To avoid any overt conflict of interest FirstStop has developed a script for use with people when they refer them to NHFA pointing out that information about other Independent Financial Advisers is available<sup>45</sup>. FirstStop has been operating since 2008 and clearly these are early days for its work and profile. Initially it was anticipated that the remit would only extend to London and the South East, but once the website was established it inevitably attracted wider interest across the UK. Efforts are being directed into building up local partners including home improvement agencies, local Age Concern branches etc.

3.8 A representative of one of the partner agencies described the ambition for FirstStop over time:

*"Ultimately I think we would like to be as well known as NHS Direct, and that people who have got queries about housing and social care issues for older people, whether its self-funders, or local authority people, or people are council tenants or own their own property or whatever, would know this number, or that it would be easy to find (...). they would come through and they would be answered at the front line or directed off to whichever partner could help most."*

And as another interviewee commented:

*"I think certainly getting a number well known, such as the FirstStop number well known out there, not just with older people but with all the organisations they might approach so that it is as well*

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<sup>45</sup> If NHFA Ltd sells policies to people as a result of their contact via FirstStop, a proportion of their profits will be paid back to FirstStop, and a similar model would apply to any other commercial partners who might exist in the future.

*known as NHS Direct. Everyone knows that if your marriage is in a mess you go to Relate; if you're ill you go to the NHS; if you're suicidal you go to the Samaritans. I'd like it to be as well known as that so that people can say 'oh yes, housing and care: FirstStop.' That would save a lot of time – there are so many organisations out there doing the same thing and giving the same advice."*

- 3.9 Ensuring that IAA services become well known and that there is brand recognition around such services as FirstStop has obvious implications for marketing. People need to know what is on offer and how to access services. In addition to the standard approaches of leaflets and publicising helpline numbers, there is scope for developing more innovative approaches. For example, speaking at the annual National Children and Adult Services Conference 2009, Stephen Burke (Chief Executive of Counsel and Care) referred to making use of adverts on the back of supermarket till receipts as one approach to target self-funders and other hard to reach groups.<sup>46</sup>
- 3.10 Part of the idea of developing local partnerships with other organisations is that people would be able to visit if they were having difficulties with form filling or anything else and a person associated with FirstStop would be available to help sort things out on a one to one basis. However, this level of personal contact is at present some way off and all interaction is by telephone and internet.
- 3.11 For FirstStop (or any other one stop shop model) to be most effective it is essential that its number and website are well known, well publicised and can be passed to people by intermediaries, but this means that – for example – duty officers in social services need to be familiar with how things work, *"have to understand what the service offers and what it doesn't offer"*.
- 3.12 Some smaller organisations with skills and experience in providing similar helpline services raised concerns about the possible implications of FirstStop causing increased referrals elsewhere in the system:

*"We're a small organisation, we don't have very much money, why should we be the backstop of very well financed front shop organisations? They've had huge amounts of money and we have not benefited from any of that."*

At the same time there were also concerns expressed about the skills and experience of smaller organisations being overshadowed:

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<sup>46</sup> 'Transforming adult social care – developing information, advice and advocacy'. *Rising to the Challenge, brighter futures for all*, Harrogate International Centre, 22 October 2009.

*“There are real issues about what happens to small organisations who have expertise being elbowed out! (...) There is a real issue about the way big players are increasingly able to monopolise the social care sector.”*

- 3.13 The idea of a one stop shop has an obvious appeal in terms of being easily identifiable for people, but there could be shortcomings as this person remarked:

*“..if it claims to be able to deal satisfactorily with everyone’s advice and information needs. I think it has to be honest and say we can only go so far (...) and the sources of expertise that it then wants to draw on need as much resourcing (...) there has to be a better understanding of what advice, support and information really means.”*

- 3.14 Some respondents drew a distinction between ‘information’ and ‘advice’, with the former referring to factual material such as what benefits are available, how the means-testing calculations are determined, how NHS continuing care works etc, and ‘advice’ referring specifically to an individual’s particular circumstances and needs. There will not always be a rigid boundary between these areas, but mixing them up can be less than ideal, as this person commented:

*“I think one the most frustrating things is when you want some information about your own particular circumstances and you go to a website or an advice or information service, and all they can do is trot out the lowest common denominator, because it doesn’t meet your circumstances! That is so frustrating, and it lowers your morale if you are trying to get detailed, specific information to meet your needs, and you can’t get it.”*

- 3.15 Some of the organisations that currently offer information and advice do so on an on-going basis, supporting a person through different stages of decision making and providing them with the information they need to make informed choices throughout.

