

# **Shifting Sands: Contested Boundaries in Adult Social Care**

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Independent Health and Social Care Research Consultant**

**Submission for the Degree of Doctor of Philosophy by Published  
Works**

**School of Social Policy, Sociology and Social Research**

**University of Kent**

**December 2015**

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## **Abstract**

In this thesis I present a narrative that describes and analyses the contested and moving boundaries in adult social care through the lens of three enduring themes: the health and social care interface; hospital discharge and NHS continuing health care; and eligibility for adult social care. The thesis draws upon a range of my published work from 2002-2011, and this in turn reflects a wider body of work undertaken from the 1980s onwards. The thesis is developed from my work which comes from a distinctive model of independent research and analysis, combining original empirical fieldwork and evaluation with detailed policy analysis and commentary. The publications are principally derived from research studies and evaluations commissioned from me by the Department of Health; by the Commission for Social Care Inspection (CSCI), and by the Putting People First Consortium and the Social Care Institute for Excellence (SCIE).

This thesis examines the problematic boundaries between adult social care (particularly in the care of older people), and the NHS which have been in evidence since the creation of the two systems, and the extent to which these boundaries are contested and fluid over time. I argue that the location of the boundary is of great significance because of the consequences not merely for respective organisational responsibilities and budgets, but also – importantly – for individual service users and their families.

The thesis was written on the cusp of the introduction of major legislation in social care, with the Care Act 2014 due for phased implementation from April 2015. It is an opportune moment to consider how and to what extent the Act offers the prospect of stabilising the shifting sands of the landscape of adult social care.

## **Acknowledgements**

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Finally, my thanks and appreciation to my family for all their care and support, and particularly to my parents Cynthia and Terry Henwood. Sadly, my father (11 November 1929 – 1 April 2014) did not live to see me complete this work, and the thesis is dedicated to his memory.

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# **Shifting Sands: Contested boundaries in adult social care**

## **Supporting Statement**

### **1. Introduction**

The study and development of social policy – and its antecedents in ‘social administration’ - occupy a distinctive position in the UK. The development of the academic study largely paralleled the post-war emergence of the ‘welfare state’ which followed the recommendations of the 1942 Beveridge report to establish a system of national insurance to vanquish the ‘five giants’ of want; disease; ignorance; idleness, and squalor (Beveridge, 1942). The academic subject as a recognised coherent body of theory and application is therefore relatively young, dating from the post-war period and developing particularly through the 1960s and 70s; notably in the establishment of Departments such as that founded in 1950 by Professor Richard Titmuss at the London School of Economics that is widely regarded as having established social policy as an academic discipline (Titmuss, 1968). Since these early beginnings, the remit and focus of social policy as a field of study has expanded and developed as a multi-disciplinary area borrowing critical perspectives and concepts particularly from sociology, economics and political science.

In addition to the evolution of the academic study of social policy, there has also emerged a robust tradition of policy-based analysis that crosses the boundary between academic investigation, critical analysis, action research, policy development and practice. By no means all of this analysis occurs within academic institutions, and much of it is located – particularly from the 1980s onwards – within various high profile think tanks, covering all parts of the political spectrum, as well as in those espousing independence from party allegiance.

Since the 1990s there has also been a growth of independent consultants – such as myself - whose work straddles the boundaries of research, policy development and evaluation. This work has a number of characteristics which distinguish it from similar academic-based research, and while these features have strengths, they can also introduce certain limitations. In particular, my research and analysis is typically commissioned by government departments, non-departmental public bodies, and

national level care and health organisations and charities seeking answers to specific policy and practice challenges, or evidence on particular aspects of policy implementation or experience. This work is usually relatively short term (weeks or months rather than years in duration). The value of this approach is that it can rapidly generate evidence and analysis around pressing public policy concerns (both in formative and summative research inquiry), and illuminate knowledge and understanding of reform and implementation issues. At the same time, however, in working within a relatively narrow focus there is often limited scope to explore related areas of inquiry, or to develop conceptual or theoretical frameworks. Equally, the practicalities of delivering work to commissioners' specifications and within tight deadlines often limit the opportunities to shape research design and methodology.

Because this research is undertaken in a particular context, its contribution cannot be judged solely by reference to academic publications and endeavour. Account needs also to be taken of outputs to a wider 'grey' literature and expert commentary (including, for example, on-line 'blogs' and analysis for outlets including *The Guardian Professional Networks* <http://www.theguardian.com/guardian-professional> and the LSE's *British Politics and Policy*, <http://blogs.lse.ac.uk/politicsandpolicy/>), and the role played in facilitating debate, developing insight and informing policy evolution. This contribution is also demonstrated in my work, such as in providing specialist advice to the Health Select Committee, being closely involved with the development of practice guidance on hospital discharge and NHS continuing care, and in working with the Commission for Social Care Inspection (CSCI) in reviewing the impact of eligibility criteria in adult social care. All such work is undertaken against a substantial background of knowledge of wider research and experience. However, the intellectual paradigms and theoretical frameworks which underpin this work are often largely implicit given the pressing requirements of commissioners and clients to seek answers to specific questions, rather than to test and develop theoretical models. In this introduction I hope to make some of these implicit paradigms visible and subject to scrutiny.

The place of ideas and theoretical perspectives in policy analysis is important. Thus understanding why social policy develops in the direction that it does demands more than a focus on institutions and structures. Béland, for example, explores the contribution of historical institutionalism in social policy research whereby policy is

viewed against a set of assumptions about “a historically constructed set of institutional constraints and policy feedbacks” directing political behaviour (2005, P.1). However, he argues that “equal attention to ideas and institutions is necessary for the analysis of policy change.” Such a perspective can illuminate understanding of apparent paradigm shifts in policy, and underline the complex interplay “between policy ideas, vested interests and political institutions during all stages of the policy-making process” (Béland, 2005, P.15).

In this thesis I present a selection from a body of my work that has been assembled over more than three decades. My entire output includes work undertaken within academic departments (University of Bath, University of Leeds, LSE and the University of New South Wales, Sydney), work conducted under the auspices of policy think tanks, and work commissioned from me as an independent consultant by a range of bodies including government departments, non-departmental public bodies, the NHS at national and local levels, local authorities, and national charities.

The material included in this thesis (see Table 1) is characterised by original empirical fieldwork and/or detailed policy analysis. My complete body of work covers a wide range of subjects, including policy analysis and implementation support for new legislation in care and health - such as around hospital discharge practice (Henwood 1994); evaluation of specific policy initiatives, for example with NHS continuing health care review and restitution (Henwood 2004, **submitted text 2a**), and with the future of the Independent Living Fund (Henwood and Hudson 2007); and exploration of people’s experiences of using care and health services and trying to find their way through the system, including work for the Commission on Social Care Inspection, the Putting People First Consortium, and the Social Care Institute for Excellence (Henwood 2011, **submitted text 3b**).

In this thesis I have drawn together a number of pieces of work that collectively address some shared themes and recurrent issues which reflect the historical origins of two separate but related models of universal healthcare and selective, mean-tested welfare. All the work presented is concerned with aspects of adult social care, particularly care for older people. The history of this area of policy and practice is characterised by a number of tensions and uncertainties which raise wider questions about the role, remit and boundaries of adult social care, and about the respective responsibilities of



individuals, families and the state. Three intersecting areas of analysis are presented which together address enduring themes and debates that have been reflected in my work over time, these are:

- Boundaries and responsibilities at the organisational level between health and care (**submitted text 1a and 1b**).
- Hospital discharge and NHS continuing health care as indicators of contested boundaries at the operational levels of policy and practice (**submitted text 2a, and 2b**).
- And, related to this, eligibility – at the level of the individual, the determination of who gets support from adult social care and who pays (**submitted text 3a, and 3b**).

In all three areas it will be argued that boundaries are problematic, contested and fluid over time; this is the territory of the ‘shifting sands’ where the landscape is not fixed and readily mapped. Furthermore, the location of the boundaries has significant implications not only for respective organisational responsibilities and budgets, but also for individual service users and their families.

Before turning to the three themes, the relevant papers are introduced and summarised briefly in Table 1 below.

The choice of papers to include in the thesis was limited by word length, and the thesis references many more of my publications. The papers submitted were selected not only for their thematic relevance, but also to reflect three additional criteria:

- Publications in peer reviewed journals (**submitted text 1a; 2b**).
- Publications that were sole authored works (**submitted text 1b; 2a; 3b**)
- Publications resulting from major empirical work (**submitted text 2a; 3a; 3b**)

**Table 1: Publications included in submission**

<i>Text No.</i>	<i>Publication</i>	<i>Responsibility</i>	<i>Description</i>
1a	Hudson B and Henwood M (2002), 'The NHS and social care: the final countdown', <i>Policy &amp; Politics</i> , 30, 2 153-66.	Joint author.	Desk-based policy analysis drawing upon a range of research we have undertaken jointly and separately on the health and social care interface, locating this within a wider literature and offering a specific critique of the approach of New Labour to partnership and integration.
1b	Henwood M (2006), 'Effective partnership working: a case study of hospital discharge', <i>Health and Social Care in the Community</i> , 14, 5, 400-407.	Sole author.	Desk-based policy analysis of the health and social care interface using hospital discharge as a case study. The paper drew particularly upon work undertaken for the Health Select Committee inquiry into Delayed Discharges, as well as specific analysis of Reimbursement and Delayed Discharge commissioned by the Integrated Care Network (Henwood 2004b).
2a	Henwood M (2004), <i>Continuing Health Care: Review, revision and restitution</i> , Department of Health.	Sole author.	Independent analysis commissioned by the Department of Health. Empirical fieldwork undertaken in 9 Strategic Health Authorities in England (approx. one third of all SHAs) involving interviews and consultation with 120 stakeholders (SHA, PCT and local authority adult social care staff; voluntary sector representatives and independent sector providers).
2b	Glasby J and Henwood M (2007), 'Part of the problem or part of the solution? The role of care homes in tackling delayed hospital discharges', <i>British Journal of Social Work</i> , 37, 293-312.	Joint author.	Policy analysis of hospital discharge challenges and the role of care homes as part of the spectrum of services and support. The analysis drew on the empirical work of both authors, particularly Glasby (2003); Henwood and Wistow (1993); Henwood and Waddington (1998); Henwood et al (1997).
3a	Hudson B and Henwood M (2008), <i>Analysis of Evidence Submitted to the CSCI Review of Eligibility Criteria</i> , London: CSCI.	Joint author.	Analysis commissioned for the CSCI Review of Eligibility Criteria. This included reviewing written evidence submissions and responses via an online survey established by CSCI.

<i>Text No.</i>	<i>Publication</i>	<i>Responsibility</i>	<i>Description</i>
3b	Henwood M (2011), 'Journeys Without Maps: The decisions and destinations of people who self-fund', in <i>People who pay for care: quantitative and qualitative analysis of self-funders in the social care market</i> , London: Putting People First Consortium and SCIE.	Sole author.	This analysis built upon earlier work undertaken (Henwood and Hudson 2009; Hudson and Henwood 2009), and involved a retrospective qualitative study exploring the decisions and destinations of people self-funding adult social care in a range of settings.

## **Methodology**

Many different methodological approaches can be used in applied social policy research. My particular expertise has been developed in policy analysis (studying policy documents at both national and local levels and critically addressing the implementation issues they raise), and through in-depth qualitative research that seeks to explore and understand the ontological world of different stakeholders (such as commissioners and providers of services; people who use services; carers of people using services, and those who are paid care workers and health and social care professionals). This exploratory qualitative enquiry allows:

*“research to provide evidence of a unique kind such that knowledge and understanding of social phenomena, and the contexts in which they arise, is extended.”* (Ritchie, 2003 P.31)

The approach I have developed throughout my research is one of applied rather than primarily theoretical research; it is less focused on testing or generating theory, so much as with using knowledge gathered from research to understand and illuminate specific policy issues and developments. In practice, the distinction between applied and theoretical approaches is not absolute, and as Ritchie comments, there is a ‘necessary and inherent interaction between social theory and social research.’ Thus:

*“...it is suggested that all research is based on certain theoretical assumptions, even if these are implicit, unacknowledged or ill formed. Similarly, it is argued that all forms of social research can contribute to ‘theory’ by providing greater understanding of, and knowledge about, the social world.”* (Ritchie, 2003. P.25)

Exploratory qualitative enquiry is sometimes described as ‘contextual’ or ‘descriptive’ research and is focused on exploring and describing stakeholders’ understanding and interpretation of phenomena. However, this approach also includes explanatory and – at times – evaluative components in both formative and summative aspects i.e. examining and informing the implementation of policy as it evolves, and evaluating the impact and consequences of particular interventions (Scriven, 1967).

The three papers that report the findings of empirical investigation (2a, 3a and 3b) require the additional exposition of some context and explanation which is not included in the published documents. All of these studies were commissioned within tight

deadlines to explore specific policy and practice issues concerning, respectively: continuing health care; adult social care eligibility criteria, and the situation of people paying for their own care and support. The limited time for completion of the work; the need to address the specific and urgent demands of commissioners, and to ensure that findings were easily translated into policy and practice implementation recommendations, created a number of logistical constraints on the research and also limited the opportunities to influence the design and refine the sampling and methodological approaches. Table 2 summarises these considerations under the heading of ‘strengths and weaknesses.’ The methodological considerations around research design, sampling and analysis are explored below.

## **Design & Sampling**

### *i Continuing Health Care*

Paper 2a (*Continuing Health Care: Review, revision and restitution*) was commissioned by the Department of Health to provide both a snapshot and ‘deep dive’ into the progress of Strategic Health Authorities (SHAs) in developing SHA-wide eligibility criteria for continuing health care, and in reviewing decisions where people may have been wrongly denied NHS funded continuing care. The work was undertaken while SHAs were in the process of their review work and trying to meet the requirements of a Department of Health deadline for compliance.

Nine English SHAs were visited. These had been pre-selected by the Department of Health and reflected a number of criteria to provide a spread of authorities in terms of geography, as well as reflecting different degrees of complexity, and to include a mix of authorities believed to be making good progress alongside some understood to be having greater difficulty. The nine SHAs accounted for approximately one third of all English SHAs and were believed by the Department of Health to be broadly representative of SHAs generally. If there had been an opportunity for me to design the purposive sample of authorities, these variables would certainly have been included and the reasons for selecting particular authorities would have been made explicit. Moreover, given a free hand to shape the research design I would have undertaken a higher level first stage of investigation, probably by means of a survey of all English SHAs, and used the findings of this to further inform the purposive selection of a

sample for deeper investigation through fieldwork. This would have included the type of criteria identified above but would also have allowed for the identification of other factors, and could have been particularly useful in highlighting the range of practice and experience.

If there had been more opportunity to shape this exploration of continuing care review, I would also have expanded the range of stakeholder involvement. The interviewees were all engaged in developing eligibility and review systems and processes, and in conducting review panels. It would have been illuminating to also explore the process from the perspective of those service users and their family members experiencing the review and restitution system as plaintiffs. However, this was not possible and insight to people's experiences was deduced from perceptions of review staff and from patient and user group representation. The focus of the research was to meet the requirements of the Department of Health in understanding how SHAs were complying with their review of continuing health criteria, and to identify particular difficulties and successes with implementation. While interviewees indicated their sensitivity to the impact of eligibility criteria on patients and their families, greater breadth and depth of understanding could have been generated by triangulating documentary analysis, and interviews with front line and management staff, with face to face interviews with patients (or more likely with their family members).

## *ii CSCI Eligibility Review*

Paper 3a (*Analysis of Evidence Submitted to the CSCI Review of Eligibility Criteria*) arose out of previous work undertaken by myself and Bob Hudson for CSCI. The annual report on *The State of Social Care in England 2006/07* had included a 'special study' exploring the impact of increasingly restrictive eligibility criteria for social care. We found poor quality of life experienced by many people deemed ineligible for support, who nonetheless had care and support needs often going unmet (Henwood and Hudson, 2008b). In response to CSCI's report the Government asked them to undertake a wide ranging national review of FACS (Fair Access to Care Services) criteria, their application by councils and the impact on people seeking support from social care.

CSCI's review had a number of components including consultation events and engagement meetings with stakeholders. In addition, there was a call for written

evidence to be submitted, and an on-line survey was established. I was commissioned by CSCI – together with Bob Hudson – to analyse the written and on-line evidence. CSCI set the terms of reference of the call for evidence. There were just over 100 written submissions to the review, and 2,940 responses to the survey (with fully usable data from 2,884 respondents).

The on-line survey was drafted by CSCI and contained both closed (tick box) and open (free text) questions, and was informed in part by our earlier study. Some aspects of design could have been improved upon. For example, Q.5 was phrased in a way which might anticipate or lead responses by asking “was the reason why you didn’t get an assessment of your social care needs because the council advised you that you did not meet its financial criteria?” It would be preferable for the questionnaire to have explored a number of possible reasons for people not having an assessment rather than just offering this one.

Similarly, some questions were expressed in ways that were unnecessarily complex and confusing. Q.15, for example, asked people about what help they think that people get, and what help they should get. In practice this was a distinction that many respondents found difficult to discriminate.

If the work for CSCI had been commissioned differently and there had been greater scope to design the research, I would have adopted a slightly different approach. In many respects the study was structured in the opposite way to which it would ideally be designed. Instead of starting with a wide ranging overview (i.e. the review) and then exploring specific issues in further detail through in-depth case studies, this work was effectively conducted the other way around. We had previously provided the detailed analysis for the special study and the wider review confirmed and elaborated our key findings and conclusions.

