Advice and information needs in adult social care

Interim report for the Think Local, Act Personal partnership

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think local
act personal

advice and support for older age
Independent
Age

Contents

Mapping social care systems

In 2012, Think Local Act Personal (TLAP) commissioned Independent Age to produce a map of the existing systems in place to support people with social care needs and the typical journeys taken through those systems. After initial work, the map was further developed at a series of meetings and a workshop with local authorities, service providers, service users and carers. The workshop also helped to identify points in the system where information and advice are most needed and also key reasons why information may not be provided or may be ineffective.

This report contains the interactive map of typical journeys and a description of the major problems identified and the relevant research. The map may be further developed in 2013/14. This work was part of TLAP's work on information and advice.
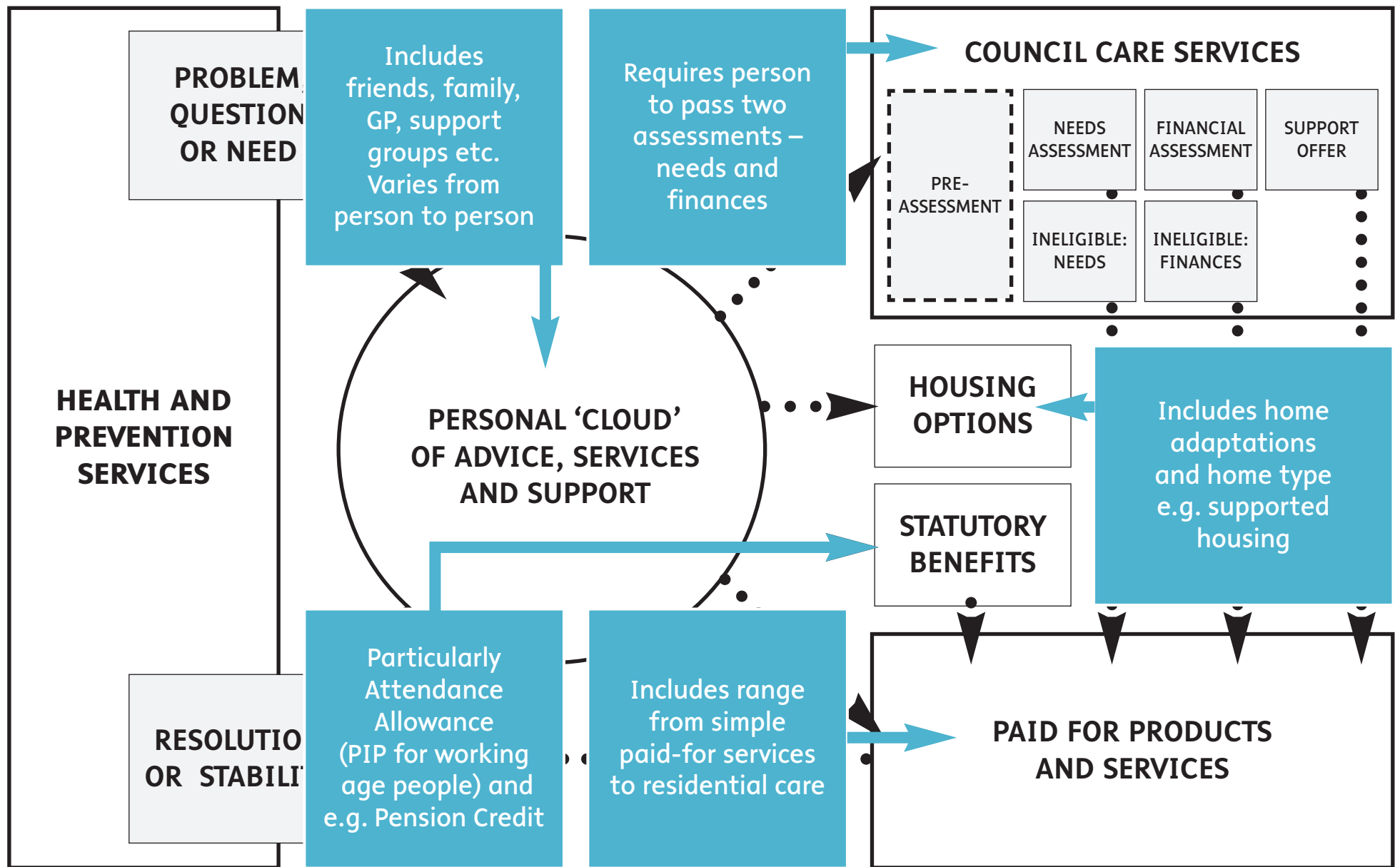
The map