- 3.16 There can be a tension between generalist and specialist knowledge and information. This person reflected on the meaning of the ‘universal offer’ in these terms:

*“I’m very sceptical about the ‘universal offer’, because I think if it’s the idea that you ring one number, you are still going to get referred on to the expertise. Having all the expertise in a one-stop shop approach is still some way down the line (...) I think if you’ve come to an advice line like ours we can offer the expertise directly. But of course, that’s not taking into account the number of steps that someone has taken to get to us.”*

And

*"I think to get to expertise is quite difficult, it is about the pathway being sympathetic and appropriate and I think one of the difficulties when you ring a generalist advice line is that you tend to get dealt with by the least expert person, and it's at that first point very often that you need the most empathetic reception that you can hope for."*

*"We feel it is essential to be able to provide in-depth advice, information and emotional support at the first point of call. We are not very happy with the 'first stop' principle and subsequent triage of calls. People generally want immediate help."*

- 3.17 If a service is to provide high quality expertise across a broad range of topics, this has obvious implications for the skills and knowledge of people responding to inquiries, and could mean a compromise between quality and quantity of response. This interviewee described how their organisation was able to provide a high quality advice line service:

*"The person that they speak to almost immediately will be someone who has solid expertise in all the issues that we deal with."*

But, this level of response operated on a very small scale.

*"We have enough staff to manage the volume of calls that we deal with, but if it were to go up, that would have great implications for us."*

## **4 Information and Assessment**

- 4.1 The issue of who provides information and advice also raises another set of issues around separating information provision from assessment. This is a particular consideration for councils who may be approached by people for information and advice but undertake some form of screening by way of the questions they might ask or the advice they provide. These interviewees captured the concerns:

*"When somebody rings X Council's number, people are actually sometimes being assessed in their first call. Now, I think that is quite frightening, on their first call to the switchboard (...) and subsequently we will get a call from them weeks later and they will tell us they were in touch with the Council and nothing ever happened, and that's because in that first call they made to the council they were assessed and put in the middle drawer."*

*"If the opening question is can you get in and out of bed, can you get to the lavatory, can you wash yourself, can you dress yourself? OK you don't need an assessment! (...) Social services have a duty*



*if there is a need and they have found a very formulaic way of establishing whether there appears to be a need or not (...) but people then go away and even if things deteriorate two years down the line they don't think of going back or are reluctant to go back."*

And

*"There are things that we hear about local authorities and the things that some of their front line workers say to callers, or say to clients and so on. And it is very difficult to know how that could be monitored or acted on but I do find that listening to callers or hearing about the experiences of callers, they are very often a very lonely lot of people who are subject to the vagaries of the attitudes of local authorities or PCTs or whatever. And it's a challenge to know how their interests can be represented (...) We are there if they get in touch with us, but the thought that there are people out there being subject to the whim of agencies is quite troubling (...) people being made to wait, or being misled, or given wrong information or insufficient information. It is a worry."*

- 4.2 While some respondents were careful to emphasise that they believe many councils and social workers do an excellent job, and acknowledged that information organisations will inevitably see disproportionate numbers of people who have struggled to get help or information, nonetheless it was remarked that there are many councils that appear to lack the knowledge and information to give to people:

*"Our experience is that a number of social workers have no idea how the funding works and for others it has become normalised in some social services agencies, there are gatekeeping strategies, and younger and newer members of staff coming in assume that's how the world is. We had one social worker asking us to send a copy of the Circular LAC 2004/20 on the right to choice of accommodation because she had never heard of it, and her finance department had told her that the client couldn't have what they wanted when it was clearly allowed by the Circular."*

- 4.3 A concern that local councils, or other organisations, may not always operate dispassionately, or may have other considerations such as budgetary pressures guiding their approach to people, raises issues about the independence of *any* organisation involved in providing information and advice. Such independence gives agencies an opportunity to highlight matters of principle or concerns about particular policy issues *"that probably would get overlooked otherwise."*

## **5 Information Gaps & Deficits**

5.1 Respondents demonstrated a high level of confidence in their ability to meet people's needs for information and advice. Almost one third of respondents declared themselves 'very confident' believing they are able to provide a comprehensive service. Another 12 respondents (63%) described themselves as 'fairly confident' in their ability to provide information, but recognised there are some issues they are less able to deal with. Just one respondent (an independent healthcare provider) acknowledged they were not very confident and there are many areas of people's inquiries they are unable to help with.

5.2 We asked respondents to indicate in which – if any – areas they felt least able to provide information and advice. The most frequent response, identified by more than 56% of respondents, was information about employing a Personal Assistant. Almost 40 per cent also identified weaknesses around information about local services, and advice on financial issues. A number of respondents made additional comments to clarify that such information giving may not be their direct responsibility, for example:

*"The above relate to areas we do not provide advice on...because we are an organisation for service providers."*

5.3 While this comment indicates a clear recognition of the expertise of other organisations in specific areas:

*"We provide a certain level of information on employing a PA, giving the main principles, but we refer onto the experts e.g. NCIL etc who know all of this stuff in-depth and do it much better. Again, we advise on rights around advocacy and principles but don't do case work – we refer onto reputable organisations."*

5.4 While others commented about the difference between general information and individual advice:

*"We are clear about our boundaries – especially about giving general financial and legal advice but not specific advice in these areas."*

## **Financial & Legal Advice**

5.5 As we documented in the review of the literature, when people have assets over £23K and are outside the means test for financial help from local councils, many receive little help in arranging any social care or support they might need. Although it is increasingly being recognised in policy that councils have a responsibility to *all* citizens and that there is a *“need to provide effective signposting and high-quality, accessible information and advice to help people make confident choices, whether or not they are eligible for support”*<sup>47</sup>, the experience of too many people who are self-funding has to-date been one of being left to make their own way.