### ***iii People funding their own care and support***

The third empirical study included in this thesis (submitted text 3b, *Journeys without maps*) developed out of two earlier pieces of work I had undertaken for the Putting People First Consortium which had explored the availability of information and advice for people who self-fund care and support. The purpose of this further study was to

provide more detailed investigation and understanding of the journeys taken by self-funders and how they made the decisions they did. Self-funders have been a relatively neglected subject of research until recent times and my analysis has been significant and influential in developing the evidence base on how self-funders navigate their way, although there remain many gaps in research evidence and there is a need for further investigation (Baxter and Glendinning, 2014).

This study was undertaken in two stages; the first explored the perspectives on self-funders of some provider organisations which included small and local organisations, as well as representatives of larger national groups (including BUPA, Barchester, Nestor and Abbeyfield), some of whom had been involved in the earlier studies. One of the difficulties in researching self-funders is that they are in many ways a hidden group, so providers were also used as a gateway to identifying self-funders within the sector who might be approached in the second stage of the study. Other points of entry were accessed via the Relatives and Residents Association, and through Counsel and Care. The investigation with people funding their own care was designed as a retrospective case study which used the concept of 'backward mapping' adapted from Elmore (1980). The purpose was to invite people to tell their stories and to explore with them the critical decision points in their journeys. The idea of backward mapping begins:

*“at the last possible stage, the point at which administrative actions intersect private choices.”* (Elmore, 1980, P.604)

In using the backward mapping method, it might be thought that there are risks of people inaccurately remembering the sequence of events and being uncertain about their journeys, particularly given the advanced years of many participants. In practice, however, interviewees demonstrated detailed recall of the critical events in their life which had brought them to their particular destination, and major changes of lifestyle (such as a move to residential care or sheltered accommodation) had typically occurred as a result of a crisis or sudden deterioration in health and independence.

Given that this study entailed face to face interviews with people funding their own care, there were potential ethical issues. The research was commissioned by the Putting People First Consortium which included SCIE and ADASS as partners, and the work was approved by ADASS. A consent form was designed which explained the purpose of the research, and promised confidentiality and anonymity. No one approached



declined to take part. There were risks that people could have become distressed in telling their stories, but in practice this did not happen and people generally seemed pleased to have the opportunity to reflect on their stories, and while some presented positive narratives, most were sanguine or viewed their situation with a level of resigned equanimity. When people expressed concern about future decisions or the need for information and advice, I provided them with details of sources of independent advice such as from Age UK and Counsel and Care.

The sample of self-funders was not designed to be statistically representative; in many ways it was an opportunistic or pragmatic sample derived from introductions by providers and other organisations. However, the sample *was* purposively selected to ensure it included people using a range of support, from domiciliary services to sheltered housing, assisted living and residential care. The sample was distributed across six locations in London, the south east and midlands (all areas with high concentrations of people who are self-funding because of their relative affluence and the value of their capital assets).

Qualitative samples for a study involving individual interviews often involve 50 or fewer participants in order to keep data collection and analysis manageable (Ritchie, Lewis and Elam, 2003). This study involved in-depth interviews with 30 people who were funding their own care, or with their close family members. The purposive sampling ensured that the range of experiences of participants provided a rich and diverse source of data. The majority of interviews (three quarters) were with self-funders themselves; the interviews with family members took place only where a person was unable to participate due to frailty or because they were now deceased, but where the family had been closely involved in helping them make their care arrangements. Interviews were semi-structured using a topic guide designed to explore people's journeys and key decision points.

## **Analysis**

Qualitative research generates a considerable volume of rich data; and a wide range of (at times overlapping) approaches can be taken to analysis including content analysis; narrative analysis; discourse analysis and grounded theory (Robson, 2002; Riessman, 1993; Tonkiss, 2000; Silverman, 2001; Glaser and Strauss, 1967; Strauss and Corbin,

1994). As Holloway and Todres (2003) observe, different approaches “are incredibly diverse, complex and nuanced.”

The approach I adopted with the three studies included here was primarily thematic analysis, i.e. analysing, identifying and organising the key themes, repeated patterns and concepts across the data, and using this thematic framework as the foundation for developing descriptive and explanatory accounts (Holloway and Todres, 2003; Braun and Clarke, 2006). Thematic analysis was chosen not least because it provides a flexible tool which – as Braun and Clarke (2006) point out – operates essentially independently of theoretical and epistemological approaches. Thematic analysis is a relatively straightforward approach (although it needs to be undertaken with rigour and thoroughness), and this is a particular consideration when carrying out research for policy and practice communities, rather than primarily for an academic audience.

#### *i Continuing Health Care*

In each of the 9 SHAs documentary analysis was undertaken of the development of key local policies and guidance around continuing care eligibility criteria. The approach to managing the review and restitution process was explored, and the percentage of cases granted restitution was documented. In addition to documentary analysis, semi-structured interviews and focus groups took place with approximately 120 stakeholders across the 9 SHAs. Lead staff members were identified by the Department of Health for each SHA and these were used as the point of entry and to identify other key contacts in SHAs, and respective Primary Care Trusts and partner local authorities.

All interviews were tape recorded and transcribed; thematic analysis was undertaken, identifying key issues and recurrent themes, highlighting cross-cutting topics and areas of coherence and contradiction (Ritchie, Spencer and O’Connor, 2003). A narrative was built up for each SHA providing a written case study; drafts were shared with main interviewees to check for factual accuracy and finalised versions were included in an appendix to the report. The individual descriptive accounts for each SHA informed the development of an explanatory account across the nine sites identifying both the process of review and the impact on practice and on individual patients and families.

## *ii CSCI Eligibility Review*

The submissions to the review were – by the nature of the review - self-selecting; people who were content with the operation of eligibility criteria would be unlikely to submit evidence. Those people who *did* participate in the review would have had a particular motivation and typically this was the result of poor experience of seeking help from social care services. As might be predicted, a large proportion of respondents were family carers (29%) rather than service users (11%). Perhaps more surprising was the fact that half of all respondents to the survey were people who worked in social care – either in council social services (22%) or in other sectors (28%).

The review was undertaken against a tight timetable (written evidence and on-line questionnaires returns were collected during April and early May 2008) and generated an extensive amount of qualitative information. Our analysis provided quantification of frequencies of survey responses, while thematic analysis of written submissions and of free text questionnaire responses identified major themes across the qualitative evidence and enabled voices to be heard through verbatim material.

While the Department of Health did not accept CSCI's recommendations on replacing FACS with a new model of 'priorities for intervention', our analysis, together with the wider findings of the review and recommendations concerning improved universal support, developing an outcomes-based approach, focusing on personalisation and strengthening the attention to fairness, prevention and inclusion, have all been influential and have helped inform and shape the direction of reform now incorporated in the 2014 Care Act.

## *iii People funding their own care and support*

As with study 2a, all interviews were digitally recorded and fully transcribed. Thematic analysis of all interviews was undertaken, triangulating findings across interviews with care and support providers, with the experiences of self-funders, and with carers.

It would be interesting for the study to have been expanded and conducted in a wider range of locations and involving larger numbers of people in order to explore similarities and differences of experience. As it was, within this sample the experiences were strikingly similar and people's journeys as self-funders were typically confusing,

bewildering and distressing; their destinations often the result of happenstance rather than deliberate choices.

**Table 2: Methodological Approach in 3 empirical studies**

<b>Empirical Study</b>	<b>Methods</b>	<b>Sampling</b>	<b>Analysis</b>	<b>Ethics</b>	<b>Strengths &amp; Weaknesses</b>
<i>2a Continuing Health Care: Review, revision and restitution</i>	Documentary analysis. Semi-structured interviews and focus group consultation. Total of 120 stakeholders involved.	Nine English Strategic Health Authorities (SHAs) visited, giving geographical spread and range of characteristics. Sites had been pre-selected by DH as commissioner of research.	Thematic analysis	No significant ethical issues – no direct contact with service users or their families.  All interviews were confidential and interviewees were not identified.  Case studies on each of the SHAs were shared with key interviewees to check factual accuracy.	<ul style="list-style-type: none"> <li>• SHAs reflected a range of characteristics but were not selected purposively.</li> <li>• Research provided a snapshot of experience of continuing care implementation.</li> <li>• Study gave detailed insight to implementation challenges and identified issues with enduring relevance.</li> </ul>
<i>3a Analysis of Evidence submitted to the CSCI review of eligibility criteria</i>	CSCI review invited written evidence and completion of on-line survey. Terms of reference for evidence and questionnaire written by CSCI.	Just over 100 written submissions and 2,940 completed questionnaires (fully usable from 2,884 respondents).	Frequencies of responses to questionnaire together with thematic analysis of open and free text responses together with written submissions.	No ethical issues – no direct contact with service users or their families.  Questionnaire responses were all anonymous. Written submissions were anonymised although submissions from named organisations were identified where relevant.	<ul style="list-style-type: none"> <li>• Design of questionnaire could have been improved – some questions were leading while others were unclear or overly complex.</li> <li>• Large sample of respondents provided rich qualitative data from service users, carers, and people working in adult</li> </ul>

<b>Empirical Study</b>	<b>Methods</b>	<b>Sampling</b>	<b>Analysis</b>	<b>Ethics</b>	<b>Strengths &amp; Weaknesses</b>
					<p>care services.</p> <ul style="list-style-type: none"> <li>• Self-selecting respondents – people chose to complete survey or submit evidence. Inevitable bias towards identification of shortcomings and frustrations with social care.</li> <li>• Review evidence strengthened findings from in-depth special study previously completed for CSCI.</li> <li>• Analysis was central to overall CSCI review of eligibility and influential in shaping debate around reforming Fair Access to Care Services.</li> </ul>
3b <i>Journeys without maps</i>	Semi-structured interviews with local and national providers of adult social care and with people funding their own care	Pragmatic and opportunistic rather than representative sample, but with purposive elements to select range of	Thematic analysis employed to draw out key issues across providers in relation to self-funders. With people paying for their	Research involved direct face to face interviews with people paying for their own care and support.  Work was	<ul style="list-style-type: none"> <li>• This study provided considerable insight to the experiences and journeys of people paying for their own care – an</li> </ul>

<i><b>Empirical Study</b></i>	<i><b>Methods</b></i>	<i><b>Sampling</b></i>	<i><b>Analysis</b></i>	<i><b>Ethics</b></i>	<i><b>Strengths &amp; Weaknesses</b></i>
	and support.	experiences and situations. Thirty in-depth qualitative interviews with people who were self-funding (23), or with their family members (7).	own care, a 'backward mapping' approach was used to identify individual stories of how people had made their decisions and the nature of their journeys.	<p>commissioned by the Putting People First Consortium and was approved by ADASS. All interviews were confidential and individuals were not identified.</p> <p>A consent form was designed to ensure people were happy to participate in the research, and a thank you gift voucher was given to participants at the end of each interview.</p> <p>There were potential ethical issues around people becoming distressed by recalling past events, although this did not happen. In a few cases people expressed concern about not knowing who to turn to for advice, or about their money running out. In such cases interviewees were given appropriate information about sources of advice and help.</p>	<p>area which has been relatively neglected by research.</p> <ul style="list-style-type: none"> <li>• Self-funders are a largely invisible and hard to find group, which creates challenges in designing research and creating a sample.</li> <li>• In-depth qualitative research provides a rich source of personal experience. There is a need to undertake further studies on a larger scale to explore similarities and differences between different types of self-funders and to examine the implications this has for policy and practice.</li> </ul>

## 2. The care and health boundary

The establishment of the post-war welfare state created, as noted above, two parallel systems of care. Thus the National Health Services Act 1946 created the health service, while the National Assistance Act 1948 gave local authorities responsibilities to provide residential and other services for people needing care and attention. It is this underlying and long-standing structural dysfunction that accounts for the division of responsibilities between health and social care. The separation of functions is compounded by differing governance arrangements, and by different cultures, while at the same time complex social needs necessarily cross organisational boundaries, and the combination of these factors necessitates repeated attempts to overcome or mitigate the consequences.

As Huxham has observed, “the need to work across organisations has long been recognised as a characteristic of the role of public sector managers” (Huxham, 2000). The interface between these two systems has been under strain and contested ever since their creation (Means and Smith, 1998; Lewis, 2001), and the relationship between health and care has long been seen as ‘troubled’ (Glendinning, Hudson and Means (2005). As Glendinning and Means have remarked:

*“Disputes over the boundary between health and social services for older people are not new. In England, this boundary has been both contentious and repeatedly re-negotiated and re-interpreted.”* (2004, P.437)

The boundary between NHS care (free at the point of need and funded through general taxation), and social care (means tested, charged for and with eligibility determined by local authorities) is in many ways the distinguishing feature of the organisation of care and health in England though it has parallels in other European systems. Since the establishment of the welfare state in 1948, this division has driven a fault line through care and health that has both deepened and widened over time. Disputed boundaries have been especially stark around the care of older people. Demographic pressures, particularly in the increased numbers of very elderly people, have been significant drivers in encouraging ‘cost shunting’ between agencies and the redefining of health needs as social care, and continuing uncertainty over how to distinguish between the two (Glendinning and Means, 2004).



Throughout the post-war period the redefinition of the health and social care boundary has increasingly pushed local authorities into providing for a more dependent and frail elderly population, while the role of the NHS has become more focused on acute and short term interventions and seen the parallel withdrawal from long term and continuing care.

The problematic nature of the shifting boundary was repeatedly recognised in policy attempts both to distinguish between health and social care, and to improve collaboration and joint working at the interface (Challis et al, 1988; Glendinning and Means, 2004; Glendinning, Hudson and Means, 2005). Indeed, the history of the evolution of social care policy is, I argue, in many respects, the story of shifting boundaries, of uncertain or disputed responsibilities, and of various attempts at both central and local levels to improve coordination or achieve some measure of integration.

The interface between health and social care has developed as a much-researched area over several decades. The theoretical and conceptual understanding of the interface and attempts to manage it has also evolved. Thus, the relationship in the 1970s is typically described and analysed in terms of hierarchies and bureaucracies directed by central government. From 1979 to 1997 under successive Conservative administrations the dominant model was one of markets and quasi-markets; the arrival of the New Labour government in 1997 saw a shift to networked governance and – particularly – an emphasis on partnerships (Exworthy et al, 1999; Hudson and Henwood, 2002; Glendinning and Means, 2004; Glendinning, Hudson and Means, 2005) as the expression of a ‘collaborative discourse’ (Powell and Glendinning, 2002). Indeed, partnership was a distinguishing feature of the rhetoric of New Labour and of the ‘third way’ that was neither about top-down centrally dictated policy implementation models, nor about the supremacy of the market. In reality it became apparent that this distinction was much less clearly differentiated, and quasi-markets continued to be a feature of governance models under the three successive Labour governments (Rummary, 2002).

The preferred terminology has also evolved over time from joint working, to coordination, collaboration, partnership and – latterly - integration. These are often described as points on a continuum, but both commentators and practitioners often use

the terms interchangeably and with little consistency or consensus on definitions (Huxham, 2000; Powell and Exworthy, 2002).

Despite the limited evidence for success in achieving real partnership in practice, the quest continues. Structural change and new models of integration continue to load hope and expectation onto the capacity of the machinery of partnership to bring about real transformation, while often failing to address wider cultural and systemic features which undermine such endeavour.

While there has long been recognition of the negative and often wasteful consequences of structural fragmentation, and recurrent political pledges to resolve the so-called ‘Berlin Wall’ between social care and health continue to be offered, solutions have been incremental and incomplete. There is often considerable reliance on cooperation and collaboration at the interface in an attempt to achieve seamless care, with lesser or greater success. Alternatively, reform is driven by a mistaken belief that partnership or integration can be made compulsory regardless of the context and culture within which it operates.

The historical development of policy initiatives and directives to address fragmentation between health and social care from the 1960s to the early part of the new millennium is examined in **submitted text 1a** (Hudson and Henwood, 2002). As Hudson and I explore, the range of centrally directed solutions over time can be traced from coordination to unification, and through the evolution from public sector bureaucracy, through government by the market, to partnerships and integration. Thus, the earliest attempts at health and care coordination were via a centrally driven national planning system (Ministry of Health, 1962, 1963) and the development of 10 year plans for hospital and community care services. At this stage, there was an aspiration that local services would take account of each other but plans were not formally integrated nor monitored for coherence.

The 1970s saw major structural changes brought into the NHS, and the transfer of community and public health functions from local authorities into newly established Area Health Authorities (AHAs). The structural changes threatened to fragment services and specific mechanisms were required to counteract such risks. The boundaries of the AHAs were designed to be largely coterminous with those of local authorities responsible for social care (or ‘personal social services’ in the terminology of

the time). Furthermore, new coordinating machinery was established in the form of elected member-led Joint Consultative Committees (JCCs), and officer-led Joint Care Planning Teams (JCPTs). Top-sliced NHS money (joint finance) was subsequently introduced as a budget to support projects and initiatives in the interests of both health and local authorities. There are clear similarities with current pooled budgets, just as the latest collaborative machinery (such as Health and Wellbeing Boards) has a direct line of descent from these earlier structures (Hudson and Henwood 2002 **submitted text 1a**, Hudson 1992, 2012). However, the impact of these earlier developments was limited,

*“partly because of an over-emphasis on structures and processes – a preoccupation with means rather than ends.”* (Glendinning, Hudson and Means, 2005 P.246)

But also because of scale – joint finance represented a tiny proportion of health and social care budgets and associated activity was therefore marginal.