The map outlines, at top level, care and support options open to an individual faced with a social care problem, question or need and whose goal is resolution (or at least stabilisation).
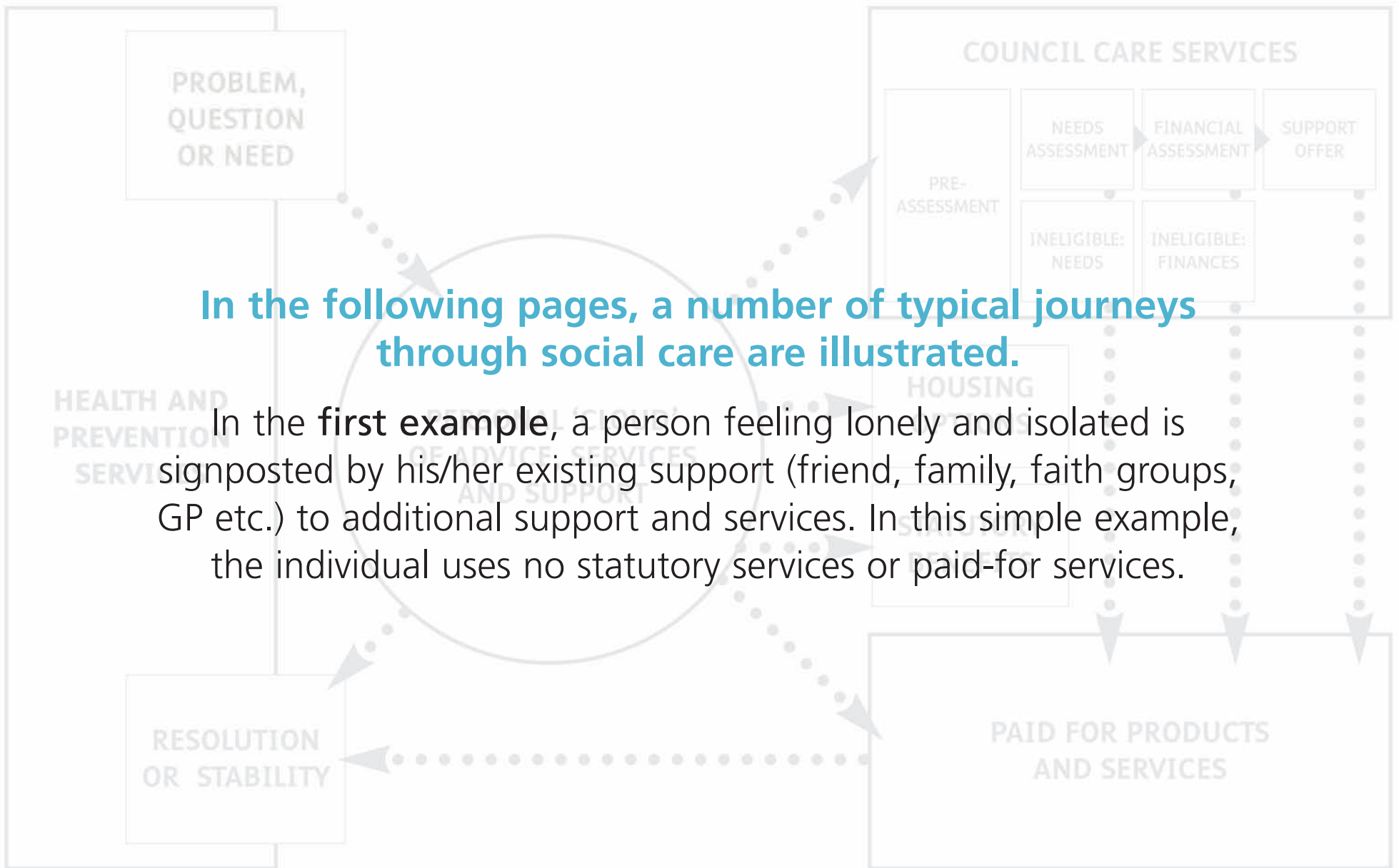
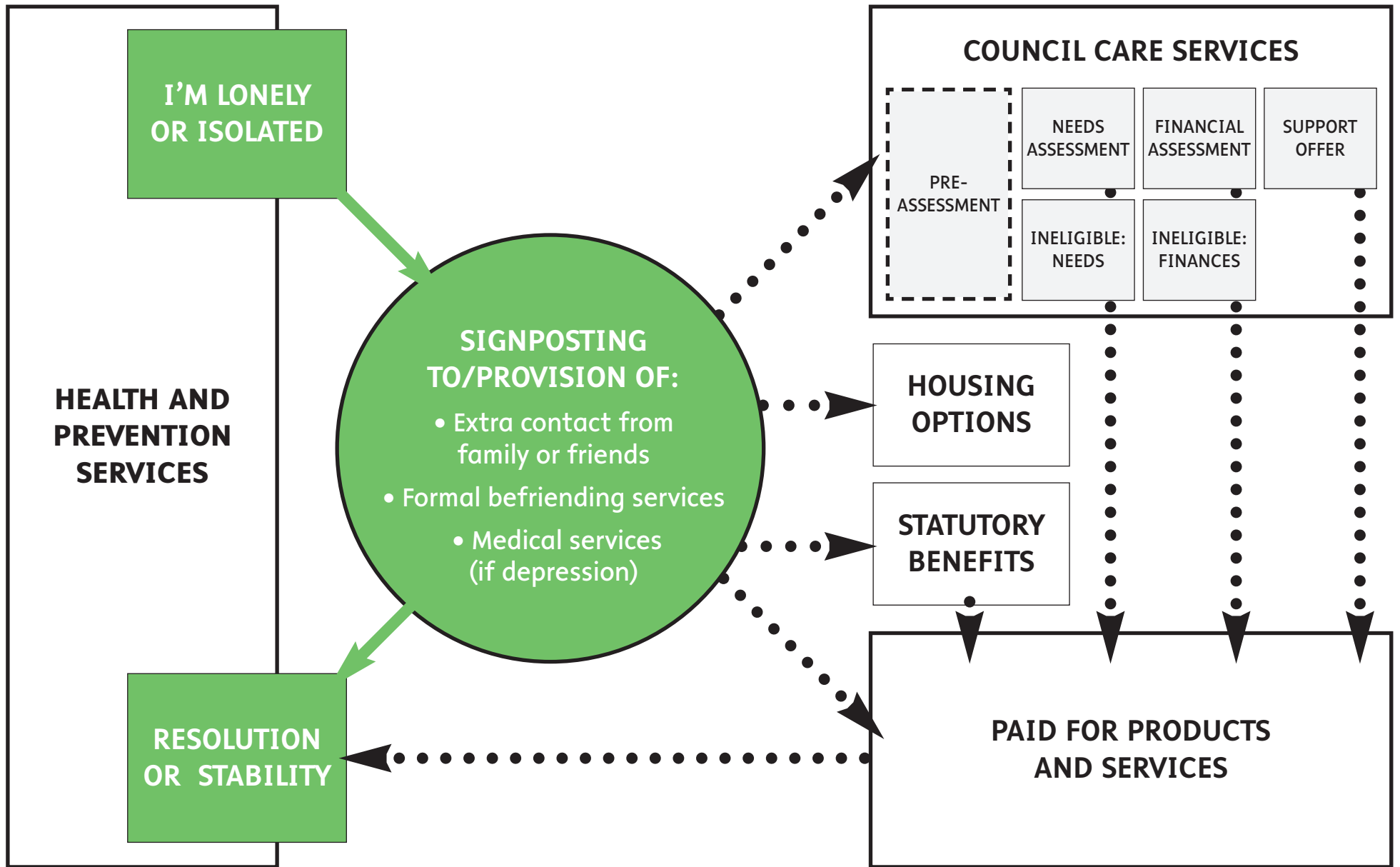There are six potential areas of support identified in the map:

1) **Prevention services**, which aim to prevent a need emerging in the first place.

2) The **personal 'cloud' of support** that surrounds each individual and to whom they will typically turn for support in the first instance – their friends, family, GP, faith groups and support organisations with whom they are in contact. This cloud will differ for each individual, partly because each individual has a different level of personal contact and partly because the support from organisations, charities etc on which the individual can draw will differ from area to area. This cloud of support will provide a range of services from information through to actual provision of services, whether informally or formally.

3) Care services funded by the **local council**. The map outlines in overview the process by which an individual is assessed by a council to identify their care needs and their financial eligibility for services. Only if successful at both stages will an individual receive a support offer.