5.6 What should be included within ‘information and advice’? The Green Paper identified ‘financial guidance and information to help people prepare for the future’ as one element of people’s information needs, although it failed to develop this or explore it in any way. It was evident from the responses to the questionnaire and from interviews that the area of financial advice is both highly specialised and relatively overlooked.

5.7 Several respondents identified the distinction between giving factual information to people about the rules around capital assets, and advising them on a course of action. As this interviewee described:

*“We obviously make sure that people are aware of their entitlements in terms of financial eligibility criteria, but if people need independent financial advice we will recommend that they get that, and we will signpost them in a number of directions but we won’t recommend a particular financial adviser.”*

5.8 Others were similarly cautious about the need to avoid giving advice in areas where they are not competent to do so, but recognised the importance of financial advice being available and people being aware of the range of options that might be relevant to their situation, and what they may need to weigh up in making a decision:

*“We would never suggest to somebody that this is the way to do it, you know – invest your money here or there, or take out an insurance policy. That would be the clear distinction; tell people that*

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<sup>47</sup> Department of Health (2009), *Consultation on the revision of the Fair Access to Care Services guidance*, para 23.

*these things exist, but it would be for them and their personal advisers, their relatives, their legal and financial advisers to help them through any decision making about it.”*

*“We can talk about the sort of broad brush issues that people have to think about, but we would in no way try to advise them about one route or another.”*

- 5.9 There is often a lack of awareness about the financial implications of needing care and support, and these issues need to be addressed within the provision of information and advice, as the following comments made by two interviewees highlight:

*“That’s obviously something that needs to be much more widely available, and more widely publicised. There is this SOLLA organisation that has been set up – the Society of Later Life Advisers - providing accreditation, but this is an area that is not widely recognised.”*

*“I think the key thing is ensuring that people do access independent financial advice.”*

*“When someone is about to go into care they get a social care needs assessment and then they get their financial assessment, and when they discover that they fall outside the means-tested threshold, very often (...) the local authority will then say I’m very sorry but we can’t really help you, and that is just a fact. Our contention is that at that point those people should be directed to independent financial advice.”*

- 5.10 Moreover, often something more than merely ‘financial advice’ is needed, as this respondent also commented:

*“A tiny proportion of Independent Financial Advisers (IFAs) are qualified to give advice in this area. And if they’re not, most people – if they buy anything at all – will end up with an investment solution, and with [that] you can just as easily run out of money. There is only one way you can avoid running out of money and that’s with one of these immediate needs annuities (...) it is **very** specialised advice.”*

*“Now we can’t **make** people who get independent financial advice buy an immediate needs annuity, but at least if they were given the opportunity to see that they could cap their liability, and still leave money to their estate.”*

- 5.11 As another person remarked,

*“To get good [financial] advice in later life (...) when people get to 60 or 65 the advice stops unless they are incredibly well off that’s it (...) most financial advisers aren’t bothered (...) it is like, well ‘there’s your annuity, off you go’.”*

And

*“Middle England is self-funding they get no choice, and all they get at the moment is ‘well come back when you’ve run out of money! Or, I’m terribly sorry, here is a list of local agencies or whatever.’ “*

5.12 Another respondent commented on the difficulty of finding relevant information or advice:

*“We cannot give financial advice, but we tell people about IFA promotion but my experience of looking at that site is that it is geared to a radius on your postcode and you get three operators operating out of a back bedroom. It doesn’t tell you that the market leaders in these sorts of products are these companies.”*

5.13 One organisation that is trying to address such issues is the Society of Later Life Advisers (SOLLA), established as a consumer body to help people and their families to find trusted financial advisers who understand financial needs in later life. SOLLA has developed a system of accreditation for Later Life Advisers who can advise on such matters as equity release, long term care options, annuities, investments and savings, tax planning etc. There should be some obvious links that councils might want to make with such a model and to be able to direct self-funders towards specialised financial expertise, not least because it could be beneficial in avoiding the sudden surprises of people running out of money in residential and nursing care.

5.14 The need for a trusted source of independent financial information is obvious. Moreover, people need to establish a relationship with such advice as much in advance of their need as possible so that they are not making major decisions at a time of crisis.

*“We are asking people to part with 80, 90 or 100 thousand pounds; to take a bet, for peace of mind (...) somebody wants to think about it (...) It’s a long slow process of the penny dropping and you’ve got to have information and awareness where these people go. You’ve got to have interesting leaflets in the garden centre and the doctor’s surgery (...) it’s a slower process.”*

5.15 It is also evident that various insurance and financial services companies are recognising the market opportunities offered by the care and support needs of a growing population of potential self-funders, as these comments illustrate:

*“We’re looking at getting involved in telecare (...) which fits in with our call centre environment (...) on the social care side we’re looking at our ability to build up information and turn that into a user-friendly proposition (...) if someone wants to stay in their own home, what do they need to do about*

*that, where do they get advice and support around things like benefits, general support, home modifications, that kind of thing.”*