During the 1980s, as Hudson and I argue (**submitted text 1a**), the context for joint working changed significantly. Indeed, this major change introduced a set of circumstances in which all three of the boundary themes set out above effectively collided, and which provide a case study in the impact of the law of unintended consequences. The existence of a ‘social security loophole,’ as it became known, created a significant public subsidy and a ‘perverse incentive’ that funded private residential placements for people who met criteria for supplementary benefit, without any assessment of their need for care. As has been well-documented (Audit Commission 1986; House of Commons Social Services Select Committee 1985, Bradshaw 1988; Evandrou et al 1991; Laing 1993; Fimister 1995, 2000; Tinker 1997), the loophole led to an exponential growth in the social security budget as both health and local authorities seized the opportunity to ‘cost shunt’ from their own limited and stretched budgets to the non-cash limited central social security budget.

The growth of private sector residential and nursing homes was initially welcomed by the then government for whom it seemed ideologically consistent with support for the market and privatisation. Little or no attention was paid to whether this growth of residential care was desirable or rational as a response to the needs of an increasingly ageing population, and others needing long term care and support, nor to the fact that

this privatisation was in fact being paid for by subsidy through public expenditure. However, as Fimister comments,

*“...the rosy glow of spreading privatisation gave way in a few short years to the clanging of alarm bells as benefit costs soared.”* (Fimister, 2000, P.154)

Quite apart from the fiscal imperative to control the demands on public spending, and the ideological case for challenging the model of care, the situation also had an impact on health and care relations. As Hudson and I pointed out, a further damaging consequence of the loophole was to make the need for a tranche of joint working totally redundant; difficult coordination processes could be readily circumnavigated, as we remarked:

*“...the policy had also dealt a severe blow to the fragile arrangements for joint working between the NHS and local authorities, which could now simply be bypassed. Acute hospitals seeking to discharge older people who were ‘blocking beds’ and long stay hospitals wishing to reduce in size or close completely now had an alternative to painstaking negotiation with the local authority – an alternative that was cost free to the NHS and required no assessment of need other than that of a financial nature carried out by the then DHSS.”* (Hudson and Henwood, 2002, P.156, **submitted text 1a**)

A review of community care commissioned from Sir Roy Griffiths was an attempt to manage both the financial and organisational arrangements for community care, but was undoubtedly driven primarily by the necessity of capping the cost of the escalating social security budget. The Griffiths report (1988) was dismissive of the recurrent attempts by central government to secure local coordination of care and health, seeing them as “the discredited refuge of imploring collaboration and exhorting action” (para 27). Rather than relying on goodwill and commitment, Griffiths recommended clearer lines of responsibility *and* accountability. The Griffiths recommendation that payment of the ring-fenced community care grant would be conditional on community care plans being submitted that demonstrated shared commitments was not adopted by government, and in retrospect was naive in believing that any plan would provide evidence of the requisite joint commitment, and would have introduced unnecessary bureaucracy and paper-chasing.

The 1989 White Paper *Caring for People*, and the subsequent 1990 NHS and Community Care Act largely (albeit reluctantly) accepted the Griffiths model in giving lead responsibility for community care to local authorities. The White Paper acknowledged that the record of joint planning and collaboration had been mixed:

*“A modest success can be claimed if judged against realistic criteria but it nevertheless falls short of the aspirations of the mid-1970s.”* (Department of Health, 1989, para 6.9)

While the Secretary of State for Health claimed the White Paper offered ‘a fresh approach to collaboration and joint planning’ (Clarke, 1989), in effect the strengthened incentives and clearer responsibilities appeared to make little difference (Hudson et al, 1997a; Henwood, 2000). In the two decades since, it has become increasingly apparent that boundaries continue to be contested. Indeed, this was anticipated at the time. The 1989 White Paper had recognised that health and local authorities would continue to need to work closely together, and particularly so in situations where “it may well be difficult to draw a clear distinction between the needs of an individual for health and social care” (Department of Health, 1989, para 4.2).

It is this blurring of definition at the margins of health and social care that creates both the need for collaboration but also provides the confusion and uncertainty that create the preconditions for disputed responsibilities and deleterious impact on people needing care and support. If it is ‘difficult’ to draw a clear line between health and social care, it is highly likely that this boundary will be contested. The policy and practice areas of continuing health care and hospital discharge both epitomise the changing boundaries and ongoing turbulent responsibilities. These themes are explored more fully later in the thesis.

The stated objectives of *Caring for People* emphasised principles that remain highly relevant and central to current policy, particularly in the pursuit of improved quality of life, and the promotion of choice and independence. Although needs and outcomes were central concerns of the reforms, it was also the case, as I have argued, that the political necessity to control the social security expenditure on residential care was a prime imperative (Henwood, Wistow and Robinson, 1996).

The period from 1990 to 1997 was one in which public sector bureaucracies were increasingly replaced by attempts to govern through the market, and specifically by separating purchaser and provider responsibilities. As we – and other commentators – pointed out, collaboration was inevitably put under pressure by the competition imperative (Hudson and Henwood, 2002; Wistow and Hardy, 1996). The different objectives of governance models introduce tensions and contradictions; quasi-markets and competition, for example, are generally held to be antithetical to collaboration and partnerships and the co-existence of these different elements is problematic. Market pressures create incentives for purchasers to define their core business narrowly and to cost-shunt responsibilities where possible (particularly where they interface with other agencies). The pressures to specify and clarify responsibilities typically saw a narrowing of remit rather than coordinated seamless activity. Certainly in the case of the NHS the incentives were to focus on episodic acute care and to withdraw where possible from areas where responsibilities were less clear and protracted – notably continuing health care.

The election of New Labour in 1997 brought partnership issues increasingly centre stage with approaches characterised both by continuity and change. The continuities certainly lay in the ongoing frustration with fragmentation and poor coordination of health and care (not surprisingly given that Labour had been highly critical of the divide while in opposition and had stated repeatedly a determination to tear down the ‘Berlin Wall’ between the two services). But the changes were evident in the language that was adopted and in the belief in the potential and reach of partnerships. The White Paper on the NHS published in December 1997 emphasised the need:

*“To integrate health and social care resources so that patients genuinely get access to seamless services.”* (Secretary of State, 1997, para 9.10)

The White Paper introduced a new statutory duty for NHS trusts to work in partnership with other NHS organisations and with local authorities for the common good. The discussion document (*Partnership in Action*) which followed in September 1998 (Department of Health, 1998) further emphasised the duty of partnership and proposed the removal of barriers by the introduction of new powers. Despite the limited grounds for optimism given past experience, the new partnership agenda was ambitious and global in its scope, and emphasised the need to address the ‘whole system’ of health and

local government support. Indeed, partnership became the leitmotif of the Labour administration which sought to develop collaboration much more widely across central and local government, and framed this in terms of the ‘modernisation’ agenda and ‘joined up government.’

The 1999 Health Act introduced the new (Section 31) ‘flexibilities’ that it was claimed ‘swept away legal obstacles’ to joint working and creating options for pooled budgets, lead commissioning and integrated provision. These would be voluntary arrangements, but the NHS plan of the following year signalled the need for ‘fundamental reforms’. Observing that

*“The 1948 fault line between health and social care has inhibited the development of services shaped around the needs of patients.”* (Department of Health, 2000, para 2.23).

Apparently frustrated by the slow progress with the Section 31 flexibilities (albeit that they had only come into being in April 2000), the NHS plan stated that it would become ‘a requirement’ for the new powers to be used in all parts of the country. As we argued ‘compulsory partnerships’ were to become an increasing feature of New Labour’s model (Hudson and Henwood, 2002). The NHS Plan proposed to establish “a new level of primary care trusts” that would enable health and social services as “new single multi-purpose legal bodies to commission and be responsible for all local health and social care” (Department of Health, 2000 para 7.9). These new bodies would be known as a ‘Care Trust’ and would provide a mechanism for all localities wishing to integrate arrangements more closely. As the Plan described, a Care Trust:

*“will usually be established where there is a joint agreement at local level that this model offers the best way to deliver better care services.”* (para 7.10)

Somewhat surprisingly, however, it was also stated:

*“Where local health and social care organisations have failed to establish effective joint partnerships – or where inspection or joint reviews have shown that services are failing – the Government will take powers to establish integrated arrangements through the new Care Trust.”* (para 7.11)

The threat of compulsion was reinforced by the Secretary of State addressing the Annual Social Services Conference in October 2000:

*“There is a choice. Partnerships, including Care Trusts, can be established by you – or they will be established by me.”* (Milburn, 2000)

In the event, the subsequent Health and Social Care Act 2001 permitted the establishment of Care Trusts but did not include the power for these bodies to be imposed.

As we argued, the evolution of New Labour’s approach to partnership revealed some fundamental tensions and contradictions. Far from offering a ‘Third Way’ that broke with the earlier dichotomy of hierarchies and markets, the increasingly mandated partnership model signalled an apparent return to hierarchical control (Hudson and Henwood, 2002). Clarke and Glendinning’s analysis of New Labour’s governance of welfare similarly concluded that the development of partnerships and ‘networked governance’ was a slow, partial and uneven process, creating some unexpected and inconsistent arrangements:

*“New Labour’s ‘compulsory partnerships’ exemplify this compound and contradictory outcome – intense central power that directs and reinforces local ‘autonomy’ and ‘working together’.”* (Clarke and Glendinning, 2002, P.45)

The complex and dynamic nature of modern governance and the ‘new partnerships’ required by the interdependencies of ‘wicked issues’ (Clarke and Stewart, 1997) sit uneasily within a hierarchical model. As we argued, the relationships in health and social care are more complex and varied, involving the public and private sectors, the voluntary sector and wider community. In such an environment,

*“Notions of ‘levels’ and ‘tiers’ of command and control, of restructuring and ‘compulsory partnerships’, are ill-suited to relationships that are more akin to spheres and networks.”* (Hudson and Henwood, 2002 P.164)

The enduring nature of the ‘troubled relationship’ (Glendinning, Hudson and Means, 2005) between health and social care has been well documented, as have the negative ramifications for continuity of care and people’s experiences of using services. The origins of the difficulties in the structural separation of services from their origins in the



1940s are well understood. The decades in between have been marked by repeated efforts to improve coordination, but the issues remain entrenched. Furthermore, different models of reform have evolved – typically analysed under the classification of hierarchies, markets, and networks – but these have blurred edges and elements of each model are to be found (or re-emerge) in each new iteration. Glendinning et al (2005) suggest that hierarchy is the most persistent feature in the health and social care relationship. Whatever the strengths and weaknesses of each approach, none has been sufficient to overcome the challenges of fragmentation and boundary dispute. Perhaps not least because the location of those boundaries has been constantly shifting and thereby increasing the points of interface and contested responsibility.

If improved coordination has been of limited effectiveness, others have argued that the solution lies not in terms of better cooperation and joint working, but that boundaries can only be aligned or removed by structural integration. Instead of ‘compulsory partnership’, this is the territory of ‘compulsory restructuring’ (Henwood and Hudson, 2000 Hudson and Henwood, 2002. P.160). The assumption of advocates of integration is that removing organisational, funding and governance boundaries will thereby resolve disputes and contested responsibilities that characterise the grey interface between services. The reality is likely to be far more complex.

The Health Select Committee, for example, conducted an inquiry into the relationship between health and social services and identified the underlying structural obstacles, concluding that despite the developments around partnership:

*“..we consider that the problems of collaboration between health and social services will not be properly resolved until there is an integrated health and social care system (...) we believe it is the only sensible long-term solution to end the current confusion.”* (Health Select Committee, 1998, para 68).

A belief in structural solutions is likely to be as misplaced as the faith in partnerships alone offering a complete solution, and is a further reflection of a hierarchical approach which assumes a top-down directive model can change organisational behaviour. Glasby et al (2011), for example, point to the limits of structural change, not least because of the blight on service development, the high cost of change, and the disruption to services, inter-agency networks, staff and people using services. As they

comment wryly, the evidence seems to make no difference to repeated political attempts at structural reorganisation:

*“Unfortunately, all the available evidence suggests that lessons from research are not heeded in practice when debating future reforms.”* (Glasby et al, 2011, P.6)

Other voices have asserted that the solution is neither wholly in partnership nor in integration, but – as the NHS Confederation has argued, for example, the best approach “would be a single assessment and single resource allocation mechanism. This means a single commissioning process” (Thornton, 2000). What is increasingly apparent with the rise of personalisation – initially in social care but now spreading to personal health budgets – is that this commissioning process need not reside solely at organisational level but can be vested in the people actually using services (Glendinning et al 2000; Glendinning et al 2008). As Hudson and I have argued, self-directed support and individual budgets potentially offer a new model for integration:

*“(…) in some respects, the personal budget agenda is an alternative model of integration to the traditional approaches that have centred on inter-agency and inter-professional coordination. Whereas the latter consists of a range of attempts (often unsuccessful) to persuade or cajole various agencies and groups to pool resources and expertise, personal budgets propose a new driver for integration – the individual service user, with support where necessary.”* (Henwood and Hudson, 2008a, P.16)

More recently, the ‘Five-year forward view’ for the NHS presented by Chief Executive Simon Stevens in October 2014 demonstrated that the partnership and integration agenda is as much about internal boundaries as it is about external:

*“The NHS will take decisive steps to break down the barriers in how care is provided between family doctors and hospitals, between physical and mental health, between health and social care.”* (NHS, 2014, P.3)

According to the ‘forward view’, the challenge is about developing radical new care delivery options because:

*“The traditional divide between primary care, community services, and hospitals – largely unaltered since the birth of the NHS – is increasingly a barrier to the personalised and coordinated health services patients need.”*  
(NHS, 2014, P.16)

While few would argue with the diagnosis of the problem, nor with the importance of ‘dissolving’ these traditional boundaries that impede service integration and cohesion, this is not merely a structural issue that will be solved by new models of service organisation and delivery. The conclusions and experience from several decades of attempts to improve coordination and create a seamless care experience for patients and their families, all point to the power both of structure *and* process factors.

Structural, legal and organisational arrangements can make joint working more or less complex, but no such change or easing of boundaries will be sufficient. As we concluded in a major study of inter-agency collaboration in the late 1990s:

*“The real issue – whether at professional or organizational level – is whether or not there is a willingness to align decisions. And this is as much a question of politics, personalities and culture, as legislation and finance.”* (Hudson, Hardy, Henwood and Wistow, 1997b, P.30)

It is this multiplicity of structural and process variables, and the apparent inability of much government policy to address both dimensions with equal fervour, that has failed to resolve the challenge of partnership but has also ensured it remains an elusive objective – always just over the horizon but tantalisingly beyond reach.

A belief in structural or bureaucratic reform offering a way forward has been termed the ‘optimistic’ tradition (Challis et al, 1988), or the ‘naive’ approach (Booth, 1988). As Hudson et al comment, this reflects a presumption both of rationality and of altruism:

*“The presumption of rationality is the belief that organizations will collaborate where it can be shown that they can achieve the same ends more efficiently by working together rather than separately (...). The presumption of altruism is the belief that organizations will collaborate purely for the good of the community they serve. There is therefore an assumption that consensus about ends and purposes is readily attainable between separate organizations.”* (Hudson et al, 1999, P.236)

The case for partnership working is usually assumed to be self-evident. The argument is made that partnerships produce better integration of services; a more ‘seamless’ experience for people who use services, and for their carers; and better use of resources. Glasby et al (2011) point out that this often goes unchallenged and that the virtues of joint working can be an act of faith:

*“..emphasising the perceived virtues of partnership without necessarily citing any evidence for the claims made.” (P.2)*

Dowling et al (2004) also examined the significant growth of interest in partnership under New Labour and the shift towards making partnership not just an option, but a requirement (Greig & Poxton, 2001, Knight et al, 2001). This enthusiasm for partnership did not appear to be evidence-based:

*“..while there is no shortage of theoretical frameworks within which to understand partnerships, or of guides to successful partnerships, evidence of success remains elusive. Although the theoretical advantages of partnerships have been well rehearsed, evidence about their benefits is thin.” (Dowling et al, 2004, P.310)*

Dowling et al point out that many evaluations of partnership focus primarily on the *process* of partnership (i.e. the nature of partnership working and the relations between partners), rather than on the *outcomes* in terms of improved services or quality of life or well-being for service users. Similar conclusions have emerged from analysis of structural integration models (Ramsay, Fulop and Edwards, 2009). Cameron and Lart’s review of joint working between health and social care also found the majority of studies looked at the processes of joint working and the perceptions of those involved:

*“Very few of the studies looked at either the prior question of why joint work should be seen as a ‘good thing’ and therefore why it should be done or at the consequent question of what difference joint working made.” (Cameron and Lart, 2003. P.15)*

In effect, joint working, partnership or integration are often ends in themselves rather than the means to broader ends, and specifically the improvement of outcomes for service users. The Audit Commission (2009) reached similar conclusions in its review of joint financing arrangements observing that:

*“It is difficult to identify the extent to which pooled funds and other joint financing arrangements have directly achieved better value for money or have made a tangible difference for service users (...) The national and local focus has tended to be on process rather than outcome.”* (Audit Commission, 2009, para 71)

Despite the potential of joint working mechanisms and the aspirations for achieving integration, most commentators conclude that outcomes failed to meet expectations and achievements were modest (Nocon, 1994), or “at best marginal” (Hudson, 2012). If the evidence base for partnerships is ‘sparse’, it does not necessarily follow that such objectives are obsolete, but rather it underlines the need for further research to examine what works best ‘for whom and in what circumstances?’ (Glasby et al, 2011).