4) **Housing and home adaptation** options available to an individual, ranging from simple equipment to aid independence through to large adaptations or a change of housing type.

5) **Statutory benefits** that an individual can use to pay for solutions of their care needs. These include Pension Credit and particularly Attendance Allowance.

6) **Paid-for services** that an individual might use to support their independence or meet their care need. These range from simple low-level services such as a cleaner or supermarket home delivery service through to more formal homecare services to help with issues such as washing and dressing. Ultimately they also include support in a care home.

PROBLEM, QUESTION OR NEED

HEALTH AND PREVENTION SERVICES

RESOLUTION OR STABILITY

Includes friends, family, GP, support groups etc. Varies from person to person

Requires person to pass two assessments – needs and finances

PERSONAL 'CLOUD' OF ADVICE, SERVICES AND SUPPORT

Particularly Attendance Allowance (PIP for working age people) and e.g. Pension Credit

Includes range from simple paid-for services to residential care

COUNCIL CARE SERVICES

PRE-ASSESSMENT

NEEDS ASSESSMENT

FINANCIAL ASSESSMENT

SUPPORT OFFER

INELIGIBLE: NEEDS

INELIGIBLE: FINANCES

HOUSING OPTIONS

Includes home adaptations and home type e.g. supported housing

STATUTORY BENEFITS

PAID FOR PRODUCTS AND SERVICES

In the following pages, a number of typical journeys through social care are illustrated.

In the **first example**, a person feeling lonely and isolated is signposted by his/her existing support (friend, family, faith groups, GP etc.) to additional support and services. In this simple example, the individual uses no statutory services or paid-for services.

HEALTH AND PREVENTION SERVICES

I'M LONELY OR ISOLATED

SIGNPOSTING TO/PROVISION OF:
- Extra contact from family or friends
- Formal befriending services
- Medical services (if depression)

RESOLUTION OR STABILITY

COUNCIL CARE SERVICES

PRE-ASSESSMENT

NEEDS ASSESSMENT

FINANCIAL ASSESSMENT

SUPPORT OFFER

INELIGIBLE: NEEDS

INELIGIBLE: FINANCES

HOUSING OPTIONS

STATUTORY BENEFITS

PAID FOR PRODUCTS AND SERVICES

In the **second example**, a person with significant care needs is signposted by his/her existing support to additional support and services. In this example, the individual:

- Is assessed as having substantial or critical needs by his/her council AND as being below the financial eligibility threshold

- Receives a support offer and is supported to buy day care services using a personal budget

- Additionally receives home adaptations such as a bath step.

I'M STRUGGLING TO WASH AND DRESS (currently in receipt of AA)

HEALTH AND PREVENTION SERVICES

SIGNPOSTING TO:
- Home Improvement Agency
- Needs assessment

RESOLUTION OR STABILITY

COUNCIL CARE SERVICES

PRE-ASSESSMENT

NEEDS ASSESSMENT

FINANCIAL ASSESSMENT

SUPPORT OFFER

INELIGIBLE: NEEDS

INELIGIBLE: FINANCES

HOME ADAPTIONS e.g. bath step

STATUTORY BENEFITS

HOMECARE SERVICES

In the **third example**, a person with fewer care needs than in the previous diagram is also signposted by his/her existing support to additional support and services. However in this example, the individual:

- Is assessed by his/her council as having moderate needs and is therefore not eligible for council-funded services

- Is however signposted to claim Attendance Allowance (AA), which in this case is successful

- Also additionally receives home adaptations.

I STRUGGLE TO COOK AND CLEAN THE HOUSE

HEALTH AND PREVENTION SERVICES

SIGNPOSTING TO:
- Needs assessment
- Attendance Allowance claim

COUNCIL CARE SERVICES

PRE-ASSESSMENT

NEEDS ASSESSMENT

FINANCIAL ASSESSMENT

SUPPORT OFFER

INELIGIBLE: NEEDS

INELIGIBLE: FINANCES

HOUSING OPTIONS

AA CLAIM

RESOLUTION OR STABILITY

CLEANER AND PRE-COOKED MEALS DELIVERED

Not all social care journeys end well. In the fourth example, a person with moderate care needs is signposted to support.

- She is assessed as having moderate needs and is not eligible for council-funded services
- In this case she is not advised to apply for Attendance Allowance and receives no advice
- Without support, she fails to access care and her care needs worsen.

In this fifth example, someone with high care needs but HIGH assets is signposted to support.

- Although she assessed as having substantial needs by her council, she is not financially eligible for support

- She receives no further support and does not access any care services.

PROBLEM, QUESTION OR NEED

HEALTH AND PREVENTION SERVICES

SIGNPOSTING TO COUNCIL FOR ASSESSMENT

COUNCIL CARE SERVICES

PRE-ASSESSMENT

NEEDS ASSESSMENT

FINANCIAL ASSESSMENT

SUPPORT OFFER

INELIGIBLE: NEEDS

INELIGIBLE: FINANCES

HOUSING OPTIONS

STATUTORY BENEFITS

NO RESOLUTION

FAILS TO ARRANGE OWN CARE SERVICES

In this final example, a person with high care needs and HIGH assets does not even present for assessment by her council.

- She proceeds directly to arrange her own high cost residential care, with her own assets

- Eventually her assets run out but the council is unwilling to continue the same high cost care and she needs to move care home.

PROBLEM, QUESTION OR NEED

HEALTH AND PREVENTION SERVICES

SIGNPOSTED DIRECT TO PURCHASED DAY CARE OR CARE HOME

ASSETS RUN OUT; MAY NEED TO MOVE

COUNCIL CARE SERVICES

PRE-ASSESSMENT

NEEDS ASSESSMENT

FINANCIAL ASSESSMENT

SUPPORT OFFER

INELIGIBLE: NEEDS

INELIGIBLE: FINANCES

HOUSING OPTIONS

STATUTORY BENEFITS

USES ASSETS TO BUY OWN CARE HOME PLACE

Advice and information needs

Information and advice on social care can make a huge difference to people's lives. In a major study of social care users, 14% of those who said information and advice was very difficult to find said their quality of life was 'very bad' or 'so bad it could not get worse'. This compares to only 2% of those who found it very easy or fairly easy to find information and advice.[1]

From the examples given earlier in this report where care is provided – and especially those where it isn't - we can identify points in journeys when advice and information is most needed. We can also identify the points at which advice and information may NOT be provided or why it may be ineffective

Our analysis suggests 8 major problems with the information and advice available to those with social care needs.