And

*“It’s the biggest growing area in financial services (...) the over 65s have been – to a certain extent – recession proof (...) and there is just their sheer weight of numbers and I think we’ll see a huge shift in a whole range of services (...) a huge number of different opportunities are there.”*

- 5.16 At the same time, opportunities are also being recognised around people who may be employing personal assistants. Again, this is attracting interest from commercial services which are not from a tradition of advocacy and brokerage:

*“Something like legal advice, especially with the market moving towards personal budgets (...) legal support for people who have never employed anyone in their lives before, or for the family who may be doing it on their behalf (...) and we’re also looking at the care provider themselves (...) advice on health and well-being in the workplace, or if they’re being accused of something.”*

- 5.17 The fact that these companies are considering moving into new markets and that they may not be organisations that would traditionally be thought of as part of the ‘social care’ territory, raises some interesting issues about how people who are self-funding may seek out information or support. A representative of one such organisation observed that his company may not be known in the field at this time, but there would be name recognition arising from people’s contact with other areas of the service, for example:

*“Those who have used [the company] will know it and value it. People may well have come across it either through identify theft or through commercial property assistance (...) travel insurance, motor breakdown (...) there are lots of routes through.”*

- 5.18 Recognising ‘market opportunities’ is obviously how the commercial and business worlds operate, but this raises questions about understandings of the wider social care policy objectives and sharing essential core values. Are service developments in this area simply an area of expansion that can be viewed in the same way as any other consumer preference? Will the public think it appropriate to use a company for social care information and advice that they may be familiar with from other spheres of their lives, or will they have doubts about expertise and skills? There are clearly considerations about the vulnerability of people and the risks of them not being sure what products might best meet their needs. It might also be argued that the market response to

perceived opportunities in social care has previously skewed the pattern of service development in directions that have run counter to major policy objectives and have made their achievement more difficult. Two obvious examples are the exponential growth in private residential and nursing care places that took place in the late 1980s, fuelled by the availability of social security payments, and secondly the emergence of a specialist market in residential provision for people with complex needs which diverted many councils from developing their own alternative models of community based supported living solutions.

5.19 If a range of different organisations become involved in the area of information and advice – such as different public and private companies offering a variation on the FirstStop model – there are issues about clarity of message and where this leaves the concept of a national care and support information brand, and how a degree of coherence or ‘connectivity’ between different providers might best be supported and needless duplication of effort avoided.

5.20 There are also uncertainties that are making some commercial organisations cautious about entering this market. The long term care insurance sector is one that (to-date) has had a short and inglorious history in the UK with most of those who developed products subsequently withdrawing from the market. In the light of such experience, there is some apprehension, as this person described:

*“At this point I don’t think we would anticipate getting into an insurance product simply because of the uncertainty (...) it is so difficult to work out actually what on an actuarial basis you should be looking at (...) we’re an insurance company, we like to avoid risk if we possibly can, and it’s too risky at the moment.”*

5.21 The issue of legal advice is also an area where people may need very specialised information and support. Interestingly, this is not a topic that the Green Paper appears to recognise as part of people’s information needs, but in some situations it can be vital, as this person described:

*“If it is something that touches on legal issues we would advise them to go to a solicitor; we would probably mention Solicitors for the Elderly (...) we would advise them about the Office of the Public Guardian, and the Ombudsman, and those sort of things.”*

## 6 Information Standards

6.1 The Department of Health is to introduce an Information Standards Quality Mark scheme to help people make confident and informed decisions about their health and care. The Quality Mark is intended to give people confidence that the information they receive is reliable, and this could be particularly important in helping people to be confident about services on offer from various providers.



6.2 Awareness of the Information Standards Quality Mark appeared generally low, other than on the part of organisations that had been directly involved in the early piloting. Nonetheless, some respondents recognised that the quality mark *could* be important both for their organisations and for the public, for example:

*“It’s given us an opportunity to tighten up and record more closely what we do in terms of the feedback and review comments that we get for our titles. To be able to see transparently that corrections are being made following on from review comments.”*

*“The accreditation, as I understand it, will stand for three years with the possibility of random assessment being made by the accreditation body at any time (...) We will only continue to be with it so long as it gets critical mass; there’s not a lot of point in it otherwise. If it demonstrates to people that our information has got an external mark of approval, that’s good, so that’s one point. The second point is that I think the Department of Health have talked about linking the funding for particular grant schemes, for example the service development, innovation and excellence fund is one such, that will require organisations either to be seeking the Information Standard accreditation or to have obtained it. Thirdly it’s been good in terms of us getting our act a bit crisper and clearer, but it has required more work (...) By the time we come up to the third year review we would want to be able to see the benefits.”*

*“We originally thought they were going to link accreditation with ‘information prescriptions’ so that if we were accredited (...) we would be able to be on an ‘information prescription’, and that is obviously of benefit (...) But we do know that there are some prescriptions being issued already and since no one has yet been accredited I’m not sure who is on that (...) I understood that accreditation was brought in to make prescriptions work because clinicians wouldn’t prescribe unless they thought the information was of quality.”*