There is no denying that the health and care interface remains problematic, and while there are grounds to be sceptical - or at least agnostic – around some of the articles of faith about the achievements of partnership, there is a wealth of research evidence on the process factors that help or hinder partnerships (Hudson et al, 1997a). The latest iteration of integration policy is emerging under the banner of devolution, with Manchester the standard bearer for the ‘Northern Powerhouse’ and the ‘devo Manc’ model of devolving power and finance for health and social care. As with previous initiatives, the evidence for embarking on such a path is far from clear and there are many issues that challenge governance and local democracy (Hudson, 2015).

A major empirical study of interagency collaboration in the mid-1990s, in which I was one of four principal investigators, concluded that a measure of consensus emerged from the research literature concerning the key principles that need to be at the heart of strengthening strategic approaches to collaboration (Hudson et al 1997b; Henwood et al 1997; Henwood 2000). Four such factors appeared to be particularly important:

- Shared vision about the purpose of collaboration and the outcomes sought.
- Clarity of roles and responsibilities.
- Appropriate incentives and rewards.
- Accountability for joint working.

Hudson et al examined this framework against four key areas of joint working of the time: community care planning; joint commissioning; primary care and social care interface; and hospital discharge and continuing health care. It was only in the last of these that – as I have argued - all four principles “could be seen to be relatively well developed and coherently expressed” (Henwood, 2000 P.171). Indeed, hospital discharge and continuing care was – at the time - seen to provide a case study in mandate and accountability. It is worth exploring this particular interface, and it is to this topic that the thesis now turns.

### 3. Hospital Discharge and NHS Continuing Care

Boundary disputes at both individual and organisational levels crystallize especially starkly around hospital discharge and continuing health care, particularly in the care of older people. As I argue in paper 1b the process of discharging patients from hospital “provides a critical indicator of the state of partnership working between health and social care agencies” (Henwood 2006, P.400 **submitted text 1b**). The fact that problematic discharge has been identified for at least the last 30 years effectively mirrors the collaborative challenges of the structural divide across health and care throughout the period. Many of the solutions and strategies developed to address discharge difficulties have focused on professional responsibilities and establishing appropriate coordinating mechanisms, while failing to address the underlying organisational and structural causes of fragmentation of which discharge issues are merely a symptom or indicator. As Glasby remarks:

*“Throughout, there has been an ongoing failure to recognise that the problematic nature of hospital discharge is not necessarily the fault of individual workers or agencies, but embedded in a system based on a rigid but highly debatable demarcation between health and social care.”* (Glasby, 2003 P.129)

As noted earlier in the analysis above, prior to the NHS and Community Care Act of 1990 the existence of the ‘social security loophole’ effectively provided a safety valve in the health and social care system enabling patients to be fast tracked from hospitals to care homes by exploiting the availability of ‘board and lodging payments’ through Supplementary Benefit. As Glasby has observed, although it is hard to be certain it seems likely that a considerable number of (mainly older) hospital patients were “prematurely admitted to institutional forms of care” not because they needed 24-hour care “but because they simply did not need to be in hospital” (Glasby 2003, P.20). The issue of delayed discharges was effectively largely concealed by the existence of the social security loophole, but the need for good procedures and arrangements took on a pivotal importance with the 1990 NHS and Community Care Act (Henwood and Wistow 1993; Henwood et al 1997; Henwood 2006).

Recognition of the key role of effective discharge arrangements came relatively late in the preparation for implementation of the (delayed) community care reforms. However,

the publication of the 'eight key tasks letter' by the Department of Health in March 1992 put 'clarifying and agreeing arrangements for continuing care', and 'ensuring the 'robustness and mutual acceptability of discharge arrangements' high on the list of requirements in order to achieve 'smooth transition'. A second letter in September underlined the importance of the tasks and the need for further progress, with all local authorities needing to have reached agreements by 31 December 1992 on strategies for placing people in nursing homes, and on the integration of hospital discharge arrangements and assessment. Evidence of such agreements was made a condition for payment of the Community Care Special Transitional Grant (introduced to support implementation of the Act).

This highly directive approach to ensuring that – at least in principle - local agreements on managing the hospital and community interface existed can be seen as a particularly clear instance of hierarchical attempts to manage complex service responsibilities and potentially disputed boundaries. Henwood et al describe the increasingly clear requirements that were attached to discharge arrangements between the publication of the White Paper in 1989 and the implementation of the new legislation in 1993 and offer two conclusions:

*“First, was the realisation of the centrality of hospital discharge to the business of both health and local authorities, and the potential for major destabilisation to develop (...) Second, the development of local agreements could not (...) be left simply to local good will and understanding.”* (Henwood et al 1997, P.11)

In 1994 the Department of Health issued *The Hospital Discharge Workbook* (Henwood 1994) which was not new guidance, emphasising that policy remained “as set out in earlier Circulars”. However, in focusing on the responsibilities of all stakeholders and emphasising the centrality of good discharge policy and practice to the health and care system, I argued that the Workbook could be seen as:

*“A further indicator of ongoing concern about the patchy quality of hospital discharges, and the need to secure improvements in routine practice.”*  
(Henwood 2000, P.176)

Throughout the 1990s and into the new century political concern about hospital discharge was a recurrent feature (and indeed remains so). Or rather, concern focused



primarily on *delayed* discharges and the impact of this on acute hospital activity, and – to a lesser extent - on patient wellbeing. The National Audit Office, for example, reported that 2.2 million bed days were lost in delayed discharges in England in 1998/99 at a cost of £1 million a day (National Audit Office, 2000). Government strategies followed a dual approach of increased funding and reform, particularly – as I have pointed out - in three inter-related areas:

- An emphasis on developing whole systems approaches focusing on the total health and social care economy and addressing the specific needs of patients/service users, and the appropriate care pathways.
- Developing models of intermediate care at the interface of hospital and community services, both to support people following discharge, and to target people in order to avoid hospital admissions.
- Building capacity across the health and care system through additional funding, particularly associated with ‘winter pressures’ and the annual difficulties in discharging and admitting patients to acute care (known as the ‘cash for change’ programme) directed at services to reduce delays in discharge (such as intensive home care). (Henwood 2004b, P.5)

While all of these components contributed to developing solutions, it is also apparent that they were short term and incremental fixes to a more fundamental fissure between health and care systems and partners.

The community care reforms of the early 1990s failed to address NHS responsibilities for continuing health care, and it became apparent that this also had great potential to destabilise the implementation of the reforms. The same factors that had created the loophole funding residential care through social security entitlement had not only taken pressure off social services budgets, but had allowed the NHS to accelerate a long established process of disinvestment in long term care. As noted previously, clarifying and agreeing arrangements for continuing health care were one of the ‘eight key tasks’ identified in 1992, and were primarily an attempt to control the withdrawal of the NHS from continuing inpatient care (Henwood, 2004b).

The limited success of the requirements was evident in guidance issued by the NHS in 1995 that had a strong sense of desperately slammed stable doors long after the

continuing health care horse had headed for the hills. Nonetheless, the guidance attempted to draw a line in the sand and to reaffirm that:

*“The arrangement and funding of services to meet continuing physical and mental health needs are an integral part of the responsibilities of the NHS.”*  
(Department of Health, 1995, para 1)

As I argued in Paper 2a, the guidance provided a clear statement of the responsibilities of the NHS for long term care, and might be seen as a tacit admission that some health authorities at least had gone too far in moving away from long term care (Henwood 2004b **submitted text 2a**). Because both the NHS and local authorities have responsibilities in relation to continuing care, the guidance emphasised that “collaboration is crucial to ensuring the effective and integrated delivery of care”. Moreover, the community care reforms were believed to have “strengthened further the need for joint working.” The apparently limited success of such joint endeavour, and the necessity for the guidance, had been highlighted in a report from the Health Service Commissioner the previous year on the failure of Leeds Health Authority to make available long term care for a patient who no longer required acute health care, but did need full time nursing care (Health Service Commissioner, 1994).

The particular concerns raised by the Leeds case had also been more widely amplified by the Health Select Committee in its enquiry into long term care. As the Committee concluded, the shifting boundaries appeared to indicate that the NHS had transferred responsibility to independent nursing homes, and thereby to other budgets and to individuals and their families:

*“Whether those residents now in nursing homes would in the past have been cared for in NHS long stay wards is difficult to establish firmly – but from our own experiences of visiting patients in nursing homes we would be surprised if this was not the case.”* (Health Select Committee, 1995, para 18)

In 1996 an executive letter (*Funding for Priority Services*) set out arrangements for targeting resources at a number of key objectives, including “tackling delayed discharge as part of the commitment to continuing care” (Department of Health 1996). The ‘Continuing Care Challenge Fund’ was introduced to avoid inappropriate admissions, enable safe discharges, and avoid readmissions. The Fund allocated money to health

authorities, and enabled money to be transferred to local authorities to support joint schemes.

The incoming New Labour government continued in much the same manner as its predecessor, with a continued focus on winter pressures and an emphasis on integrated planning and action across health and social care. New requirements for 'Joint Investment Plans' for services to meet the 'continuing and community care needs' of the local population followed, largely in response to central monitoring indicating problems with continuing care implementation.

This pattern of incremental adjustment and targeted funding continued to characterise the approach to hospital discharge and continuing care, but increasingly this was also accompanied by stronger arrangements to monitor, review and hold to account local performance (with delayed discharges being a key performance indicator). Nonetheless, problems remained and reducing delayed discharges (or – more pejoratively - in the language of many policy documents of the time, ending 'bed-blocking') was a recurrent feature. It is not surprising, perhaps, that this area of practice proved so difficult. As I commented in 2000, the area of hospital discharge:

*“can be identified as one in which the boundary between health and social care, and the need for clarity of respective responsibilities, is especially stark (...). Examples of 'cost shunting' and of otherwise stumbling across the 'Berlin Wall' between the two agencies are still legion in this area.”* (Henwood 2000, P.183)

In April 2002 a major shift in the Government's approach to tackling delayed hospital discharges took place. Although strategies to reduce delayed discharges had apparently been achieving some success and numbers of recorded delays were falling (McCoy et al, 2007), new legislation was proposed that would introduce a system of financial penalties (described as “stronger incentives in the system”) as a lever to ensure avoiding discharge delays remained a high priority. This development can be seen in the context of the foregoing analysis of joint working and demonstrates the simultaneous (and somewhat confused) adoption of hierarchical, quasi-market, and partnership models of policy implementation, with a reliance on a combination of cooperation, incentives and sanctions. Interestingly, the Department of Health presented its approach to delayed discharges as the antithesis of a top-down model which it held to be unsustainable and inconsistent with the delegation of power and autonomy to the front line in health and

social care (Department of Health, 2002). There are some obvious areas of tension between these different models, and while local agreements were vital for securing enduring solutions to delayed discharges, the policy drive was centrally directed and indeed mandated.

The House of Commons Health Select Committee's inquiry into delayed discharges (to which I was a Special Adviser) explored the reimbursement proposals and was highly critical of their likely impact and identified:

*"...real risks that perverse incentives will be created that will undermine partnerships that have taken time to develop, and foster an unproductive culture of buck passing and mutual blame between health and social care."* (Health Select Committee 2002, para 168)

The reimbursement idea was seen by the Committee as a 'crude solution' to a complex and multi-dimensional issue, and one which effectively penalised social services authorities alone for wider failings of the system and for under funding of local councils. The Committee concluded (as had its predecessor in 1999) that the problems of collaboration between health and social care evidenced in delayed hospital discharges would not be fully resolved without an integrated health and care system and "radical structural reform." (Health Select Committee 2002, para 190)

The Community Care (Delayed Discharges etc.) Act received Royal Assent in April 2003, with implementation from January 2004. Widespread hostility to the proposals during the passage of the Bill had led to compromises that enabled a longer shadow preparation period (from October 2003), supported by the Delayed Discharges Grant which transferred money from the NHS to local authorities to enable discharge capacity to continue to develop. Implementation was also supported by the engagement of the Change Agent Team – a high profile team operating nationally from the Department of Health to support policy change, and established in 2001 as part of a wider 'cash for change' initiative (Henwood, 2004c). The Act brought new duties and responsibilities for local authorities *and* the NHS. In particular, the NHS had a new statutory duty to notify social services of a patient's likely need for social care support, and to provide a discharge notification following completion of the assessment, giving a minimum of 24 hours notice. As I commented, the new duties provided:

*“an explicit recognition of the joint responsibility for ensuring timely discharges, and also of the fact that many delays in the past have been attributable to a failure of communication between health and social services.”*  
(Henwood 2004b, P.9)

The reimbursement model can be seen as consistent with the long standing policy and guidance to health and social care to improve coordination, cooperation and coherence at the boundary. However, I also identified a significant difference in emphasis and approach:

*“In place of closer cooperation, the focus is increasingly on developing genuinely joint solutions – typified through shared protocols, whole systems working, and – ultimately – pooled budgets. If health and social care economies adopt the characteristics of ‘mature systems’, the problems of delayed discharges should be minimal; conversely the costs of reimbursement payments will fall heavily on those that fail to invest in capacity development and continue to contest respective responsibilities.”* (Henwood 2004b, P.16)

Delayed hospital discharges, and particularly a recurrence of such delays with the onset of winter pressures, have been a feature of health and social care systems over many decades (Henwood 2000, 2004b; Glasby 2003; Glasby 2004; Glasby & Henwood 2007 **submitted text 2b**). The reimbursement model appeared to offer a solution that would embed good practice as the norm and reinforce joint working. Nonetheless, it was not a panacea, and any regression to old styles of operation would be likely to see a return of familiar problems. There is also some evidence that rapid (and premature) discharges have been achieved at the cost of higher readmission rates; increased patient dissatisfaction, and also an increase in admissions directly from hospital to care homes (Glasby et al, 2004; McCoy et al, 2007; Bryan, 2010). The crisis in Accident and Emergency units during the winter of 2014/15, with many hospitals declaring ‘major incidents’ as they became unable to manage demand, once again underlined the complexity of the hospital admission and discharge relationship, and capacity issues across the entire health and social care system.

The model of reimbursement was based on one that had apparently worked successfully in Sweden, Norway and Denmark. The fall in delayed discharges following the legislation in England might also be seen as a positive development, but the causal

relationship is not clear. In practice the changes in patterns of delayed discharges reflect the complex interplay of a range of factors in addition to, and alongside the fines mechanism and new procedures for multidisciplinary assessment within minimum intervals. These include the additional investment in intermediate care and rehabilitation, but also reflect the influence of changes in monitoring and reporting of delays (Manzano-Santaella, 2011). Moreover, delayed discharges were already falling and although there was a rapid decline following implementation of the Act, this appeared to plateau in 2004 (Godden et al, 2007).

The reimbursement policy can be judged to have focused attention on tackling delayed discharges, but also “to encourage shared responsibility of the problem and the forging of solutions (...) to facilitate patient journeys through and out of hospital” (Godfrey et al, 2008, P.104). This has major implications for the much wider development of rehabilitation, intermediate and transitional care, and community support and social capital.

The inability to totally eradicate delayed discharges points to factors which are not about administrative or professional inefficiency or disputed boundaries, but wider capacity issues. Godden et al identify a ‘residue’ of ongoing delays that appear resistant to change:

*“The bulk of these delays were due to waits for a nursing or residential home placement followed by delays in providing home care packages, which also implies that SSDs were unable to provide interim placements for these patients.”*  
(Godden et al, 2007. P.21)

Close monitoring of delayed discharges has been a requirement since the new legislation, and from August 2010, monthly information has been published using Situation Reports (SITREPs) from all NHS Trusts. Analysis of the data provides insight to causes of delays and – in particular – indicates that *most* delays are attributable *not* to local authority social services but to the NHS (more than two thirds). Indeed, the single largest cause of delay (more than 21%) is accounted for by patients awaiting further non-acute NHS care, which includes intermediate care and rehabilitation services (NHS England 2014). Similar proportions of delays are attributable to patients awaiting residential or nursing home placement or availability (respectively 11.5% and 11.1%).

Recurrent alarm about delayed hospital discharges frequently draws the response that the solution lies in ‘more care homes’, or that lack of capacity in long term care is a major cause of delays. The complex reasons for delay point to the need for similarly varied responses, and as Glasby and I (2007) argue (**submitted text 2b**), care homes are part of the answer, but increasingly need to become very different places and to perform a different role in rehabilitation and recuperation as part of a spectrum of services, and “as a genuinely positive choice for the few rather than the only option for the many” (Glasby and Henwood 2007 P.311,). As the 2002 Health Select Committee inquiry into delayed discharges concluded, evidence of lost capacity does not lead automatically to a case for more long term care, particularly if services are to be developed in more appropriate and responsive models:

*“While we accept that developing capacity in areas where there are shortages has a contribution to make within a wider strategy, we are concerned that too much effort is being put into developing ‘more of the same’, with insufficient attention being paid to focusing on providing the most appropriate care for people, and developing the necessary alternative service models to ensure that the right care, in the right place, at the right time is available.” (Health Select Committee 2002 P.46)*

The Community Care Act of 2003 can be seen in some respects as consistent with the adoption of quasi-market solutions to the health and care interface, and particularly with establishing a new quasi-market relationship between acute hospitals and social services through the operation of financial penalties and cross-charging (McCoy et al, 2007). In reality, and with hindsight the situation was more complex. Various studies of implementation found that local solutions developed that generally sought to avoid cross-charging, and instead chose to pursue partnership and joint agreements (McCoy et al 2007; Godden et al, 2007; Godfrey et al, 2008; Bryan, 2010; Manzano-Santaella, 2011). Furthermore, the reimbursement model did not fit well with joint commissioning and partnership objectives, and as Godfrey et al argue, it was “conceptually uncomfortable and divisive” (2008, P.105) in both attributing delays to social care, and in focusing on just a small part of the health and care system (i.e. the acute care interface).