1) The social care system is too complex and localised to comprehend

2) Decisions are typically taken in a crisis

3) There are problems with the quality and availability of information, advice and referral

4) The availability and quality of council information services and assessments is patchy

5) There is a lack of independent support for the assessment process

6) There is a lack of joined-up advice covering care and housing/benefits options

7) There is a lack of information about service availability and quality

8) There is a lack of signposting to financial advice.

In the map overleaf we show where these issues most commonly occur and examine each problem in turn.

1) System too complex and localised to comprehend

2) Decisions typically taken in a crisis

3) Availability and quality of council assessments

4) Lack of independent support for assessment process

PROBLEM, QUESTION OR NEED

HEALTH AND PREVENTION SERVICES

PERSONAL 'CLOUD' OF ADVICE, SERVICES AND SUPPORT

COUNCIL CARE SERVICES

PRE-ASSESSMENT

NEEDS ASSESSMENT

FINANCIAL ASSESSMENT

SUPPORT OFFER

INELIGIBLE: NEEDS

INELIGIBLE: FINANCES

HOUSING OPTIONS

STATUTORY BENEFITS

RESOLUTION OR STABILITY

PAID FOR PRODUCTS AND SERVICES

5) Problems with quality of information, advice and referral from support groups

6) Lack of joined-up advice covering care and housing/benefits options

7) Lack of information about service availablity and quality

8) Lack of signposting to financial advice

1) The social care system is too complex and localised to comprehend

A Counsel and Care and Help the Aged survey conducted in 2008 found that over 51% of people found the system of social care confusing[2] while another survey conducted in 2010 by Counsel and Care found that just 5% of people considered that it was easy to navigate. In the same survey, 79% thought that not enough was done to tell people about the care options available and 71% did not think the government has a clear and consistent policy on care and support of older people.[3] While in other research looking at people 'in the system', 39% said it was difficult to understand what was free and what had to be paid for.[4]

This complexity is accepted by the 'Caring for our Future' White Paper. It found the following problems with the provision of information and advice:

- People do not know or have a clear idea of what social care is, how it is organised, funded, assessed and how it relates to other services. The public profile and therefore understanding of social care issues is low, with the result that people are less likely to take steps to plan for their potential care needs.

- People do not know how or where to access the information that would help them plan and prepare at key points in their lives, or support them to make appropriate choices if they are in receipt of care or expect to need care in the near future.

- Individuals, including self-funders, and carers need access to a comprehensive range of help to navigate the care system and support them to get the right 'personalised' care.

These findings are supported by a range of other research:

- The quality of information available currently varies between areas and understanding the services available in adult social care is a complex exercise, according to research by the public affairs group MHP.[5]

- The Social Care Institute for Excellence counted at least 35 separate independent sites providing information to assist users of social care services in identifying providers.[6]

- The great deal of overlap between social care, health and housing means people may require access to multiple advice services/sources simultaneously. It also means that people find it difficult to distinguish which advice and information service may best meet their needs.[7]

- Most advice services have been fragmented across a range of voluntary and statutory agencies and have relied on short-term funding, leading to patchy provision.[8]

2 'Right care, Right deal Scary, depressing and confusing: Voter's view of Social Care revealed' Counsel and Care, Carers UK and Help the Aged (2008)
3 'Exclusive Research Reveals Widespread Confusion over Care for Older People' Counsel and Care (2010)
4 CELLO mruk Social & Market Research (2009) 'Cost and Provision Adult Social Care Survey' Prepared for London Councils
5 An Atlas of Variations in Social Care: an analysis of the quality of social care services in England, MHP Health Mandate, June 2012, P.47
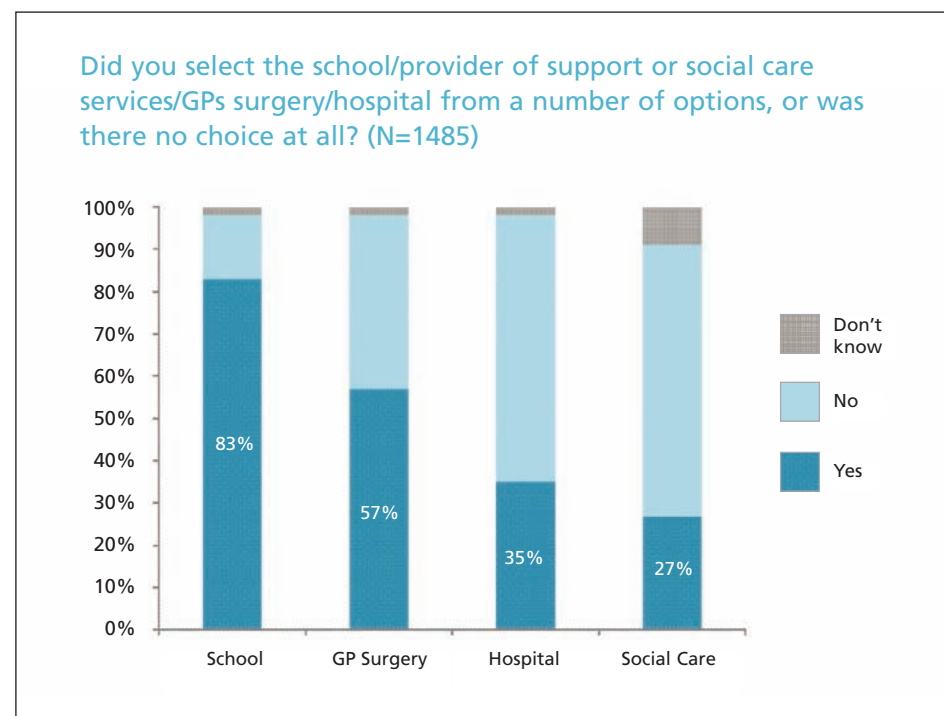6 Steen 2012, in Using Online Reviews in Social Care, Personal Social Services Research Unit, July 2012, P.5
7 Independence, Choice and Control, Accompanying IA for the White Paper "Caring for our future: reforming care and support" (Annex B), Department of Health, July 2012, P. 15-18
8 Oldman, 2003 in FirstStop Evaluation Phase 2 Source Document, Cambridge Centre for Housing and Planning Research, June 2011, P.11-13

Perversely, there is evidence that the complexity of the system leads not to greater choice for individuals but **less** choice:

- Social care performs much worse than health and education in providing choice, with only 27% of people in a 2012 Ipsos Mori poll saying they got a real choice of social care against a 46% overall average.[9]

Did you select the school/provider of support or social care services/GPs surgery/hospital from a number of options, or was there no choice at all? (N=1485)

This research further found:

- Service users least likely to say they got the provider they wanted are social care users, although even then, three in four (76%) got the provider they wanted, against an 87% average across other services.[10]

- The biggest barrier to choice is the difficulty and expense getting to any of the other alternatives (22%). The other main barriers mentioned are not having any other real alternatives (20%), not being aware of alternatives (16%) and having the decision made for them by a professional (12%). Despite the sense that people had enough information, there was a demand for more face-to-face support for choosing (38%).[11]

- Research suggests that service users see choice more broadly than just receiving direct payments. They tend to give more priority to their health, quality of life and 'personal dignity and respect' than to exercising choice.[12]

In attempting to navigate the social care system, individuals turn to their immediate network of support – their family, friends, GP and community/advice groups. However these individuals and organisations are often themselves confused by the system's complexities.