6.3 Other organisations also commented on their interest to be part of the information prescribing arrangements, but had little awareness of the Information Standard quality mark:



*“If we can be an authorised information giver to the health service, obviously that will mean that the service gets to an awful lot more people. GPs are looking at a limited list of sources of information, if FirstStop is up there near the top it will direct people in the right direction.”*

- 6.4 While some respondents remarked that they ‘knew little about it’, they recognised that there may be growing pressure to acquire a quality mark in order to compete:

*“..if it becomes more accessible then we would need to think seriously about going for it; if it exists it is something than one needs to acquire (...) in principle.”*

- 6.5 At the same time, some respondents expressed a measure of scepticism about the purpose of the accreditation process:

*“The danger is that you force everything through a very restrictive channel of things that either you can talk about or not talk about (...) so long as you can maintain the quality of the relationship between caller and respondent.”*

- 6.6 Others drew attention to the administrative and organisational burden of obtaining accreditation of any type:

*“All these quality marks and what have you, there is a huge piece of administrative work to be done in order to get it. What the organisation is doing may already meet the requirement but the demonstrating of that is normally a massive piece of administrative work. Sometimes it can be very good, but in a small organisation it is time consuming.”*

## **7 Follow up and monitoring**

- 7.1 Just as we explored the question of record keeping, we asked respondents about processes for monitoring any actions people take as a result of the advice they are given. Some 62 per cent of respondents indicated that they *did* monitor in this way (or in one case that they intend to do so), and the following comments were typical:

*“We follow up with members and ask them how useful the advice was, if it could have been improved and if it was followed, and the impact on the business or organisation of following the advice.”*

*“Asking for feedback from callers and building good continuing relationships where callers feel comfortable in keeping us informed.”*

*“Record all action taken following the advice given and whether the advice has been taken up.”*

*“We ask them what the broad outcomes of our advice was and whether their lives improved, looking at outcomes rather than outputs. We also look at whether our advice and the support they [carers] got maintained or improved their health.”*

*“We do send out questionnaires from time to time and they get sent back (...) it’s validated what we do; it is rare that we get a critical response.”*

*“We get a lot of – anecdotally on the ‘phone – ‘thank goodness I got hold of you eventually; you’re the first person who has made any sense, or the first person who has told me what I am actually entitled to’.”*

- 7.2 The nature of this monitoring or follow-up activity requires further examination but it appears that very little focus is being directed towards outcomes. One person identified the key issue that organisations often wrestle with around monitoring in these terms:

*“Do we want to know the experience people had in approaching this service, or do we want to know the extent to which it solved their problem? I think those are two completely different areas; one is about (...) is our customer care good? And the other is – did it make a difference to granny?”*

- 7.3 Not everyone will get what they want from a service in terms of the final outcome if that is not possible within the rules of the system, so part of any evaluation should also be around whether the *reasons* for this were properly explained.

## **8 Overview & Conclusions**

- 8.1 In this paper we have explored the approach of a number of key organisations to providing information and advice to people needing care and support. In this concluding section we summarise the key messages arising from both parts of this initial study – from the literature review and the study of provision of information and advice by non-statutory agencies. We identify ten key message from each part as shown in the boxes below

## **Self-Funders Literature Review: Ten Key Messages**

1. **The issue of self-funders is growing in urgency but the concept is not watertight:** the combination of demographic change, wealth distribution and a broader conceptualisation of social care away from the Poor Law safety net are all contributing to a change of focus but defining a 'self-funder' is not straightforward and misconceptions abound.
2. **The evidence base on people who are self-funding is limited:** it is dated, biased towards those people already in care homes and fails to capture the longer care journey that people undertake.
3. **Numbers:** again data is poor, but there has been a steady rise and self-funders account for as much as 40% of the social care market. There are considerable local variations; some councils have undertaken studies to understand their situation more fully, but there are untested possibilities around some figures in JSNAs.
4. **Policy exhortation is already in place:** The original FACS Guidance, and the latest consultative draft revised guidance, impose a duty to assess care needs separately from means, and to actively encourage people to seek out advice.
5. **There is a policy-implementation gap:** attitudes and approaches are highly variable with a continuum ranging from service denial through to minimal support and (rarely) a robust strategy;
6. **Access to information:** there is some evidence of improvement in recent years but persistent problems remain including limited information, highly variable responses, poor web sites, information written for professional rather than lay audiences; and people have specific needs that require more than just an information bank.
7. **Assessment of needs and means:** there is only limited access to need assessment for self-funders which is highly variable often depending upon the attitudes of care managers; care home admissions of people who are self-funding frequently occur without a needs assessment, and there is inadequate forward financial planning supported for individuals.
8. **Access to ongoing support:** there is a failure to support 'contract-making' for self-funders; signposting often occurs with little or no follow-up and there are limited channels for redress of grievance.
9. **The universal offer:** of access to information and advice about care and support that should be available to everyone is central to the future position of self-funders. It is also central to the Green Paper – a 'care and support information brand' – and there needs to be a robust IAA strategy addressing all three of these dimensions.
10. **A robust evidence base:** there is an urgent need to underpin policy and practice with proper research and both quantitative and qualitative evidence.