Hospital discharge and NHS continuing care have, in recent years, often been rolled into a single set of policy issues. In particular, hospital discharge arrangements for people with ongoing support needs are required to consider eligibility for NHS continuing care prior to making any other arrangements. Continuing care focuses attention on the boundary between health and care particularly sharply, and much of the debate in recent years has pointed to the problems of distinguishing between health and care needs, the extent to which the boundary has moved away from NHS responsibilities, and the impact of this on patients and their families in paying for long term care rather than receiving fully funded NHS care.

The publication of successive government guidance on NHS continuing care was indicative of ongoing problems and disputed responsibilities, and attempts to manage local actions by central direction. The 1994 report by the Health Service Commissioner on the case of who should have responsibility for the care of a severely brain damaged patient (Health Service Commissioner, 1994) found the NHS failing in its duties. Guidance was issued in 1995 in response to the concerns raised by the Health Service Commissioner (Department of Health, 1995), and the Health Secretary of the time described the guidance as “seeking to reassert the NHS’s continuing responsibility for continuing health care and where appropriate continuing in-patient health care” (Health Select Committee, 1995). While reaffirming the responsibilities of the NHS for continuing care, and requiring all health authorities to develop eligibility criteria for such care to be operational by April 1996, the guidance also effectively redrew the boundaries and set responsibility for nursing care of chronically, but not acutely, ill patients out with the health service (Lewis, 2001).

The significance of this issue is not only in contested responsibilities between care and health agencies but between public and private funding. The changing balance can also be seen as a shift from universal to selective and conditional entitlement:

*“The cumulative impact of these changes has been to shift the balance from a universal service free at the point of delivery – albeit dominated by professional medical and nursing concerns – to a selective, residual and discretionary service domain, in which bureaucratic and procedural processes now exert additional influence over access to and levels of provision.” (Rummary and Glendinning, 1999, P.339)*



The means-testing of social care has enormous implications for people who use long term care services; rather than access being determined by ‘need’ or other universal principles (such as with access to health care through the NHS), access is mediated by ability to pay. In place of any ‘rights’ to universal health care, access to long term social care is described by Rummery and Glendinning as “the ill-defined and highly contingent domain of social rights” (Rummery and Glendinning, 1999, P.339). Meeting criteria for NHS continuing care (where there is judged to be a ‘primary health need’ which is substantial and ongoing) effectively provides the winning lottery ticket of fully funded care. While failing to do so can – and does – lead to paying the full costs of care where assets are above the means-testing threshold, and often necessitating the sale of the family home to release capital.

Because the needs of people receiving care either from the NHS or arranged through the local authority or paid for privately may appear indistinguishable, long term care has become a highly contentious issue in a ‘through the looking glass’ world of confusion and reinterpretation. As Rummery and Glendinning, among others, have argued, this shift from NHS to local authority responsibility for long term care can be seen as a reduction in citizenship rights (Rummery and Glendinning, 1999, P.339).

The unstable and contested boundary in long term care was underlined by the need for further guidance to be issued in 1999, and again in 2001 (Department of Health 1999; 2001). A report from the NHS Ombudsman in 2003 reviewed four complaints about NHS continuing care and highlighted deficiencies in eligibility criteria that were overly-restrictive, or were not compliant either with Department of Health guidance or with legal judgments, resulting in injustice and hardship (Health Service Ombudsman 2003). In response to the report the Department of Health required Strategic Health Authorities (SHAs) and Primary Care Trusts (PCTs) to undertake a review of continuing care criteria in use since 1996, and to establish procedures to retrospectively investigate cases where people may have been wrongly denied care, and to provide recompense where appropriate (as the Ombudsman had also recommended).

My review, commissioned by the Department of Health, of the approach and processes in a sample of around one third of SHAs found that continuing care criteria in use had sometimes been unlawful, and more generally the health service had difficulties in applying criteria consistently and explaining them meaningfully to the public (Henwood

2004a **submitted text 2a**). The review also highlighted the support which existed for moving to national criteria for NHS continuing care, although this option was not at that time under policy consideration. I identified considerable concerns across all the sites that:

*“...the review process favoured those who were best equipped to present their case (typically the middle class and articulate relatives of a deceased older person); that these cases were not typical, and may not include many of those who had been most unfairly treated by past decisions.”* (Henwood 2004a, P.58, **submitted text 2a**).

The review and restitution process that was required was (and continues to be) arduous, time consuming and costly. The necessity for such a process was purely because of the highly contested boundary between health and care, and the extent to which that boundary had been breached inappropriately and resulted in decisions that were open to legal challenge. The inquiry by the Health Select Committee in 2005 (to which I was also a Special Adviser) was deeply critical of the division between health and care in general, and of its manifestation around continuing care in particular, remarking that inquiries by successive Health Committees:

*“...have time and again been confronted by the problems caused by the current division of systems for funding and providing health and social care. Nowhere are these problems more evident than in the area of funding for continuing care.”* (Health Select Committee 2005, para 40)

The Committee argued that in practice the boundary has shifted over time such that “the long term care responsibilities of the NHS have reduced substantially”, and:

*“The question of what is health and what is social care is one to which we can find no satisfactory answer, and which our witnesses were similarly unable to explain in meaningful terms.”* (Health Select Committee 2005, para 42)

The Committee argued that long term care funding has been characterised by “confusion, complexity and inequity”, and concluded:

*“The artificial barriers between health and social care lie at the heart of the problems surrounding access to continuing care funding, and we believe that it*

*will be impossible to resolve these problems without first establishing a fully integrated health and social care system.”* (Health Select Committee 2005, para 190)

Whether a solution of this nature would resolve the issues is open to debate, and as discussed previously, the boundary problem between health and social care is not solely structural but also reflects process and cultural factors that would also need to be addressed.

Ongoing concern about variability and inconsistency in continuing health care practice led in 2007 to the introduction of a national eligibility framework and common assessment tools to support consistent decision making. Nonetheless this has not removed the underlying problem of the shifting boundary between care and health and the apparently arbitrary designation of needs. Evidence of ongoing difficulties was underlined, for example, in the 2013 inquiry by the All Party Parliamentary Group on Parkinson’s (APPGP 2013). A submission to the inquiry by the Health Service Ombudsman summarised the ‘key problem’ with continuing care in these terms:

*“The distinction between a primary need for healthcare or social care is not a clear one. There is a continuum of care needs and the threshold for achieving eligibility for NHS funding is not derived from hard fact, but from the range of subjective personal and clinical opinions of people involved with each patient.”*  
(Parliamentary and Health Service Ombudsman 2013)

The inquiry report was stronger in its critique, pronouncing the continuing care system to be “shrouded in mystery and disarray” and leaving:

*“Thousands of vulnerable and sick people with no choice but to pick up the costs of specialised care they cannot live without – with those living with long-term degenerative conditions particularly at risk.”* (APPGP 2013, P.3)

The recurrence of familiar criticisms of continuing care, and of the health and care interface, underline the enduring and pernicious effects of the divide. The issue is not just about shifting and uncertain organisational boundaries, but also about the determination of individual eligibility. This is a wider debate that provides the third strand of analysis in this thesis, as examined below.

#### **4. Eligibility and access to adult care and support**

How public resources are used and allocated in health and welfare systems throughout developed countries raises issues about approaches to both explicit and implicit rationing. In England health care is rationed in various ways, and traditionally waiting lists were a major rationing tool, while in recent times (and particularly since the advent of NICE - the National Institute for Health and Clinical Excellence) rationing also occurs through the exclusion of funding for specific treatments or procedures on the basis of expert clinical and economic judgement (Klein and Maybin, 2012). Social care is rationed differently; unlike the NHS it isn't – and never has been – a 'universal' service.

Access to adult social care and support in England is mediated by eligibility criteria and assessment processes operated by local authorities. Since the community care reforms following the 1990 NHS and Community Care Act, the way in which these systems operate has continued to be identified as problematic. Increasingly research and monitoring have found processes are complex, opaque and highly variable between councils. Attempts to improve consistency led to the introduction in 2002 of the Fair Access to Care Services (FACS) framework, but problems remained (Henwood and Hudson 2008b; CSCI 2008a). Further reforms will follow with the implementation of the 2014 Care Act, and the debate that surrounded the legislation focused both on questions of eligibility and entitlement – who gets access to care and how it is funded – and also on parallel matters about the nature of care and support and how it is provided, typically referred to by the shorthand of 'personalisation' (Henwood and Hudson 2008b; Leadbetter 2004; Lymbery 2010; Carr 2010; Needham 2011).

The evolution of adult social care policy over the past two decades can in many ways be understood by analysing the debate and changing parameters of eligibility criteria and frameworks. Eligibility is not only about who gets access to social care, but it is the mechanism by which the macro objectives of social care are delivered. It is the multiplicity of such objectives that give rise to the complexity and confusion surrounding eligibility. The reform of eligibility and the establishment of a single national eligibility threshold that will follow the implementation of the Care Act 2014 may be necessary to achieve a fairer and more coherent model (Dilnot 2011), but – as I have argued - of itself it will not be sufficient to ensure equity of access or of outcomes (Henwood 2012a).

As outlined above, the *Caring for People* reforms enacted in the 1990 NHS and Community Care Act gave local authorities responsibility for funding residential and community based care and sought to refocus support to “enable people to live in their own homes wherever feasible and sensible” (Department of Health 1989, P.5). The means to this end were to be “proper assessment of need and good case management.” Such a model was largely untested in England (Davies and Challis 1986; Davies et al 1990; Lymbery 1998; 2010) and Lymbery argues, for example, that the aspirations of a professional social work model became overtaken by an administrative managerial model with “priority given to the efficient allocation of resources” (Lymbery 1998, P.875). It was apparent that there were multiple objectives associated with eligibility criteria including managing demands and resources; achieving greater equity and meeting individual needs, and that balancing these demands is highly complex (Parry-Jones and Soulsby, 2001). The Audit Commission’s review of progress in 1996 highlighted the dominance of financial issues and the wide variation in criteria between councils. While stating that authorities needed to use eligibility as a rationing tool to keep within budget, the Commission recognised the difficulties this posed in trying to meet wider objectives:

*“In a rationing environment, how are the relatively low level needs of some carers to be balanced against the high costs of some users? What is the role of prevention in social care?”* (Audit Commission, 1996, P.34)

Such tensions and trade-offs were increasingly evident, as Janzon remarked:

*“While local authorities are viewing eligibility criteria mainly as a way of managing demand and resources, campaigning organisations still see eligibility criteria as a way of clarifying standards and achieving equitable access to care.”* (Janzon 1998, P.215)

These tensions and contradictions have expanded with new layers of objectives – such as around the personalisation agenda in social care. Successive incremental attempts to square the circle were made, with the Department of Health urging in 1998 that all councils “should have clear rules about who can get help” so that “everyone in the area gets treated fairly” (Department of Health 1998). Guidance on ‘Fair Access to Care Services’ (FACS) followed in 2002 and the establishment of a national framework for eligibility (but *not* national eligibility thresholds). The framework designated four

bands of eligibility (Critical; Substantial; Moderate and Low), but councils could set their eligibility threshold where they wished in the light of available resources (Department of Health 2002).

The apparent unfairness and arbitrariness of variability in criteria have attracted increasing attention (and been widely referred to as ‘the postcode lottery’ of care). How people experience the impact of eligibility criteria, and the consequences for those deemed ineligible, have been the focus of considerable debate within policy and practice analysis and research (CSCI 2008a; Henwood and Hudson 2008b; Hudson and Henwood 2008 **submitted text 3a**; Newton and Browne 2008).

Work commissioned by the CSCI in 2008, as part of their annual report on the state of social care, to examine the impact of FACS identified the cumulative impact of rationing by directive, by discretion and by diversion (Henwood and Hudson 2008b). The role of professional judgment (rationing by discretion) has been a recurrent theme in a range of research (Ellis et al 1999; Foster et al 2006; Charles and Manthorpe 2006; Cestari et al 2006; Fernandez and Snell 2012), and underlines the gatekeeper tensions between organisational demands and advocating for a service user, as well as the scope for frontline decision making and ‘street level bureaucracy’ to mediate top-down implementation models (Lipsky 1976; Ellis 2007, 2011; Evans 2011).

Table 3 below compares different models of rationing operating in health and social care. There are both similarities and differences between the two systems. Much of rationing in health care takes place within ‘priority setting’ which describes the allocation of resources to particular services or programmes, while rationing *per se* is about the effect of such allocations at the level of the individual (Klein et al, 1996). Klein and Maybin’s category of ‘deflection’ equates with ‘diversion’ in social care, and rationing ‘by selection’ is comparable to the ‘rationing by directive’ with FACS which effectively spells out what type of needs will be selected as eligible. Klein and Maybin observe that rationing by dilution “is the most insidious, because it is the least visible, form of rationing” (2012, P.43). Moreover, in both health and social care there are growing risks that “efficiency savings become a euphemism for rationing by dilution” (2012, P.ix).

**Table 3: Conceptualising Rationing in Health and Social Care**

<p><b><i>Rationing mechanisms in the NHS</i></b> <b>(Klein and Maybin, 2012)</b></p>	<p><b><i>Rationing mechanisms in social care</i></b> <b>(Henwood and Hudson, 2008b)</b></p>
<p><i>Rationing by Denial</i> Exclusion of specific interventions from NHS services on grounds of lack of effectiveness, high cost or both.</p>	<p><i>Rationing by Directive</i> Top down rules and procedures to locally implement national policy on FACS eligibility criteria.</p>
<p><i>Rationing by Selection</i> Patients selected who are most likely to benefit from interventions, or threshold for treatment raised.</p>	<p><i>Rationing by Discretion</i> Professional judgement and discretion intervenes to reformulate and interpret rules. Informal and individually focused case by case.</p>
<p><i>Rationing by Delay</i> Waiting lists – making patients wait for access to treatments.</p>	<p><i>Rationing by Diversion</i> Limiting demand by diverting to other parts of the system (by means of ‘signposting’) or returning responsibility to the individual.</p>
<p><i>Rationing by Deterrence</i> Other barriers to entry including lack of information, unhelpfulness of receptionists etc.</p>	<p>A dimension of rationing by diversion, particularly around pre-diversion barriers to accessibility. The existence of eligibility criteria creates belief systems about who will and will not get help. People are put off applying for support they are unlikely to qualify for or believe to be stigmatising.</p>
<p><i>Rationing by Deflection</i> ‘Shunting’ patients to other institutions, agencies or programmes.</p>	<p>Comparable to rationing by diversion, particularly around signposting and onward referral to other discretionary sources of help and support, or diverting self-funders to the private sector. The disputed territory of NHS continuing care and means tested residential/nursing care is an obvious example of rationing by deflection.</p>
<p><i>Rationing by Dilution</i> Quality of care and treatment declines with fewer staff and poorer services.</p>	<p>Overlaps with rationing by discretion and directive – squeezing and reinterpreting eligibility in order to manage demand and providing support to fewer people.</p>

In response to the annual CSCI report on the State of Social Care, the Care Services Minister commissioned CSCI to undertake a comprehensive review of FACS eligibility criteria, their application by councils with social services responsibilities and their impact on people (CSCI 2008b). Analysis of the evidence submitted to the review (almost 3,000 on-line survey responses and just over 100 written submissions), was commissioned from Hudson and Henwood and we found widespread criticism of lack of clarity and transparency, lack of fairness, prevalence of service-led approaches, neglect of the prevention and inclusion agendas; dominance of budgetary considerations and tensions with the personalisation agenda. As we commented:

*“None of the criticisms is new or unexpected, but taken together they do constitute a formidable body of dissatisfaction with current arrangements.”*  
(Hudson and Henwood 2008, P.40 **submitted text 3a**)

The evidence submitted to the review provided strong support for the analysis we had offered previously in research for CSCI (Henwood and Hudson 2008b), and confirmed our conclusions that too often people are:

*“left to flounder outside a narrowly conceptualised eligibility framework which tends to address needs only when they reach substantial or critical levels, and which has little to offer people with needs for support below this threshold (albeit that this was never an intention of the FACS framework; there have been serious unintended consequences).”* Hudson and Henwood 2008b, P.62)

Evidence pointed to shortcomings and flaws of the social care system, and particularly to the impact of tightening eligibility criteria (with most councils moving to a threshold of ‘substantial’ needs) and restricted access to care and support. The failure to find an easy remedy points to the complexity of the task, but also to the fact these failures are in large part an indicator of a much bigger question about public and private responsibilities for financing long term care that have exercised successive administrations (Royal Commission 1999; Dilnot Commission 2011).

The Dilnot Commission proposed a new model of funding to replace the current system it judged as “not fit for purpose”, recommending there should be a cap on the lifetime contribution people should be required to make to long term care, and significantly



raising the means testing threshold. The Commission's critique of the system echoed the findings of previous reviews and analysis:

*“The current system is confusing, unfair and unsustainable. People are unable to plan ahead to meet their future care needs. Assessment processes are complex and opaque. Eligibility varies depending on where you live.”* (Dilnot Commission 2011, P.11)

In place of the significant variation in eligibility, the Commission recommended there should be a single eligibility threshold set nationally. A White Paper provided the Government's response to Dilnot a year later (Department of Health 2012), and presented a 'vision for care and support' subsequently enacted in the Care Act 2014.

The question of who pays for care and in what circumstances brings the situation and experience of people who are 'self-funding' centre stage, whether these are 'pure' self-funders (paying for all their care privately); quasi self-funders (receiving third party top-ups to their residential fees paid by a local authority), or 'full' payers who pay the entire costs of care organised and contracted by the local authority (Baxter and Glendinning, 2014). Until relatively recently, understanding what happens to self-funders has been poor and largely absent from the discourse around social care beyond a recurrent concern about people forced to sell their homes to pay for care.