- Relatives often report how difficult it is to navigate knowledgeably around the care system and to make well-informed choices about the care options that may be available.[13]

9 *Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 37*

10 *Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 18*

11 *Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 19*

12 *Wood C. (2010), Personal Best, Demos, London. In Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 37*

13 *Adult Social Care: LGO – The single point of complaints, Local Government Ombudsman, July 2012 p.6*

2) Decisions are typically taken in a crisis

Not only is the social care system complex, it is also often accessed first during a crisis caused by illness, accident or the sudden deterioration of a loved-one's condition. It is hard to think of circumstances in which decision-making would be more fraught with difficulty.

This in turn is made worse because people do not anticipate needing care and do not learn in advance how the care and support system works. Ipsos MORI research in 2010 found that 54% of the public think that, should they need to use services in the future, they will be free at the point of use.[14]

Decisions may be made in response to a crisis and without adequate information or time to reflect. Older people, who have often never used a formal advice service, can find themselves in need of one at a time when they may be less physically able or less confident in seeking it out (Russell, 1999) and may have to depend on someone else to help them.[15]

A 2012/13 review of choice by the Cabinet Office concluded that the current system assesses people too late in the process, and in a way that emphasises need and financial support, and tends to ignore other non-financial resources.[16]

The government's Impact Assessment (White Paper) recognises that *"High quality information and advice is essential to ensure that the care market functions effectively – not least because users and potential users cannot assess the quality of care and support services without experiencing them. Historically, the private sector has not provided the necessary information, probably because of relatively high costs and low demand, possibly driven by the fact that these are often distressed purchases"*.[17]

3) There are problems with the quality and availability of information, advice and referral

When navigating a complex system under pressure, people need especially high quality information and advice. Unfortunately, the evidence suggests that it is often not available.

"I couldn't find any information on local services. I just got gobbledegook from the phone." – Older woman, Dorset[18]

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14 *Department of Health/Ipsos MORI, Public attitudes towards care and support, 2010 in Reforming the law for adult care and support: The Government's response to the Law Commission report 326 on adult social care Department of Health / Secretary of State, July 2012 p. 16*

15 *FirstStop Evaluation Phase 2 Source Document, Cambridge Centre for Housing and Planning Research, June 2011, P.11-13*

16 *Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 47*

17 *Caring for our Future: Reforming Care and Support, Impact Assessment Summary Document, Department of Health, July 2012 P.17*

18 *Case study from Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 45*

"Recent frequent changes to NHS and social services structures and responsibilities have left most, including our trained advisors, confused about which authority/agency is now providing which service."
– **Information Specialist, Voluntary Sector, South**[19]

- An IDeA review found that many sources documented problems that service users (or more widely members of the public) face when trying to access information, advice and advocacy services. These included:[20]
  - lack of or mis-information
  - fragmentation of information. Information is rarely held in one place, pertains to different groups of people, is about different departments or service types. There is little signposting between services.
  - information sources can be overwhelming and non-personalised, with an over-use of jargon or non-accessible language
  - inadequate service provision for certain groups
  - lack of robust evidence-based research around 'what works' in relation to Information, Advice and Advocacy (IAA)
  - specific gaps in relation to evidence on IAA provision for:
    - ethnic minority communities
    - those with chaotic lifestyles

- people with fluctuating support needs
- visually impaired
- multiple impairments
- private purchasers of social care services (Baxter et al, 2006).

- Official information available is often limited to statutory services, and misses out vital facts about what is available from the voluntary sector[21]

- Evidence from recent consultations suggests that information is not routinely being provided in the most effective manner, either to help people take steps to prevent or delay the onset of social care needs, or to help those users and carers who do have needs to identify and access appropriate support[22]

- Research by Demos in 2010 asked people what help they would need to make changes to their lives. The most common answers for all care users were: more information about what I can do (54%), more face to face advice (52%) and someone to speak to in an emergency (46%)[23]

- A 2011 report on the care home sector in England by the Office of Fair Trading found that consumers are not always aware they have a choice and the information available can be complex and difficult to compare[24]

19 *Accessing Information about Health and social care services, Picker Institute Europe, April 2007, P. 57*
20 *Transforming Adult Social Care: Access to Information, Advice and Advocacy, IDEA, Feb 2009 p.13*
21 *Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 44*
22 *Issues relating to carers' assessments and eligibility for services are discussed separately in the corresponding Impact Assessment "Assessment, eligibility and portability for care users and carers" in Reforming the law for adult care and support: The Government's response to the Law Commission report 326 on adult social care Department of Health / Secretary of State, July 2012 p. 16*
23 *Wood C. (2010), Personal Best, Demos, London in Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 44*
24 *Office of Fair Trading, 2011 in Using Online Reviews in Social Care, Personal Social Services Research Unit, July 2012, P.2*

- A 2012/13 Cabinet Office review of choice for those accessing social care support identified a need, not just for information, but also for signposting, interpretation and support, and particularly for intermediaries capable of supporting people who prefer not to employ personal assistants directly[25]

Part of the problem is a mismatch between how information and advice is presented and how people would prefer to access it. Too often information consists of a leaflet and a website, rather than access to the face-to-face support needed.