## **Provision of Information & Advice: Ten Key Messages**

1. **'Information and Advice'** is a **simple phrase** which conceals the underlying complexity. This issue is multi-dimensional and covers both very general and highly specific needs and responses. There are also major differences in the particular information needs of various groups of people, for example older people will have different requirements from people with long term conditions, although there will also be some issues in common.
2. **Location:** the location of IAA can be local or on a wider basis, including national level. There is enormous potential for both duplication and inconsistency of messages. Some combination of centralised core information with signposting to local material of most direct relevance to a person's situation is probably the ideal arrangement.
3. A **'care and support information brand'** as well recognised as the NHS is currently a long way from being a reality. Something like FirstStop may be a model for the way forward but it will need major development.
4. **The pathway to information and advice is rarely smooth:** partly because of the complexity of IAA needs and the variety of organisations involved in providing different parts of the picture, people often struggle to get to the right information and may go through multiple steps before finding the right point of access.
5. **Quality Vs Quantity:** providing IAA to people in an appropriate and personalised way can take time. Because this is rarely about standard information a 'one size fits all' approach cannot work. People may need more than one contact and to be able to find support over a period of time; the quality of their experience will be crucial.
6. **Gatekeeping and information giving** are not good companions. There is a widespread view that councils have a conflict of interest and that too often they respond to people's preliminary inquiries by effectively undertaking a pre-assessment and diverting people from seeking support, or giving them the impression they are not entitled to support.
7. **Outcomes:** What happens to people as a result of receiving information or advice is an area where little is known. Follow-up monitoring or evaluation is rarely undertaken beyond customer-satisfaction surveys.
8. **Financial Advice:** The provision of financial advice is regulated by the Financial Services Authority and people giving information are aware of the need for this to be provided by independent advisers. However, financial advice for long term care or for later life planning is highly specialised and many IFAs would not be able to address people's needs and people who are self-funding can struggle to find such expertise.
9. **The Information Standard Quality Mark** being introduced by the Department of Health has achieved little profile or awareness at the present time. Its value will depend on sufficient organisations seeking accreditation and on that accreditation providing access to other opportunities (for example, if it is a pre-condition for organisations able to respond to 'information prescriptions' issued for people with long term conditions).
10. **Understanding people's pathways:** the picture that is building up needs to be expanded and deepened by research which explores people's pathways and experiences. How people get the information and advice that they do; how they navigate their way through the system, and what they do subsequently are all areas where information is incomplete or anecdotal. In-depth qualitative research is needed to illuminate this experience and inform policy and practice development.

8.2 Reading across the two sets of messages reveals a high level of consistency. Four general issues recur. First that the issue is complex and multi-faceted – even definitions are unclear. This suggests that an effective strategy will require much more than a tweaking of current arrangements. Secondly, that although the contours of good practice are fairly clear, current performance is highly variable across the country. If IAA is to be a key component of the ‘universal offer’ then there will have to be both clarity on what should be achieved and greater consistency of attainment. Thirdly, the position of self-funders has grown in importance and will become even more significant in a post-Green Paper future. Doing nothing is not an option, but exhortation alone will be insufficient.

8.3 The final recurring issue relates to the limited evidence base, and therefore feeds into the next stage of this work. The current evidence base on self-funders – their numbers, their ‘care journey’ and the quality of their lives – is weak. Although quantitative information is slowly emerging in some localities it has not been pieced together nationally, whilst the qualitative data is alarmingly weak. What is needed here is some in-depth investigation of a representative sample of self-funders to determine how decisions are made about their care and support, and with what outcomes. We therefore propose that the next stage of this work should – in conjunction with key stakeholders - include the following components:

- Work with a representative spread of provider organisations to identify self-funders who are using their services and to use this sample for in-depth work tracing people’s pathways into care and support.
- Work with a number of councils – some of whom have been identified as being well-advanced with their strategies for supporting self-funders, and others that are at various points of engagement with this agenda. Multi-dimensional work across councils (including with officers, elected lead members and front line staff) would identify the features of good practice and how this might best be nurtured.
- Follow up with representative samples of people using IAA services (for example through FirstStop and partner agencies) to assess the value of information and advice received, explore gaps and deficits, identify the features of a quality IAA brand, and to inform conclusions about

how best to target support at key groups and life stages, and to maximise coherence of message.