Henwood and Hudson's study for CSCI found self-funders "often disadvantaged and isolated" and "rather than making active choices, many appear to end up in situations as a matter of chance" (Henwood and Hudson 2008b). Subsequent research similarly found "in almost every situation it was evident that people had not made their choices in a deliberate and planned way" (Henwood 2011, **submitted text 3b**). Major life changing decisions were often made in crisis situations on the basis of little or no information or advice on navigating the complex world of care and support. Although it was – I would argue - never the intention of policy or guidance that self-funders should be left to find their own way, that has been the reality for many (Glendinning 2008; Henwood and Hudson 2008b; Hudson and Henwood 2008 **submitted text 3a**; CSCI 2008a; Henwood 2011 **submitted text 3b**; Henwood 2014). The risks of screening people out of assessment processes as soon as they are identified as self-funding and in providing inadequate signposting to other sources of help include vital lost opportunities for prevention and reablement, and premature admission to permanent residential care.

The shift in public services through the 1980s and onwards brought increasing focus on principles such as choice, citizenship and consumerism. However, it cannot be assumed that people funding their own care are able to exercise normal consumer preferences that might characterise market transactions. The market in social care is not directly comparable to other markets where people understand their requirements and preferences, and where consumerism is associated with efficiency, choice and quality - the 'voice, choice and exit' framework (Farrell, 2010). Exploring the choice directive in the provision of elective health care Exworthy and Peckham observe that:

*“The exercise of choice by patients is mediated by knowledge, resources, family circumstances, residential location and the availability of alternative providers.”* (Exworthy and Peckham, 2006, P.268)

Very similar features can be identified in respect of the social care market. Baxter and Glendinning's scoping review of people who fund their own care confirmed that while self-funders represent “a large and increasingly important proportion of the market for social care, there are many gaps in the research evidence” (P.28). Nonetheless, the evidence which *does* exist paints a picture less of well-informed consumers choosing to buy care that best meets their requirements, and more one of uncertainty and lack of meaningful choice:

*“Self-funders often approached their local authorities as the first point of contact for advice but could feel disadvantaged by their perceived unwillingness to help. They are often signposted elsewhere and not followed up by local authorities. The main information issues for self-funders living in or considering residential care were fees and finances, particularly the long term financial implications of care.”* (Baxter and Glendinning, 2014, P.i)

The cap on the lifetime contribution that people make to their own social care costs was to be introduced from April 2016. However, the incoming Conservative government announced in July 2015 that there would be a delay in implementation until 2020, citing the difficulties of local government funding as the justification. Whether the Act will ever be fully implemented is now uncertain, but the failure to resolve the long standing question of who pays for long term care is a well-trodden political path (Henwood 2015a; 2015b). Introducing the capped cost model would require local authorities to establish an independent personal budget, or a virtual 'care account' for people paying

for their own care, and recording the notional value of care the council would expect to pay to meet assessed eligible needs. The local council would have to monitor the accrued costs and when a care account reached the ceiling (set initially at £72,000), would have to inform people that they had become eligible for publicly funded support.

In practice there are many questions about how this model would function, and some commentators have pointed out that in practice many people will still pay considerably more than the cap, not least because self-funders often pay higher fees than local councils and effectively subsidise publicly funded residents (Henwood 2012a, 2014; 2015b Lloyd 2013). Consultation on draft regulations and guidance issued before the decision to delay indicated that it would take 3-4 years for most people in residential care to reach the cap, and having done so they would continue to be responsible for not insignificant 'living costs' of around £12,000 per year. Research indicates that average length of stay in residential care is around two years, with a little over a quarter of residents living more than three years (Forder and Fernandez, 2011). Most people entering residential care would therefore fail to reach their capped contribution.

The new approach to eligibility and assessment that the Care Act 2014 is intended to bring about should focus on national consistency and fairness, with national eligibility (albeit set at a 'substantial' threshold), and the likelihood of standardised assessment models being introduced. The Department of Health has restated the role of assessment in these terms:

*“Rather than acting primarily as a gateway to the adult either receiving care and support or not, the future system will place more emphasis on the role of the assessment process in supporting people to identify their needs, understand the options available to them, plan for meeting care needs and for caring responsibilities and reduce or delay needs where possible.”* (Department of Health 2013, para 1.8)

The new model potentially represents a complete reconfiguration and *could* replace a deficit model of assessment with a dynamic asset-based approach to enabling independence (Slasberg 2011; Henwood 2014). Draft guidance and regulations accordingly described the assessment and eligibility process as “one of the most important elements of the care and support system” (Department of Health 2014, P.69). Decisions about eligibility are to be made only after completion of assessment, and

similarly the assessment of financial means should follow the needs assessment “and must not affect the local authority’s decision to carry out an assessment.”

Section 72 of the Care Act 2014 allows regulations to be made to make provision for appeals against eligibility decisions by local authorities. The clause was added to the Bill during Committee Stage by the Coalition Government, recognising the need for a process for challenge without the necessity for judicial review, and acknowledging the anomaly of the absence of a formalised appeal system in care and support. The exact nature of the system has not been set out in draft regulations and implementation has been delayed. However, acceptance of the *principle* of introducing an appeals system is significant, and creates some parity with other appeals procedures in public services. Moreover, an appeals mechanism would arguably necessitate considerably more transparency in decisions about eligibility, the absence of which has been the focus of much criticism (**submitted text 2a, 3a and 3b**). The experience of appeals in NHS continuing care is instructive, and it will be important to avoid replicating processes that are biased towards the most articulate and well-informed citizens, or which prove so ineffective that a programme of review and restitution is required to redress major failings and ensure equity.

The magnitude of the cultural shift that may be required to achieve a new approach to eligibility cannot be overstated (Bottery and Holloway 2013; Henwood 2012a, 2012b, 2014). Furthermore, the new responsibilities towards self-funders and all adults seeking assessment for care and support come at a time of growing financial pressure on local councils (ADASS 2014; Barker Commission 2014). The multiple requirements of an eligibility framework will not suddenly alter the tensions and contradictions which have previously created the poor experiences and outcomes for people seeking care and support; it remains a rationing tool and this will inevitably require trade-offs and compromise of objectives. The decision to postpone implementation is the first indicator that rationing objectives continue to be predominant and overshadow wider aspirations around fairness or transparency.

## 5. Conclusions

In my work I have explored three inter-related themes and issues, all of which concern disputed and turbulent boundaries between health and social care. The thesis has explored the evolution of solutions and conceptual frameworks which have developed from managerial/bureaucratic models, through markets and quasi-markets, to partnership and integration. My work has analysed the ‘shifting sands’ of this landscape, and in particular how these have manifested and been problematic in the areas of hospital discharge and continuing health care (**submitted text 1a, 1b, 2a, 2b**), and around the questions of eligibility and paying for care (**submitted text 3a, 3b**). This thesis has drawn on a range of my published work over a considerable period, and located this within a wider research and theoretical literature.

As I have argued throughout, the need to address the interface is principally the result of the historical separation of health and personal social services, but also – and increasingly – because of the complexity of needs (particularly of older service users) which cross those boundaries and demand an integrated and coherent response. Despite several decades of addressing the interface, and different models being promoted by various political administrations, there remains little evidence for comprehensive success in achieving real seamlessness. As my work has demonstrated, solutions have typically been incremental and incomplete and have arguably failed to understand the complexities of partnership working. Thus there has too often been reliance on good will, or alternatively on mandate and compulsion. Neither model, I conclude, is likely to succeed given the complex interplay of structural, organisational, cultural, professional and behavioural variables.

At the present time new models of integration are once again in political fashion, particularly with the much heralded ‘Devo Manc’ approach to devolved responsibility for health and care in Greater Manchester, and the wider approach to regional devolution. The significance of such a development cannot yet be judged, but it has many characteristics of political opportunism and a large scale ‘quick fix’ rather than any informed, evidence-based and consensual merger.

Despite the often-stated commitment of governments to ‘evidence-based’ policy, the pursuit of partnership or integration lacks a robust foundation. My work has argued that although the theoretical case for partnership can be compelling, the evidence for benefit

is surprisingly scant. In effect, much of the pursuit of partnership has become an end in itself rather than as a means to wider ends in the form of better outcomes for people using services. This does not mean that partnership working is a failure or should be abandoned, but certainly that objectives and evaluation need to focus more precisely on what works best, for whom, in what circumstances.

I have shown how the area of hospital discharge policy and practice can be seen both as a case for better partnership working, and also as a critical indicator of the state of such relationships, and indeed of the coherence of the wider health and social care economy (**submitted text 1b; 2b**). It is the area of practice which is precisely at the boundary not just of two care systems, but often of conflicting professional and ideological models. I have analysed the growing recognition of the need to address the ‘whole system’ of social care and health and not to focus simply on the point of discharge as the problem. Accordingly, capacity building and investment in alternatives to prevent hospital admission and support post-hospital recovery have been promoted (notably intermediate care and reablement). Nonetheless, the recurrence of annual alarm over the impact of winter pressures on the capacity of acute hospitals to remain functional (apparently reaching crisis levels during the winter of 2014/15) underlines the fragility of many of these arrangements and the risks of reverting to traditional models of cost shunting and mutual blame rather than developing shared strategies and protocols.

Hospital discharge is often discussed – particularly in the care of older people – as part of a wider conundrum around continuing health care. The reduced responsibilities of the NHS in long term care have been an historical trend over many decades, and a return to a model of long stay hospital wards is neither desirable nor practical. Nonetheless, as my work has explored, how and in what circumstances the NHS should pay for long term care remains a vexed issue that is far from resolved, and remains a grey area despite the 2014 Care Act. At the level of individual patients and their families this is one of the most contentious matters that is poorly understood and relies heavily on people proactively requesting assessment and challenging decision making (**submitted text 2a**).

The apparent inequity between people who qualify for fully funded continuing care and those who do not remains highly divisive and contentious, particularly when the reasons for eligibility appear arbitrary or inconsistent. The proposed appeals system to be

introduced in care and support offers the prospect of greater fairness and transparency in eligibility decisions, although much will depend on the ability of a complainant (or their advocate) to pursue a challenge.

Questions of eligibility and access to adult social care have attracted increasing attention, particularly over the last decade. While the care reforms of the early 1990s were intended to address questions of efficiency and best use of resources it became increasingly evident that on the ground implementation has focused ever more narrowly on a tightly circumscribed group of eligible clients. Evidence from my own research and from wider sources has demonstrated that failing to meet eligibility criteria to gain access to social care often leaves people unsupported and without access to other forms of preventive intervention or universal services that might meet sub-eligible needs (Henwood and Hudson 2008b; Hudson and Henwood 2008 **submitted text 3a**; Henwood 2012b; Comas-Herrera et al 2010). The impact of this has been further complicated by local eligibility determination, and the consequent inequity and confusion in the system have been identified repeatedly.

The Care Act 2014 is the latest major legislation to attempt to address these substantial issues. In place of local eligibility models, a new national eligibility threshold is to operate, and there is an intention to change the nature of assessment to ensure a 'universal offer' of information and advice is provided at minimum. It is an ambitious objective and its success will depend critically on changing hearts and minds and bringing about wholesale transformational change in local councils struggling to balance competing objectives and resource management.

As I have demonstrated through my in-depth research on self-funders, the situation of people who are paying for their own care has often been particularly bleak with many failing to be offered any support or advice on finding care once it is discovered they have the financial means to pay for it (Henwood 2011, **submitted text 3b**). The 2014 Care Act aspires to change that by capping the amount that people should pay for care over a lifetime, and by introducing positive reasons to approach the local council for an assessment. Indeed, it could be argued that self-funding should be viewed as another form of self-directed support and that the responsibility of commissioners is to ensure the social care market works effectively for all who use social care (Miller et al, 2013).

How this will work in practice is uncertain and many practical implementation difficulties have been identified.

However, although I have argued that the care and health boundary is certain to remain contested at the level of the individual, and paying for social care is likely to continue to be widely resented and misunderstood, the latest legislation can be seen as an attempt to soften the cliff edge between the systems and to offer some assurance that people will not face unlimited liability for catastrophic care costs, as has been the case previously. The difficulties of squaring this circle have become apparent with the unravelling of the implementation of the 2014 Care Act, and postponement by four years of the introduction of capped costs which will ensure that boundaries in responsibilities between organisations and between the state and individuals continue to be both uncertain and politically volatile.

Paying for care has long been the *bête noir* of the English care and health system; various solutions have been explored but found to be politically unacceptable or publicly unaffordable. The latest reforms are open to the criticism that they fail to address the fundamental question of whether the social care and health boundary should remain at all, and whether the solution offered will in practice ameliorate the historical sense of injustice and inequity that has come to characterise this fundamental question of who can access care and support and who must pay.

I have argued that the shifting sands of adult social care have created a landscape over time in which critical boundaries between health and care, between 'free' and means-tested services, and between collective and individual responsibilities, have become blurred, widely contested, poorly understood. The consequences of this for people who use services and their families who must attempt navigation as 'strangers in a strange land' (Heinlein 1961) are frequently dismal. Whether the most substantial legislation in adult social care for a generation will prove capable of stabilising the terrain or will merely create a shimmering mirage that fails to offer substance remains to be seen.



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## **Appendix 1**

### **Supporting Statements**

Professor Bob Hudson

Professor Jon Glasby

**Melanie Henwood**

**Independent Health and Social Care Research Consultant**

**Submission for the Degree of Doctor of Philosophy by Published Works**

**School of Social Policy, Sociology and Social Research**

**University of Kent**

I am happy to confirm that Melanie and I co-authored the two following publications and that her account of our respective contributions is accurate.

Hudson B and Henwood M (2002), 'The NHS and social care: the final countdown', *Policy & Politics*, 30, 2 153-66.

Hudson B and Henwood M (2008), *Analysis of Evidence Submitted to the CSCI Review of Eligibility Criteria*, London: CSCI.

I would also like to add that we have co-authored numerous additional papers – academic, applied, official, developmental – for various government departments and other official bodies, as well as for the academic, professional and trade press. In my view Melanie is one of a small number of people in the UK who can comfortably cross academic, policy and practice audiences with her writing and reflection. Her standards of writing and analysis are impeccably high and it has been a joy for me to be a co-author. A PhD by published works is a long overdue recognition of the contribution she has made to a wide variety of aspects of social policy.

**Bob Hudson,  
Visiting Professor in Public Policy,  
School of Applied Social Sciences,  
University of Durham**

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# UNIVERSITY OF BIRMINGHAM

Health Services Management Centre

To whom it may concern,

I am writing to provide supporting evidence of behalf of Melanie Henwood as part of her submission for a PhD by publication. I have known and admired Melanie's work for many years, and am in full agreement with her account of her contribution as set out in Table 1 (pp 4-5) of her covering paper. I can also confirm that Melanie is co-author of paper 2b – indeed, the paper could not have been written without Melanie's contribution and expertise and I regard myself as very much the junior partner in this publication.

Although not my place to comment, I'm delighted that Melanie is making this submission and I can't think of anyone more deserving of a PhD by publication.

Yours faithfully,

A handwritten signature in black ink that reads 'Jon Glasby'. The signature is written in a cursive style and is underlined with a thick black line.

Prof. Jon Glasby  
Director, Health Services Management Centre  
Head of School Designate, School of Social Policy

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## Appendix 2

### Submitted Publications

- 1a Hudson B and Henwood M (2002), 'The NHS and social care: the final countdown', *Policy & Politics* 30, 2, 153-66.
- 1b Henwood M (2006), 'Effective partnership working: A case study of hospital discharge', *Health and Social Care in the Community*, 14, 5, 400-407.
- 2a Henwood M (2004), *Continuing Health Care: Review, revision and restitution*, London: Department of Health.
- 2b Glasby J and Henwood M (2007), 'Part of the problem or part of the solution? The role of care homes in tackling delayed hospital discharges'. *British Journal of Social Work*, 37, 293-312.
- 3a Hudson B and Henwood M (2008), *Analysis of Evidence Submitted to the CSCI Review of Eligibility Criteria*, London: CSCI.
- 3b Henwood M (2011), 'Journeys Without Maps: The decisions and destinations of people who self-fund', in *People Who Pay for Care: quantitative and qualitative analysis of self-funders in the social care market*, London: Putting People First Consortium and SCIE.

This is a post-peer-review, pre-copy edited version of an article published in *Policy & Politics*. The definitive publisher-authenticated version Hudson B and Henwood M (2002), 'The NHS and social care: the final countdown?', *Policy & Politics* vol 30 no 2 153-66 is available online at: <http://www.ingentaconnect.com/content/tpp/pap/2002/00000030/00000002/art00001>

## **The NHS And Social Care: The Final Countdown?**

### **Abstract**

The boundary between health and social care in England has been problematic throughout the post-war period. The 1997 Labour Government put a specific emphasis upon partnership working across these two policy areas and developed a coherent strategy for promoting the collaboration agenda. However, it has almost simultaneously turned against partnership working and in favour of restructuring as a way of securing integrated care. This has caused confusion and resentment in the field and is argued to be inconsistent with the complex requirements of governance and the management of 'wicked issues'.

**Key Words:** integrated care; partnership; restructuring; wicked issues.

### **Introduction**

Since the inception of social policy in Britain in the nineteenth century through to the way in which 'partnership' has become the *zeitgeist* of the 1997 Labour Government, ideas about working together have been important in public policy. Although the problems created by fragmentation are now more widely recognised, and the need for a shared approach is deemed more necessary than ever, the reality is that past policies have tended to be half-hearted and achievements correspondingly negligible. Using the boundary between health and social care as a case study, this article looks back at these policies and compares them with the new partnership thrust of the Labour Government. It is argued that, notwithstanding this fresh policy focus upon partnership, strategies are still characterised by a mixture of confusion and manipulation which may undermine the very objectives the policies are intended to achieve.