- The most common way people said they received local authority information was via leaflets[26]

- Age UK/Fujitsu research found that 94% of councilors say "my council is encouraging more people to use local council website for information on local services". However, 73% of older people would still visit or phone the local council to receive services even if more services were online.[27]

- One preferred method of finding out about local services includes the 'One Stop Shop' service provided by the local library. This is popular with participants who like to be able to speak to someone in person. They appreciate that the One Stop Shop staff "go the extra mile for you", by either putting them in contact with the right person or

printing off a hard copy. Other participants found their town hall a useful place to find out about local services.[28]

- The Audit Commission in 2004 concluded that the availability of information and advice for older people is limited. This is particularly the case for hard to reach groups which include very frail or housebound older people, BME elders or older people with mental health problems.[29]

- The Audit Commission in 2012 found that good information and advice for people who use services can reduce the time spent by staff responding to telephone calls. Information can be confusing and badly coordinated. It found one example of a council had producing over 70 advice leaflets.[30]

There are also issues about the quality of information provision:

- Out of an analysis of 100 county council website home pages, 72 had accessibility errors, 26 listed accessibility warning and only two had a clean bill of health[31]

- A research project in October 2007 revealed that 43% of enquiries to the adult social care contact centre in Stockport were not, in fact, related to adult social care. The remainder could have been reduced by improving the quality and accessibility of information on the website.[32]

25 *Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 47*
26 *Transforming Adult Social Care: Access to Information, Advice and Advocacy, IDEA, Feb 2009 p.23*
27 *Online Government Services and the Offline Older Generation, Fujitsu / Age UK, July 2011 P. 7*
28 *Online Government Services and the Offline Older Generation, Fujitsu / Age UK, July 2011 P. 21*
29 *Audit Commission 2004 in FirstStop Evaluation Phase 2 Source Document, Cambridge Centre for Housing and Planning Research, June 2011, P.11-13*
30 *Reducing the cost of assessments and reviews: An adult social care briefing for councils, Audit Commission, August 2012, P.24*
31 *Online Government Services and the Offline Older Generation, Fujitsu / Age UK, July 2011 P. 10*
32 *Reducing the cost of assessments and reviews: An adult social care briefing for councils, Audit Commission, August 2012, P.25*

- National level websites (eg Carers Direct's service directory) can have problems with:[33]
  - too many results – not able to find what you need
  - not enough local information for people to judge relevance

"If you're looking for a personal assistant, where do you go? If you're looking for a service without a form of accreditation, there is nothing to say "this is what they offer and they're good"." – Microprovider, Nottinghamshire[34]

Some user groups experience more issues than others:

- Notably, a national annual survey of social care users shows that non-white groups say they find it harder to get the information they need[35]

- 41% of social care users say they found choosing difficult. The people who find it difficult to exercise choices tend to be women, non-white, renters rather than owners and people who are not working.[36]

4) The availability and quality of council social care information services and assessments is patchy

Local authorities should be a natural and logical starting point for individuals who have care needs. But initial contact can be poor and access to assessment patchy, particularly for those who present as obvious 'self-funders'.

The problem starts with lack of awareness of the role of councils. A survey from 2010 suggested that 42% of people did not know that local authorities offered a free assessment of a person's social care needs.[37]

Even if they are aware, many older people in particular have a strong sense of fairness and don't want to feel they have to 'fight' for support, or even an assessment that they would otherwise expect to receive from their local authority.[38] Sadly this is not always the case, with many people 'screened out' of the assessment process at their first contact with their local authorities social care department despite it being an obligation for local authorities to offer assessment to all local people who believe they have a need for care, as a statutory service.

33 *Review of Carers Direct Information and Advice, Department of Health, August 2012, P.12*

34 *Case study from Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 45*

35 *Personal Social Services Adult Social Care Survey, England 2010-11 (Final Release), NHS Information Centre, November 2011, P.56*

36 *Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 15*

37 *Counsel and Care, Exclusive Research Reveals Widespread Confusion over Care for Older People, 2010 in Reforming the law for adult care and support: The Government's response to the Law Commission report 326 on adult social care Department of Health / Secretary of State, July 2012 p. 16*

- Only 5 out of 150 English local authorities rated as carrying out a good or excellent exploration of needs at first contact. Only a handful rated 'good' or 'excellent' on three indices of whether callers understood the assessment, outcomes and next steps.[39]

Recent *Which?* research on those who have organised care found that, of the formal advice channels used, local authority advice performed worse than other providers on all counts of quality (independence, range of options, knowledge) apart from one (professionalism) where PCT's came last.[40]

Anecdotal evidence demonstrates that older people who are less confident in their ability to challenge a denial of assessment, or unaware of the local authorities legal obligation to assess them can be passed over, while those more assured of their rights receive the assessments they are entitled to.[41] Self funders face an even greater problem, the *"typical experience of the typical self-funder is to be told to go away"*.[42]

Fair Access to Care Services (FACS) makes a distinction between 'presenting needs' (the needs described by adults seeking social care support or made by others on their behalf) and 'eligible needs' (those needs that are assessed as falling within a council's eligibility criteria, and which should be met). FACS guidance is clear that local authorities should be able to monitor both those people whose needs are deemed eligible, and those who's 'presenting' needs are not considered eligible - characterised as 'unmet need'. However a 2006 study found that there was little evidence that information on 'unmet need' was gathered from individual assessments and that should any data exist, it is rarely used for commissioning purposes.[43]

There are variations in assessment approach according to age. The Commission for Social Care Inspection's 2008 report on the state of social care in England 2006/07 found differentiated approaches to various groups of people evident throughout the process of assessment, with 'less comprehensive information collected about older people'.[44]

Even more subtle biases also exist. LSE/PSSRU research showed that when asked to assess the eligibility of a number of case studies of older people who might be eligible for care, care managers from councils with higher eligibility criteria tended to attribute a higher Fair Access to Care Services need than those care managers from less strict councils.[45]

38 *Lost: Low earners and the elderly care market, Resolution Foundation, 2008, P.14-15*

39 *Getting over the Threshold for Advice, Lorna Easterbrook for Independent Age, 2011, P. i*

40 *Which? Nov 2011 in Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 47*

41 *Lost: Low earners and the elderly care market, Resolution Foundation, 2008, P.14-15*

42 *Judy Downey, Relatives and Residents Association, in 'Self-funding social care users left in the cold by councils', Community Care, 23 February 2011*

43 *Clough, R. And Manthorpe, J. (2006), The Support Older People Want and the Services they Need. Joseph Rowntree Foundation. In Lost to the System, Melanie Henwood Associates for CSCI, 2008. P. 21*

44 *CSCI in Ageism and Age Discrimination in social care in the United Kingdom, Centre for Policy on Ageing, December 2009, P. 25*

45 *Fernández J-L, Snell T, A survey of Fair Access to Care Services (FACS) Assessment among local authorities in England, LSE PSSRU, 2012, P.26*

Those with high levels of income or assets – who are likely to be outside the financial criteria for receiving a funded care package - may not receive assessment at all. In a study looking at how local authorities deal with self funders, only 2/3 mentioned assessment.[46]

"There's also proper assessment required, because I do think assessment is an area where self funders are very badly served." – Provider comment on the experience of self funders.[47]

"[A friend] made enquiries [for me] with social services but he very soon realised that they thought – I've got a few coppers more than £23,000 – and they really didn't want to know." – Anonymous comment[48]

"For old people, it's scary to go down a new pathway, looking at residential nursing care – and the first question is "do you own your own home?" There is no choice. Lots of information, but it's difficult to wade through it. What I wanted was to keep my mother at home – but there was no support for making that decision. I had to sell her property to get a place in a home." – Carer, Trowbridge[49]

"If you are old, you are constantly asked if you own your own home, so they can wash their hands of you." – Service user, Trowbridge[50]

5) There is a lack of independent support for the assessment process

The more complex the system, the greater the need for independent support to help people navigate it with advice or advocacy. In some areas, this support may be limited or non-existent.