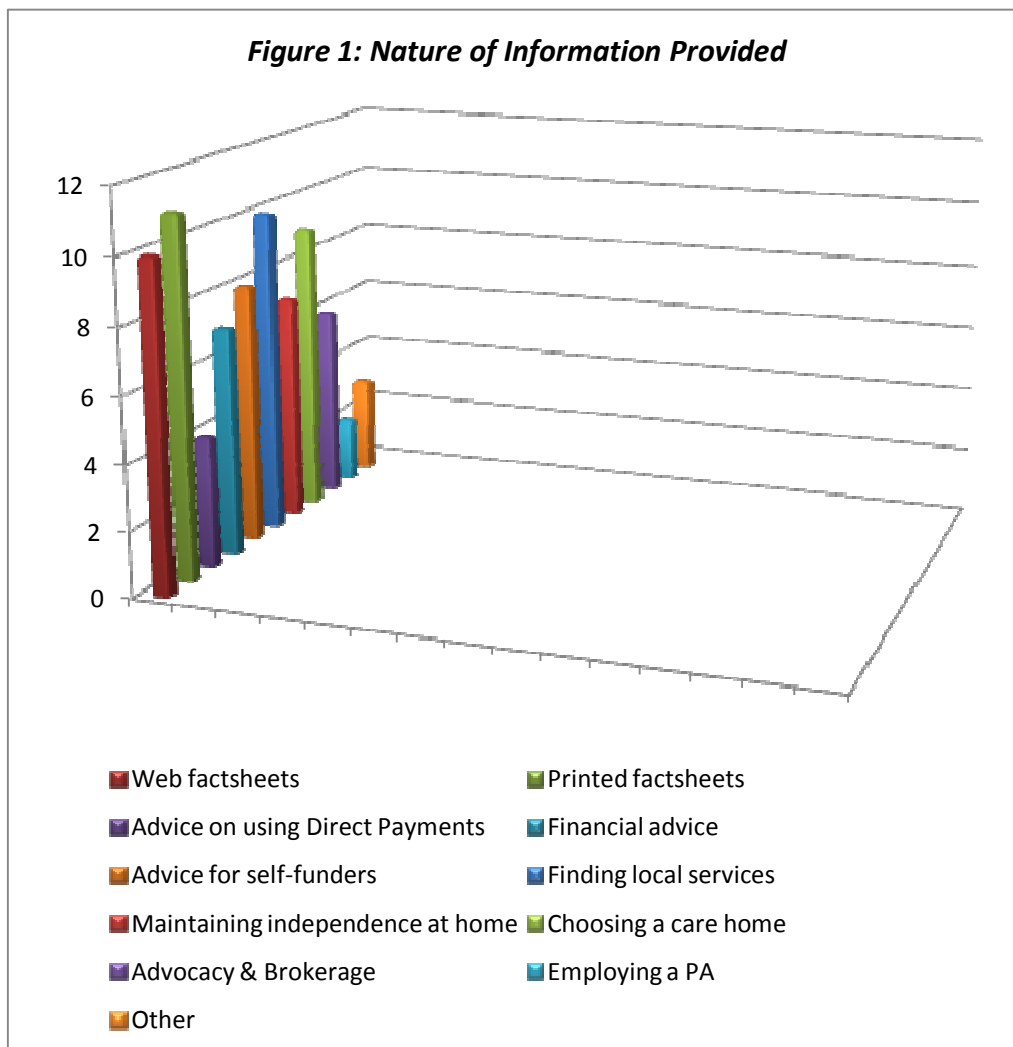
- Attempt to identify a sample of 'hard to reach' potential self-funders who are not currently in touch with council services or with IAA. This might be achieved, for example via SAGA and/or University of the Third Age membership bases. This would explore people's information needs and their knowledge of what is available.

8.4 Depending on feedback from key stakeholders we will develop detailed methodologies and a costed proposal for this new stage of work. We would hope to be able to begin work early in 2010, and in view of the multi-dimensional nature of the components of this study we would not anticipate it being completed before the end of September 2010. We believe this work would address the key gaps that we have identified in current knowledge and would be invaluable in assisting the implementation of some key milestones for transforming adult social care.

## **Appendix 1: Organisations invited to participate**

Age Concern/Help the Aged  
Anchor Trust  
BUPA  
CAB  
Carers UK  
Centre for Policy on Ageing  
Counsel and Care  
Crossroads Care  
ECCA  
Elderly Accommodation Council  
Europ Assistance  
FirstStop  
FSA  
Housing 21  
Leonard Cheshire  
MS Society  
National Care Association  
National Care Forum  
NHFA  
Partnership  
Princess Royal Trust for Carers  
Registered Nursing Homes Association  
Relatives and Residents Association  
SAGA  
SCOPE  
SSAFA  
Voluntary Organisations Disability Group

## Appendix 2: Key findings of the questionnaire



It can be seen that personal advice, factsheets (web-based or printed), and information on finding local services are the most frequent types of information provided. 7 (44%) respondents indicated they provided financial information on individual circumstances, while 8 (50%) provided advice specifically for people funding their own support. The least frequent areas of information were on advocacy and brokerage services (37%); the use of Direct Payments (25%), and employing a Personal Assistant (12%).

### Record Keeping

One quarter of respondents indicated that they keep no records about the number or nature of inquiries they receive. Of the remaining 75%, *all* recorded the location of callers, the broad nature of the inquiry and



whether they were calling on behalf of themselves or a third party. As Table 1 indicates, age and gender of callers are frequently logged, but ethnicity is much less likely to be recorded.

**Table 1: Information collected about inquirers**

	Age	Gender	Ethnicity	Location	Nature of inquiry	Repeat caller	On behalf of self or other	Other
Per cent of organisations keeping records N=12	83%	83%	33%	100%	100%	83%	100%	66%
Per cent of all respondents N=16	62%	62%	25%	75%	75%	62%	75%	50%

### Changing volume and pattern of inquiries

Whether the volume and pattern of inquiries is changing is a matter of interest, and respondents were asked about their experience in both areas.