It is important to recognise the problematic nature of 'partnership' as a concept as well as a way of working. Aiken et al (1975) describe it as a term that is overworked, underachieved and seldom defined. While Weiss suggests that:

*"...the definitional ambiguity which makes co-ordination a handy political device has led to a chasm between rhetoric and operationalisations; co-ordination is discussed in the political arena as though everyone knows precisely what it means, when in fact it means many inconsistent things and occasionally means nothing at all."* (1981: 41)

It is not the purpose of this article to explore and discuss the multiplicity of meanings given to the term, but the key issue is the extent to which the potential partners retain the autonomy to engage in a relationship with each other. The article also explores two alternative positions – mandated partnership and unification. The working definition made by Warren et al implicitly encapsulates this dimension of autonomy, where 'collaboration' is described as:

*"...a structure or process of concerted decision-making wherein the decision or action of two or more organisations are made simultaneously in part or in whole with some deliberate degree of adjustment to each other."* (1974: 16)

## **Half A Century Together and Still Unconsummated: Inter-Agency Collaboration in the Post-War Period.**

### *Policies in the 1960s*

The early 1960s saw the first attempt to co-ordinate health and social services through national planning systems, with the introduction of ten year plans for hospital and community care services respectively (Ministry of Health 1962 and 1963). However, local authorities were merely exhorted to take account of proposed developments within hospital services, and central government had neither the means nor the inclination to ensure that the two sets of plans were brought together at local level. In any case, the initiative proved to be short-lived and the plans were not revisited after 1966, by which time the need to improve co-

ordination was becoming an integral element of a wider debate about reorganising the health service.

### *Policies in the 1970s*

The 1974 reorganisation of the NHS is significant in the history of joint working for several reasons. First, it sought - through the creation of new Area Health Authorities - to bring the different health services under the same organisational umbrella. It did this predominantly by moving most of the local health authority services out of local government and into the NHS. The list of transferred services was long, covering community health services for mothers and pre-school children, school health, vaccination and immunisation, home nursing, health visiting, domiciliary midwifery, family planning, health education, chiropody and ambulance services (Ottewill and Wall, 1990). General practitioner services, however, continued to be separately administered and funded, and remained outside mainstream NHS planning and service co-ordination mechanisms. Although this change was intended to secure a more integrated approach to the provision of *health care* services, it also had the potential to further deepen the cleavage between health and social care services, as well as other local authority services that contributed to health and well-being. In particular, the changes reduced the potential for social workers in social services departments (which had been set up in 1971) to work closely with community nurses, who now had different employers and possibly different priorities. Also the public health duties of local authorities were fragmented by the loss of the Medical Officer of Health role to the new Area Health Authorities.

To counteract these divisive tendencies, two other measures were introduced. First, the boundaries of the new AHAs were, in most parts of the country, made coterminous with those of local authorities providing personal social services. Second, the two types of authority were required to set up joint consultative committees (JCCs) composed of elected and appointed members (rather than officers) to facilitate the collaborative development of services. Parallel forums for officers (Joint Care Planning Teams) were subsequently established in 1976. These structures were to open the way to reallocation of the resources of both parties to conform to mutually agreed plans - an objective which in 1976 resulted in a further innovation, joint finance, or as the then Secretary of State for Health, Barbara Castle, described it, 'collaboration money'. This consisted of 'top-sliced'



NHS money which was allocated to AHAs for the purpose of supporting selected projects for which local authorities were bearing the prime responsibility. The money was expected to be used on projects which were in the interests of both the NHS and the local authority, and which could be expected to make a better contribution in terms of total care than if directly applied to health services. On the face of it, a new era was set to begin with a policy lead from the top and a financial incentive to kick-start change.

### *Policies in the 1980s*

If the 1970s could be said to be the policy era when the health-social care divide was both recognised to be problematic, and for which - for the first time -there was an ostensibly coherent strategy, then the 1980s was the decade when it all seemed to go wrong. At first the critique was confined to the effectiveness of the collaborative mechanisms set up during the 1970s, but the debate then became broader and contributed to the growing New Right critique of 'socialist' state welfare.

The amount of joint planning that resulted from the 1970s initiatives has generally been held to be disappointing (Nocon 1994). Part of the reason for this was argued to be the over-emphasis on structural links and processes, but in any case, the total amounts of money channelled through joint finance were relatively small – between 1976/7 and 1985/6 around £604 million had been incurred. On the other hand, Nocon suggests that the 'Care in the Community' initiative in 1983, geared to the transfer of long-stay hospital patients into the community, "*gave a new lease of life to collaborative working*" (1994: 11). This initiative permitted the transfer of both responsibility and resources for such hospital residents from the NHS to local authorities, partly through the extended thirteen year tapering of joint finance, but mainly by allowing health authorities to "*offer lump-sum payments or continuing grants to local authorities or voluntary organisations for as long as necessary in respect of people to be cared for in the community instead of in hospital*" (DHSS 1983, para.6).

At the same time, however, a more significant factor affecting the climate for joint working was growing in influence – the provision of a subsidy through social security entitlements for people who entered residential or nursing homes provided by either the private or the voluntary sector. In 1979 this subsidy was relatively minor and amounted to only £10 million, but a widening of the regulations in 1980 resulted in a

massive expansion. By early 1986 the bill had reached £459 million, with the number of residents funded by this route rising from 12,000 to 90,000 - a trend which was to go even further in the following decade. Although initially the Conservative Government of 1979 had seen this trend as a striking a blow for the privatisation of welfare (and a blow against statutory provision), the fact that this was private supply almost entirely paid for by public subsidy soon led to alarm about the rising scale of demand-led and non cash-limited public expenditure. Less obviously, the policy had also dealt a severe blow to the fragile arrangements for joint working between the NHS and local authorities, which could now simply be by-passed. Acute hospitals seeking to discharge elderly people who were 'blocking beds' and long-stay hospitals wishing to reduce in size or close completely, now had an alternative to painstaking negotiation with the local authority – an alternative that was cost-free to the NHS and which required no assessment of need other than that of a financial nature carried out by the then DHSS.

The seeming general inability of health authorities and local authorities to work together (Nocon, 1994) began to attract political interest as the 1980s progressed, with two particularly critical reports about fragmentation in community care coming from the House of Commons Social Services Select Committee (HCSSSC, 1985) and the Audit Commission (1986). The analysis of the Audit Commission led it to the implicit conclusion that the difficulties of inter-agency collaboration were such that fragmentation should be designed out of the organisational framework for community care as far as possible. Consequently, it recommended the allocation of responsibility for particular client groups to separate agencies: mental health to the NHS, learning and physical disabilities to local government, and elderly people to a single manager supervised by a joint board of health and local authority representatives (1976, para.174). The House of Commons Select Committee had advocated a similar course for mental health and learning disability services the previous year. Thus, from being the *leitmotif* of the 1960s and 1970s, within a decade collaboration was being widely viewed as an elusive chimera.

In the wake of this sustained criticism, Sir Roy Griffiths was commissioned by the Conservative Government to conduct an independent review of the financial and organisational arrangements for community care. His report denounced the approach of central government to joint working as "*the discredited refuge of imploring collaboration and exhorting action*" (Griffiths 1988, para.27), but he also

emphasised that mandatory administrative restructuring would be unduly disruptive. Rather he felt that the essential change needed was to specify responsibilities more clearly and hold authorities accountable. He accordingly proposed that effective collaboration should be a condition for receipt of a new specific, ring-fenced grant, with payment dependent upon the submission of community care plans which demonstrated appropriate commitment. The lead role in these arrangements which Griffiths envisaged for local government did not find favour with a Conservative Government intent on reducing the powers and responsibilities of local authorities, but the absence of an acceptable alternative resulted - after considerable procrastination - in a broad affirmation of this lead role in the 1989 White Paper, *Caring for People* (DoH, 1989) and the subsequent 1990 NHS & Community Care Act. Despite a record of shortcomings and failure, inter-agency collaboration was back on the agenda. However, it also was to have a strange new bedfellow - the quasi-market.

#### *Policies from 1990 to 1997*

The 1990 Act was part of a wider programme for replacing traditional public sector bureaucracies with 'government by the market'. The main principle on which these changes were based was the separation of responsibilities for purchasing and providing. Purchasing power was to remain in the hands of agencies acting on behalf of consumers - District Health Authorities in the case of the NHS, and Social Services Authorities in the case of social care - but these proxy consumers were able to choose who should provide the services. The notion of 'state welfare', based upon an implicit conflation of purchasing and providing roles was to disappear. Although the 'internal market' model in the NHS restricted most purchasing to public sector providers, the social care market model rested upon purchasing more services from the independent sector. The intention was that provider competition would provide incentives for greater responsiveness to the needs of consumers while also being more attentive to cost and quality, and at the same time purchasers would be freed from protecting the vested interests of in-house providers. As far as collaboration was concerned, the inference seemed to be that purchasers could simply require providers to work jointly through contractual obligations, and that this would be most effective where purchasers themselves acted in concert – what came to be termed 'joint commissioning'.

The introduction of markets posed a fundamental dilemma: while collaboration has long been recognised as the essence of effective service delivery in health and social care, the essence of markets is competition. Wistow and Hardy (1996) argue that the question is whether the collaborative imperative is compatible with the competitive imperative. Drawing on their work on the mixed economy of care (Wistow et al, 1996), they argue that markets add new complexities to collaboration by requiring health and local authority purchasers to manage relationships with a larger number of providers, including their own 'in-house' suppliers. However, while the collaborative imperative dictated that these purchaser-provider relationships should be based on long-term, trusting relationships, the competitive imperative required the maintenance of competition *between* providers - a difficult balancing act to achieve. Private home owners, for example, were seeking the security of a stable price and a guaranteed share of the market from local authority purchasers, whereas local authorities were encouraged to drive down costs through competitive tendering. Overall, Wistow and Hardy (1996) conclude that the introduction of quasi-markets made the management of complex inter-organisational networks more difficult.

In general, during the 1990s, the boundary between health and social care still threatened to be a focus for competition and conflict between agencies and professions, rather than for cooperation and collaboration. It was unclear that the introduction of assessment and care management would remove the differences in professional perspectives and status which had bedevilled multi-disciplinary working in the past, particularly since social services departments had no power to require the involvement of any other agency or profession in the process. In the absence of a single health and social care budget, individual care managers would be no more able to commit resources for a unified package of care than their predecessors. In addition, the distinction between health and social care responsibilities was particularly unclear in relation to the purchase of 'continuing health care' for patients with long-term support needs. *Caring for People* (DoH, 1989) stated that NHS responsibilities were unchanged by its proposals, and that Health Authorities were still expected to purchase continuing health care alongside the new responsibility of local authorities for purchasing nursing home care. Moreover, the rules of engagement of local agencies in relation to continuing care were designed to differentiate and define the boundaries of their separate responsibilities, rather than work together in more flexible partnerships. In parallel with this, Acute Trusts were

under pressure from the Department of Health to reduce waiting lists and increase throughput, as a result of which the prospect of 'bed-blocking' due to a shortage of social care facilities in the community became a potential 'hot spot'. Even where agencies were prepared to work together much more closely, there remained legal ambiguities which could restrict them. All of this proved to be fertile ground for conflict and confusion.

### **Wedding Plans Announced: New Labour and the Promise of Partnership.**

The Labour Government came to power in May 1997 with a clear view that the quasi-market approach to health and social services had been a failure, and that the key to effective service planning and delivery lay in the development of 'partnerships'. Health ministers referred repeatedly to the need to break down the 'Berlin Wall' between health and social services, and managers of both services were warned that collaboration was no longer an optional extra. The shift in values seemed to be clear; collaboration was not simply back on the agenda, but was at the very heart of new policies on health and social care in the shape of 'partnership'. Box 1 below outlines the main initiatives other than sections 29-31 of the Health Act 1999 which are separately examined.

#### **Box 1: Key Partnership Initiatives Introduced After 1997**

<b>Initiative</b>	<b>Key Partnership Features</b>
<b>Primary Care Groups/Trusts</b>	<ul style="list-style-type: none"> <li>• PCGs expected to work closely with social services on planning and delivery of services</li> <li>• PCG Boards to include social services membership</li> </ul>
<b>Duty of Partnership</b>	<ul style="list-style-type: none"> <li>• NHS bodies and local authorities required to 'work together for the common good'</li> </ul>
<b>Health Improvement Programmes</b>	<ul style="list-style-type: none"> <li>• The means to deliver national targets in each Health Authority area</li> <li>• Health Authorities have lead responsibility but the process should be inter-agency</li> </ul>
<b>Public Health</b>	<ul style="list-style-type: none"> <li>• Green Paper, <i>Our Healthier Nation</i> (DoH, 1998a) and White Paper, <i>Saving Lives</i> (DoH, 1999a)</li> </ul>

Initiative	Key Partnership Features
	<ul style="list-style-type: none"> <li>• New duty on local authorities to promote the economic, social and environmental wellbeing of their areas</li> <li>• Encouragement of local authority participation in health authority planning activities, and reciprocal arrangements for Directors of Public Health to attend relevant meetings of the local authority</li> </ul>
<b>Health Action Zones</b>	<ul style="list-style-type: none"> <li>• Pilot projects using inter-agency partnerships to improve health and relevant services</li> <li>• First wave in 1998</li> </ul>
<b>Personal Social Services</b>	<ul style="list-style-type: none"> <li>• 1998 White Paper, <i>Modernising Social Services</i> (DoH, 1998b)</li> <li>• Promoting Independence Partnership Grant of £647 million 'to foster partnership between health and social services'</li> </ul>
<b>Joint Investment Plans</b>	<ul style="list-style-type: none"> <li>• NHS bodies and local authorities to review and plan together, services for frail older and disabled people</li> </ul>
<b>Joint National Priorities Guidance</b>	<ul style="list-style-type: none"> <li>• National Priorities Guidance set out for <i>both</i> the NHS and social services since 1998</li> <li>• Social Services lead on children's welfare, regulation and inter-agency working</li> <li>• Health lead on waiting lists/times, primary care, coronary heart disease and cancer</li> <li>• 'Shared Lead' on cutting health inequalities, mental health and promoting independence</li> </ul>
<b>Joint National Service Frameworks</b>	<ul style="list-style-type: none"> <li>• Set national standards and define service models for a specific service or care group</li> <li>• First NSFs for coronary heart disease and mental health, followed by older people (DoH, 2001)</li> </ul>
<b>Better Government for Older People</b>	<ul style="list-style-type: none"> <li>• Set up in 1997 'to improve public services for older people by better meeting their needs, listening to their views and encouraging and recognising their contribution'</li> <li>• Chaired by cabinet Office, supported by partnership working between central and local government, together with national charities, and</li> </ul>

Initiative	Key Partnership Features
	organised through 28 pilot projects

The specific proposals on partnership working between the NHS and social care that resulted in the Health Act 1999, first appeared in a Discussion Document, *Partnership in Action* (DoH, 1998c). Given the disappointing past record of partnership achievement, the Discussion Document stressed the need to view the problem holistically. It was noted that:

*“We must deal with every link in the chain, from the strategic planners to people accessing services in their local communities. Past efforts to tackle these problems have shown that concentrating on single elements of the way services work together...without looking at the system as a whole, does not work.”* (1998c: p5).

*Partnership in Action* had focused solely upon the health-social services interface, but the responses to it prompted a widening of the range of possible statutory partners (Department of Health 1999). The Government received around 500 written responses, with about 36% from the NHS, 27% from local government, 27% from the voluntary sector and 10% from others (DoH, 1999b). Some concern was expressed that the flexibilities would only be available to health and social services in the first instance, and the subsequent Health Bill made provision to ensure that wider local authority functions could be included from the outset provided these involved a health related function – itself a concept open to local determination. The eventual Health Act contained three particular sections designed to encourage and improve partnership working.

*Section 29: Expanded Funding Transfers From the NHS to Local Authorities.*

Section 29 amends Section 28A of the 1977 NHS Act. It gives health authorities and Primary Care Trusts the ability to fund any function of a local authority which is connected to public health provision or the role of the NHS. This is much wider than the old power to fund specific functions within social services, education or housing - it makes possible transfers to support healthy living centres, leisure facilities or indeed anything for the general benefit of the community.

*Section 30: New Funding Transfers From Local Authorities to the NHS.*

In the past there was no reciprocal arrangement allowing local authorities to transfer funds to the NHS. Section 30 accordingly permits local authorities to transfer funds to health authorities and Care Trusts for certain functions. The functions that can be supported include general health and community health provision including rehabilitation and anything avoiding hospital admission. Some NHS functions are excluded such as surgical treatments and ambulance services.

*Section 31: The New 'Flexibilities'*

Section 31 removes legal obstacles to joint working by introducing three 'flexibilities'. First, pooled budgets, where health and local councils put resources into a single budget to fund services. Secondly, lead commissioning, where either the local authority or NHS body takes the lead in commissioning services on behalf of both. And finally, integrated provision, where local authorities and health authorities can merge their services to provide a 'one-stop package'.

All told these measures amounted to the first coherent strategy on partnership working in the history of British social policy. Structural change had been explicitly eschewed, a spirit of goodwill was assumed to be in the ascendant and the doorway was opened for voluntary partnerships to flourish.