In social care this is a particular problem since decisions affecting care and support are, to some extent, subjective:

"Eligibility criteria are not clear and it often feels like a lottery as to whether somebody is accepted for a care package or not." – Care manager feedback[51]

The Caring for our Futures engagement exercise found evidence of this problem, noting that "many people told us that this support was not available in their local area, meaning that it was difficult for them to articulate what they wanted from their care and support".[52] However there is limited research into the need for and availability of quality advice and advocacy services for individuals who need to support to access the social care system.

46 *People who pay for care: quantitative and qualitative analysis of self-funders in the social care market, ADASS, January 2011, P. 23*
47 *People who pay for care: quantitative and qualitative analysis of self-funders in the social care market, ADASS, January 2011, P. 59*
48 *People who pay for care: quantitative and qualitative analysis of self-funders in the social care market, ADASS, January 2011, P. 74*
49 *Case Study from Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 45*
50 *Case Study from Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 45*
51 *Fernández J-L, Snell T, A survey of Fair Access to Care Services (FACS) Assessment among local authorities in England, LSE PSSRU, 2012, P.21*
52 *Independence, Choice and Control, Accompanying IA for the White Paper "Caring for our future: reforming care and support" (Annex B) Department of Health, July 2012, pg 13-14*

There is also limited research into the objectivity of needs assessments by councils (See point 4 above). However evidence from other areas suggests that supporting people to challenge decisions can make a significant difference to outcomes:

- 1995 figures showed that 58% of applicants for Attendance Allowance were successful and 64% of appeals succeeded in overturning a rejection[53]

- 1995 figures show that 40% of people appealed their Attendance Allowance decision on the basis the decision was incorrect, and additional 20% did so having been informed they may have grounds for an appeal. In total, the DWP considered at least half of appeals were 'relevant'.[54]

6) There is a lack of joined-up advice covering care and housing/benefits options

Social care has very significant overlap with the benefits system, housing and, of course, with health. Yet information and advice is often not joined-up.

The Department of Health's own analysis of the state of social care for its 2012 White Paper concluded that "The great deal of overlap between social care, health and housing means people may require access to multiple advice services/sources simultaneously. It also means that people find it difficult to distinguish which advice and information service may best meet their needs."[55] Even experienced carers say they are unsure of where to get information and advice, most replying on informal advice from other carers or a single individual (helpful social worker etc) they had come across by chance.[56]

Recent research has shown that local authorities are ambivalent about their ability to know the advice needs of their local populations[57] and that the authorities themselves identified quality assurance and sufficient marketing and accessibility as the biggest shortcomings with the information and advice that they offer.[58]

FirstStop's telephone advisors found that some people who contacted FirstStop had concerns about elderly parents who were struggling to manage at home and assumed that the only option was residential care. The telephone advisors said that many callers were unaware of alternative options such as home adaptations and care at home that would enable their parent to remain in their own home. Yet simple housing adaptations can enable continued independence and can bring large savings.[59]

53 *Evaluation of Disability Living and Attendance Allowance, DSS, SPRU, 1995. P. 225*
54 *Evaluation of Disability Living and Attendance Allowance, DSS, SPRU, 1995. P. 195-196*
55 *Independence, Choice and Control, Accompanying IA for the White Paper "Caring for our future: reforming care and support" (Annex B), Department of Health, July 2012, P. 15-18*
56 *Lost: Low earners and the elderly care market, Resolution Foundation, 2008, P.17*
57 *Transforming Adult Social Care: Access to Information, Advice and Advocacy, IDEA, Feb 2009 p.18*
58 *Transforming Adult Social Care: Access to Information, Advice and Advocacy, IDEA, Feb 2009, P.21*
59 *FirstStop Evaluation Phase 2 Source Document, Cambridge Centre for Housing and Planning Research, June 2011, P.11-13*

Another report found that people struggle to access and navigate the system, often finding it difficult to distinguish between health, housing and care services.[60] One potential cause of confusion is an overreliance by local authorities on care management teams and websites for the delivery of advice and information about options for care,[61] but who do not have enough knowledge to deliver advice and information in a joined up way.

Service users in one study described the common failure of professional staff to anticipate their information needs and to be ready to provide appropriate information as when it is needed. Some said they were given too much information at a time when they were unable to take it in, others said it was offered much too late. This indicates a clear need for better training for professional staff to enable them to understand users' information needs, how to access relevant information and when to provide it.[62]

7) There is a lack of information about service availability and quality

For self-funders and those in receipt of a direct payment, there is limited information about what care services exist and – crucially – how good they are.

"If you're looking for a personal assistant, where do you go? If you're looking for a service without a form of accreditation, there is nothing to say "this is what they offer and they're good"." – **Microprovider, Nottinghamshire**[63]

The government's Impact Assessment (White Paper) recognises both a shortage and the implications of high quality, reliable information about organisations and individuals offering care and support and the quality of that care.[64] The paper continues to say that *"High quality information and advice is essential to ensure that the care market functions effectively – not least because users and potential users cannot assess the quality of care and support services without experiencing them. Historically, the private sector has not provided the necessary information, probably because of relatively high costs and low demand, possibly driven by the fact that these are often distressed purchases".*[65]

60 *Counsel and Care, Exclusive Research Reveals Widespread Confusion over Care for Older People, 2010 in Reforming the law for adult care and support: The Government's response to the Law Commission report 326 on adult social care Department of Health / Secretary of State, July 2012 p. 16*

61 *Transforming Adult Social Care: Access to Information, Advice and Advocacy, IDEA, Feb 2009. P.21*

62 *Accessing Information about Health and social care services, Picker Institute Europe, April 2007, P. 64*