Of those respondents able to know from their records whether volume is changing, 61% indicated that the numbers had increased either a little or significantly; none had experienced a decline in requests, and around 38% believed the volume to be largely unchanged.

**Table 2: Change in number of people seeking advice and information in past 12 months**

	Numbers remained roughly constant	Numbers in decline	Numbers increased a little	Numbers increased and rising
Respondents indicating change in numbers of inquirers in previous 12 months. N=13	5 38%	0 0%	2 15%	6 46%

Respondents were invited to indicate whether there had been any noticeable change in the *pattern of information and advice* people have sought in the previous year. The most frequent responses (from one third of respondents in both cases) were that:

- There has been an increase in people seeking information as self-funders
- And an increase in people wanting information and support to remain independent.

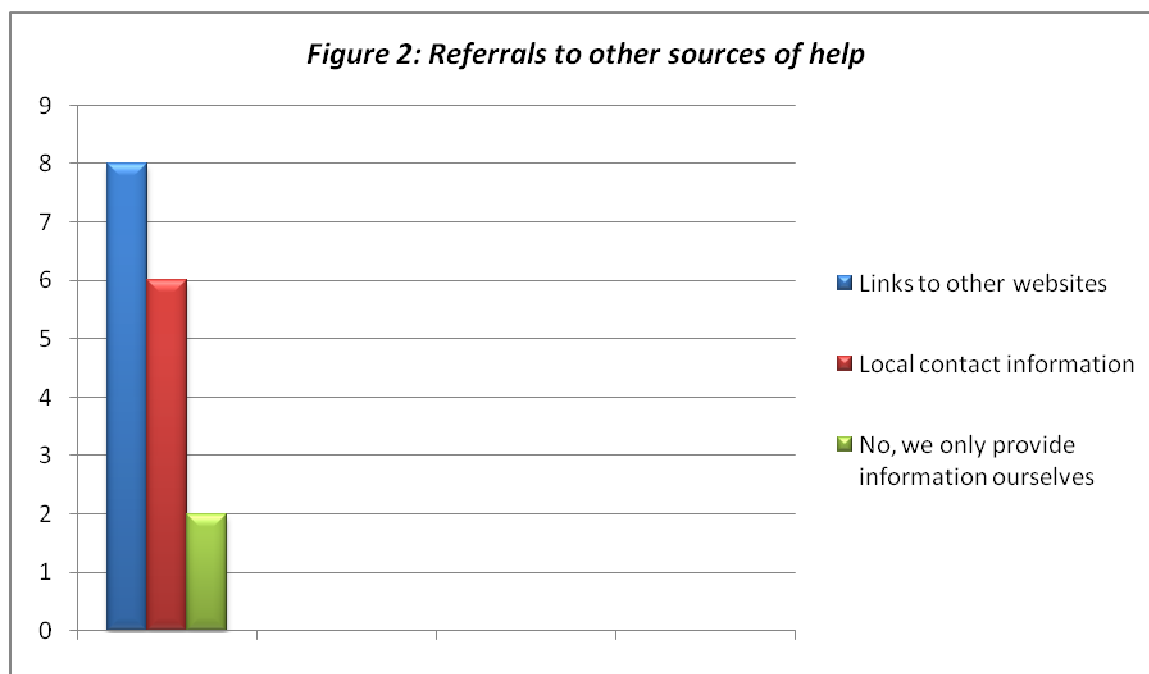
**Table 3: Change in pattern of advice and information sought in past 12 months**

	Pattern much the same	Increase in information for self-funders	Increase in help to remain independent	Increase in practical help	Increase in befriending	Increase in inquiries about care homes	Increase in advocacy & brokerage information	Increase in information about employing PAs
Per cent of organisations keeping records N=12	25%	33%	33%	17%	8%	17%	17%	1%
Number	3	4	4	2	1	2	2	1

## Referrals to other help

It is evident that people seek information and advice about a wide range of issues. It is reasonable to assume that not all organisations will be able to address all such issues themselves, and may need to refer inquirers elsewhere. We asked respondents to tell us how they deal with such situations.

**Figure 2** demonstrates that 50 per cent of respondents (n=16) provide links to other websites to facilitate access to other information. It is not known how effective this is as a method of referral, or whether it meets people's needs. Almost 40 per cent of respondents provide local contact information to better address the specific needs of people seeking help and advice. Two responding organisations (13%) stated that they do **not** provide referrals to other sources but only provide the information themselves.



## Information Standards

We asked respondents if they plan to apply for certification under the scheme once it is launched. **Figure 3** summarises the responses we received. It is striking that fewer than one in five respondents expressed a clear intention to seek the Information Standard certification, and a further one in four indicated that they would *not* apply for certification. Half of all respondents were non-committal with a 'don't know' response, which may conceal lack of awareness about the scheme (indeed only one respondent indicated they had never heard of the scheme).