63 *Case study from Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 45*

64 *Independence, Choice and Control, Accompanying IA for the White Paper "Caring for our future: reforming care and support" (Annex B) Department of Health, July 2012, pg 15-18*

65 *Caring for our Future: Reforming Care and Support, Impact Assessment Summary Document, Department of Health, July 2012 P.17*

Another study cited evidence that poorly performing firms have a disincentive to provide accurate information about their services,[66] and others use highly complex contracts that cannot be clearly interpreted.[67] Moreover, information around quality can be subjective and may require labour-intensive collection. Investing in this research may be particularly unattractive if, as set out above, the demand for information and advice is limited.[68]

In other evidence:

● Even when there is brokerage information available for people on direct payments, it often omits details about more informal local solutions, from pooling budgets to time banks. The result is that people often have to pay more money out of personal budgets than they need to.[69]

● A recent report published by IPPR says that *"the development of choice and personalisation in social care has not been accompanied by an adequate supply of information"*[70]

● Only 1% of care home residents said that the CSCI 'star rating' of the home they chose had any bearing on their final decision[71]

● A 2012/13 review of choice identified a serious lack of signposting right across social care, from the difficulties in finding out about which

personal assistants are available locally to the quality of local care homes, but – where this information is available – it is sometimes only available informally.[72]

8) There is a lack of signposting to financial advice

Lack of financial advice, particularly for those entering care homes, is a significant problem for all involved in care – the individuals, the homes and the local authorities.

One impact of not receiving a council care assessment (see Point 4 above) is that a person may instead go directly to finding a service of their choice without any support to do so. If this service choice is a care home, the individual may enter it earlier than necessary because they lack understanding of other options, such as telecare or supporting housing.

66 *Salop, S. and Stiglitz J., 'The theory of sales: a simple model of equilibrium price dispersion with identical agents', American Economic Review, December 1982 in Independence, Choice and Control, Accompanying IA for the White Paper "Caring for our future: reforming care and support" (Annex B) Department of Health, July 2012, pg 18*

67 *Office of Fair Trading, Care homes for older people in the UK: A market study, 2005 in Independence, Choice and Control, Accompanying IA for the White Paper "Caring for our future: reforming care and support" (Annex B) Department of Health, July 2012, pg 18*

68 *Independence, Choice and Control, Accompanying IA for the White Paper "Caring for our future: reforming care and support" (Annex B) Department of Health, July 2012, pg 18*

69 *Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 44*

70 *Social Isolation Amongst Older Londoners, Clifton ed, Institute of Public Policy Research, IPPR (October 2011)*

71 *Using online reviews in social care: Lisa Trigg / Personal Social Servicess Research Unit, July 2012, P.5*

72 *Barriers to Choice Review, David Boyle, Cabinet Office UK, January 2013, p. 44*

"People are going into care homes because they didn't realise that there were all these options that they could stay home, and they've never heard of things like telecare and dom-care and live-in care (...) There's so many alternatives now that they don't know about, so they're being forced down a road because they've heard of residential homes and nursing homes and that's all they know."[73]

A further risk is that they will be making one of their largest financial outlays without any advice about the best financial product to fund this expenditure. This can lead to a 'lose-lose' scenario in which an individual chooses an expensive care home and lives in it until their assets are so depleted that they require council support, at which point the council is unwilling to pay the fees charged by the home. All the options in this scenario are bad: either the individual has to move, their relatives have to pay a top-up fee or the council has to pay more than it would like to allow the individual to retain continuity of care.

● Research suggests that 25% of self funders have to fall back on local authority funding at a later date.[74]

● Less than half of local authorities were able to confidently say they knew how many self-funders fell back on state funding every year.[75]

This problems starts because of lack of awareness of the social care system and, in particular, what an individual may be responsible for paying:

● An ICM poll on behalf of Counsel and Care, Carers UK and Help the Aged found that 87% of people had not made any plans to pay for personal care in older age, while just 5% of people had plans in place already.[76]

In addition, research suggests some degree of enduring 'market failure' in the provision of financial advice for care:

● Commercially reasonable financial advice on care is underdeveloped and 60% of people agree a national service would benefit them[77]

● In 2006, the Resolution Foundation concluded that people on low/moderate incomes are particularly poorly served by financial information unless it is offered at reasonable commercial rates[78]

● In government engagement exercises conducted in 2009, 69% of respondents said that they did not feel sufficiently informed about the financial implications of long-term care[79]

73 *People who pay for care: quantitative and qualitative analysis of self-funders in the social care market, ADASS, January 2011, P. 59*
74 *Independent Ageing: Council support for self funders, LGIU, March 2011, P. 7*
75 *Independent Ageing: Council support for self funders, LGIU, March 2011, P. 8*
76 *Counsel and Care, Carers UK and Help the Aged, Scary, depressing and confusing: Voter's view of Social Care revealed, 2008 in Reforming the law for adult care and support: The Government's response to the Law Commission report 326 on adult social care Department of Health / Secretary of State, July 2012 p. 16*
77 *Closing the Advice Gap: providing financial advice to people on low incomes Resolution Foundation, May 2006, P.4*
78 *Closing the Advice Gap: providing financial advice to people on low incomes, Resolution Foundation, May 2006, P.2*
79 *Independent Ageing: Council support for self funders, LGIU, March 2011, P. 11*

- Only 3% of councils in 2011 told the LGiU that they provide a list of independent financial advisors who could give advice about care funding products[80]

- Research by Oliver Wyman found that only 14,000 out of 53,000 self-funders received independent financial advice about funding their care.

Of these, only 7,000 received advice from an adviser with care specific qualifications.[81] The Financial Services Authority carried out a mystery shopping exercise of 42 IFAs, product providers and mortgage brokers to test the quality of financial advice for older people considering using equity release. It found:[82]

- 70% of advisers did not gather enough information about their customers before offering them advice

- 79% failed to ask whether customers had considered alternative methods of raising the required funds

- 79% failed to ask about health and life expectancy

- 64% failed to ask about future life plans (for example, moving home)

- 83% failed to ask about Pension Credit eligibility, and 74% about eligibility for other benefits

- 60% failed to ask about other debt

- 52% did not explain what would happen if the customer or their partner died or went into a residential or care home, and 57% did not explain what would happen if the customer wanted to move house later.

Despite these failings, 64% of the financial advisers involved said that the customer would be eligible or suitable for an equity release scheme.

80 *Independent Ageing: Council support for self funders, LGIU, March 2011, P. II*
81 *Independent Ageing: Council support for self funders, LGIU, March 2011, P. 12*
82 *Housing Wealth: First Timers to Old Timers, IPPR, May 2006, p.78*