**Jilted at the Altar: The NHS Plan and Social Care.**

Notwithstanding the emerging evidence of an improvement in partnership working (Hudson et al, 1998; Hudson and Lewis, 1999; Wilkin et al, 1999; Local Government Association, 2000), nor its own initial protestation that partnership working would remain on a voluntary footing and that structural change was ruled out, the publication of the NHS Plan (DoH, 2000) radically changed the policy and political context. The Plan recognised that major blockages to patients receiving the best care were “the old divisions between health and social care” which deny access to a seamless service tailored to individual needs, and result in thousands of older people being in the wrong place for their needs (“stuck in hospital when they could be better cared for in their own homes”). In March 2000 the Prime Minister identified partnership at all levels as the first of the five key challenges, in order “to end bed blocking, reduce unnecessary hospital admissions and provide the right level of beds and services for each level of care”.



Although the Health Act flexibilities had only been available since April 2000, some of the commentary on the build-up to the NHS Plan seemed to suggest the Government was so impatient with the lack of progress on partnership working that it was inclined to move towards structural integration as an alternative. Indeed, the Plan itself confirms this dissatisfaction, stating that *“the 1948 fault line between health and social care has inhibited the development of services shaped around the needs of patients”* (DoH, 2000: p28) and concluding that *“the division between health and social services can often be a source of confusion for people. Fundamental reforms are needed to tackle these problems”* (p 28).

These 'fundamental reforms' concern not only the health service itself, but also have significant implications for social services authorities. Moreover, they constitute a substantial shift in the relationship between central and local government. Two new aspects of centrally driven compulsion are especially relevant: compulsory partnerships and compulsory restructuring.

#### *Compulsory Partnerships*

The NHS Plan set out ten core principles, one of which was that:

*“The NHS will work together with others to ensure a seamless service for patients. The health and social care system must be shaped around the needs of the patient, not the other way round. The NHS will develop partnership and co-operation at all levels of care.”* (DoH, 2000:5).

The Plan refers to the 1999 Health Act as having *“swept away the legal obstacles to joint working”* (para 7.2) by introducing flexibilities. However, because *“only a small minority of patients are benefiting”* (i.e.: formal notifications were low) the Government, in future, *“will make it a requirement for those powers to be used in all parts of the country”* (para 7.3). The Government stated that: *“The result will be a new relationship between health and social care ... In turn it will bring about a radical redesign of the whole care system”* (DoH, 2000, para 7.3). No time scale was given for the introduction of these compulsory partnerships. The apparent lack of enthusiasm in terms of formal take-up of the new flexibilities may well have been a turning point in the evolving tale of partnership working, but the low number of

notifications does not accurately represent the numbers of localities already working in ways that closely resemble the routes offered by the 1999 Act. Creative partnership working did not need to await the passage of the Act.

The 1998 Discussion Document, *Partnership in Action* (DoH, 1998c) itself pointed out that “*some perceived constraints do not require legislative change but the clarification of common misunderstandings*” (para 4.5). It noted that in many areas, health and social services authorities had not yet taken advantage of opportunities allowed within the framework existing at that time, such as using Section 28A payments. Some localities were said to believe incorrectly that this could only be used in the context of re-provision schemes for long-stay hospitals. Other arrangements, including joint commissioning, multi-disciplinary teams and aligning budgets, are well known and appear to be used effectively in some areas or in some parts of some areas. Such options remain available and do not require notification under the 1999 Act. To this extent the legislation is building on some foundations – it is evolutionary rather than revolutionary. Some localities, however, appear to have made more progress than others.

### *Compulsory Restructuring*

One alternative to partnership working is to restructure organisations and allocate responsibility for a shared area to one specific agency. The allocation of responsibilities between the NHS and local government has a particularly chequered history (Hudson, 1998) and the political emphasis upon partnerships has never dispelled the suspicion that restructuring remains a serious political alternative. The initial reactions to *Partnership in Action* of national representatives of social services and health interests were cautious. Whilst welcoming the overall direction, social services directors were said to be concerned that the government viewed social services as an adjunct to the health service rather than a genuine partner with a distinct and important mission (*Community Care*, 24-30 September 1998). Again, although welcoming the proposals, a spokesman for the NHS Confederation said he hoped ministers did not expect a cash-strapped NHS to bail out an equally cash-strapped social services (*Health Service Journal*, 17 September 1998).

Subsequent developments failed to quell suspicion and rumour. The 1998 report of the Health Select Committee on the relationship between health and social services

acknowledged that the lead commissioner and integrated provisions of *Partnership in Action* were:

*"..a step in the right direction. However, we consider that the problems of collaboration between health and social services will not be properly resolved until there is an integrated health and social care system, whether this is within the NHS, within local government or within some new, separate organisation (...) we believe it is the only sensible long term solution to end the current confusion."* (Health Select Committee, 1998, para 68).

In its response to the Health Committee, the Government stated that it "does not believe it is necessary to formally integrate health and social services", and underlined the significance of the new operational flexibilities across the interface, providing "a framework to develop working arrangements from the ground up." (DoH, 1999c). Moreover, it was emphasised that these developments needed to be seen alongside other initiatives including the forthcoming National Service Frameworks and the closer alignment of the NHS and Personal Social Services (PSS) Performance Assessment Frameworks. The 1998 White Paper on modernising social services had also considered the question of structural reorganisation and concluded that it did not provide the answer since it "would simply create new boundaries and lead to instability and diversion of management effort" (DoH, 1998b).

Despite these denials of structural change, the bodies potentially affected continued to jockey for position. The NHS Confederation argued that partnership was only a partial solution to the interface between health and social care:

*"We believe that the best approach for patients would be a single assessment and single resource allocation mechanism. This means a single commissioning process"* (Thornton, 2000).

The Association of Directors of Social Services similarly pointed out that there are various models of integration which might be considered, and one clear alternative to the NHS Confederation route would be for local authorities to take back the responsibilities for personal health care services at home which had been lost in the

1974 reorganisation of the NHS (Williams, 2000). The particular advantages claimed for such an approach include the greater inclusivity of local authorities and their considerable experience in working with users and carers in a way that is still rare within the NHS.

The proposal in the NHS Plan to permit the creation of new Care Trusts has fundamentally altered the nature of this debate. The Plan introduces the model as one which can be developed as “a new level” of primary care trust. These have been referred to in other literature and commentary as ‘level 5’ (commissioning) and ‘level 6’ (providing) Primary Care Groups, although the National Plan does not itself use this terminology. The New Care Trusts are outlined in broad brush terms only, but can be seen as a development both of the model of Primary Care Trusts (PCTs), and of integrated provision developed through partnership flexibilities. At first sight, the proposal falls considerably short of the scenarios which had been outlined in some quarters prior to the Plan’s publication, with nothing to suggest the health ‘take over’ and demise of social services which had previously been trailed by the NHS Confederation and apparently embraced by the Health Secretary

The outcry that greeted these earlier announcements from the Local Government Association and others pointed to the lack of consultation with the modernisation action teams on issues of major significance, and raised concerns about the upheaval of major structural change, and about the consequences for service users of services dominated by a ‘white coat’ or medical model of care, and by the ‘empire building’ of an acute sector dominated service that views older people as a ‘burden’. The apparent dilution of the proposals that reached the NHS Plan might be seen as an indication that the Government had listened to the weight of opinion, and opted for a more moderate course. However, given that by April 2004 all primary care groups are expected to have moved to primary care trust status, which in turn will “provide a suitable means for the commissioning of social care services, using the Health Act flexibilities, for older people and those with mental health problems” (para 7.8), then the NHS Plan proposals might best be viewed as evolutionary.

Underlying the concerns of those in local government is the fear that Care Trusts might be performance managed in ways inimical to partnership working in general and unsympathetic to social care priorities. In particular, the risk of an NHS ‘takeover’ may be increased if the performance management of Care Trusts is

closely tied to the hospital bed and hospital waiting list agendas. The development of National Service Frameworks, especially the NSF for older people (DoH, 2001), also seems likely to lock local government into an NHS-led system and its associated performance measures, whereas the remit of the NHS in relation to local authority-led Best Value initiatives remains unclear.

Restructuring has shifted from being a local voluntary agreement to one in which compulsion is exercised from the centre in three important respects:

*The terms of creation:*

The NHS Plan raised the possibility of the compulsory creation of Care Trusts. It noted that these would 'usually' be established where there is a joint agreement at local level that this is the way to deliver better care services, but goes on to warn that:

*“Where local health and social organisations have failed to establish effective joint partnerships - or where inspection or joint reviews have shown that services are failing - the Government will take powers to establish integrated arrangements through the new Care Trust.” (DoH, 2000: 73)*

The Secretary of State pressed the message home in his address to the Annual Social Services Conference in October 2000:

*“I want to see a flowering of local partnerships that put the needs of the individual at the centre of all they do. And where that does not happen - or where local services are failing to deliver - I have a duty to act, and I will not hesitate to do so. There is a choice. Partnerships, including Care Trusts, can be established by you - or they will be established by me.” (Milburn, 2000)*

The proposed governance arrangements for Care Trusts will only have confirmed local government suspicions. Although early guidance proposed a framework which genuinely reflected the partners' shared responsibilities (DoH, 2001a), subsequent detailed guidance effectively sets out an NHS body with social care tacked on (DoH, 2001b).

### *The speed of creation*

Although robust in tone, the remarks made by the Secretary of State still leave scope for local determination of partnerships. Indeed, as long as local partnerships are delivering effective care, then it would seem that the creation of a Care Trust would not be necessary - effective use of the Section 31 opportunities, for example, would be sufficient. However, in an interview given in November 2000, Health Minister, John Hutton, seemed to be putting a different interpretation on the creation of Care Trusts. Speaking to the weekly *Community Care Magazine*, he made it clear that Care Trusts could not be viewed as an option for just some services, and that he expected *all* adult social care services to be commissioned by Care Trusts within five years (*Community Care*, 9-15 November 2000, 10-11). Whether the government can achieve this without legislative change remains to be seen.

### *The parameters of creation*

A further twist to the emergence of Care Trusts came in an announcement following the Queen's Speech, that housing services (and indeed other local authority services) could also be transferred to Care Trusts. Such incorporation is seen as supporting the development of 'one-stop shops' and facilitating the rehousing of older people after hospital discharge, amongst other things. It is not yet clear whether the same elements of compulsion would apply to 'failing' housing agencies in respect of their inclusion in the new Care Trusts.

These proposals on Care Trusts will have an impact on the partnerships emerging through Section 31 notifications, for in some respects the latter appears to have been superseded by the former. Both have the underlying themes of integrating the planning, purchase and provision of services, but whilst the flexibilities are likely to be applied to only *some* services, Care Trusts can be inclusive of all adult care - the inclusive option favoured by the Health Minister. The other feature of the proposals which has attracted comment is the presumption that where partnerships are failing the local authority is implied to be culpable and therefore at risk of 'losing' responsibilities; there is no equivalent proposal to put failing NHS bodies under the auspices of local government. This raises questions about the 'collaborative capacity' of the nascent primary care organisation - an issue discussed elsewhere (Henwood and Hudson, 2000).

The political thirst for integrated structures is related to the apparent success of the

integrated Health and Social Services Boards in Northern Ireland - a model praised by the Health Select Committee (1998) and the Royal Commission on Long Term Care (Sutherland, 1999). In fact, recent experience suggests that Northern Ireland faces very similar difficulties to the mainland in managing health and social care pressure points, and in some respects may manage them *less* successfully. An urgent review of the provision of care in the community, and its relationship with admission and discharge practices, was commissioned by the Minister for Health, Social Services and Public Safety at the beginning of January 2000. The report identified a number of shortcomings including: services shortfalls in every aspect of community care provision; delayed discharges from hospital; waiting lists for day care and respite care; and inappropriate placements in residential care. (Social Services Inspectorate, 2000).

Indeed, the review concluded that such was the scale of difficulty that:

*“The Minister may wish to commission a comprehensive review of the implementation of community care policy, to include funding and arrangements for delivery of services in Northern Ireland (...) In undertaking such a review, account should be taken of the important interfaces between hospital, primary and community care.”* (p 20)

Such recommendations hardly suggest that the integrated model as practised in Northern Ireland is without problems or offers a solution which should be emulated. A further recommendation highlights:

*“..the need for greater collaboration across hospital, primary and community care so as to develop a co-ordinated approach to the planning and management of hospital admissions and discharges to ensure care pathways for patients and clients with appropriate thresholds.”* (p 20)

These are precisely the problems that are familiar in England, and which advocates of the Northern Ireland model have argued are satisfactorily resolved by structural integration. In other words, much of the ‘integration’ between health and social care in Northern Ireland would seem to be more apparent than real, and structural integration evidently does *not* guarantee well co-ordinated practice on the ground.

Just as structural problems are often identified between health and social care in England, so too in Northern Ireland it is acknowledged that difficulties “can be traced to the organisation and management of the HPSS”, that ‘whole system’ approaches remain “difficult for services to operate”, and that “collaboration between hospital, community care and primary care services is not consistently effective.” (NHS Executive/Social Services Inspectorate, 2000: para 3).

### **'Wicked Issues' and the Decline of Structures.**

Paradoxically the interest in an 'Old Labour' solution - structures - has re-appeared at a time when there is widespread recognition that partnership working increasingly has to respond to 'wicked issues' that transcend any restructuring solution. This new requirement can be distinguished from the issues that can be addressed by 'old partnerships'. 'Old partnerships' are typified by the arrangements that developed for resettlement from long-stay hospitals, especially in the case of people with learning difficulties. While it is important to avoid regarding such contexts as 'simple', there tend to be elements in place that make a successful outcome more likely. Such features are similar to the characteristics of what Challis et al (1988) have described as 'planned bargaining':

- partnerships come together with the intention of delivering pre-set common objectives;
- there is confidence that the objectives are the right ones, based upon experience of what works;
- the focus is the resolution of existing problems rather than the anticipation of future ones;
- partnership working is relatively small scale and *ad hoc*, rather than part of a broader partnership design.

Partnerships of this type will continue to have an important role to play, but increasingly it will be necessary to participate in new partnerships related to different sorts of issues. The conceptual underpinning of the notion of 'new partnerships' has two elements, the first of which is the shift from government to governance. Governance is a broader term than government, with services provided by any permutation of the statutory, private and voluntary sectors. The complexity arising out of this functional differentiation of the state makes inter-agency linkages a defining characteristic of service delivery. Rhodes (1997) goes on to define



governance as 'self-organising inter-organisational networks' characterised by: inter-dependence between agencies; continuing interactions between partners arising from the need to exchange resources and negotiate shared purposes; and a significant degree of autonomy from the state, which can only indirectly and imperfectly steer networks.

The second feature is the growing focus on '*wicked issues*' (Clarke and Stewart, 1997) - those policy matters that are particularly difficult to resolve because:

- the problem itself is hard to define;
- the causal chains are difficult (if not impossible) to unravel;
- complex inter-dependencies are involved.

Such issues require ways of working that are different to those found in 'old partnerships'. These include:

- *understanding*: recognising that understanding is partial and is best seen through a variety of perspectives;
- *thinking*: pursuing the holistic and looking for interactions and their relationships;
- *working*: tolerating not knowing, and accepting different perspectives, approaches and styles;
- *involving*: being inclusive, drawing in as wide an array of organisations and interests as possible, and open to public involvement;
- *learning*: encouraging experimentation and diversity, and reflecting upon what has been learned.

In this context, organisational structures and boundaries (and any re-shuffling of them) becomes a secondary matter. In so far as there is a 'system' it refers to something that assembles itself around a shared purpose, and the key issue is 'what is the right mix of people for that purpose and how do their voices get heard?' (Pratt et al, 1999). New Labour has, at least in part, turned its back on markets, but seems unable to decide between hierarchy and network as its guiding principle. Wicked issues are best suited to a network approach nested in the partnership imperative, but the NHS Plan heralded a return to hierarchical control.

This approach is out of step with the complex conditions facing modern governance. Policy fields such as health and social care are best viewed as a mixture of relationships which change and vary over time and space. Simple hierarchies and tiers have given way to delivery systems which use a mix of governmental relationships, new partnerships between the public and private sectors, market mechanisms and 'marketwise' public policy; and new roles are being defined for the voluntary sector and the 'community'. Notions of 'levels' and 'tiers', of command and control, of restructuring and 'compulsory partnerships', are all ill-suited to relationships which are more akin to spheres and networks.

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## **Abstract**

The process of discharging patients from hospital provides a critical indicator of the state of partnership working between health and social care agencies. In many ways hospital discharge can be seen to epitomise the challenges which beset partnership working. For patients who have care needs which continue following their discharge from hospital, how well health and social care partners are able to co-ordinate their policies and practice is critical. Where arrangements work well, patients should experience a seamless transition; where things go wrong patients are all too often caught in the middle of contested debate between health and social care authorities over who is responsible for what.

In 2002 growing concerns over the numbers of mainly elderly people who were experiencing delays in being discharged from hospital led to the announcement that a system of "cross-charging" would be introduced to target delayed discharges that were the responsibility of local authority social services departments. The government's proposals were widely criticised and were the focus of much antagonism. The intervention of the Change Agent Team (an agency with responsibility for providing practical support to tackle delayed discharges) marked a turning point in the presentation of the policy and in supporting local implementation efforts.

This paper examines partnership working between health and social care by exploring the specific issues which this case study of hospital discharge provides. The analysis highlights the importance of understanding the dynamics of partnership working on the ground. It also underlines the need for a new relationship between central government and local agencies when old style models of command and control are no longer fit for purpose. A new approach is required that addresses the complex and multiple relationships which characterise the new partnership agenda.

**Keywords:** hospital discharge, older people, partnership working, reimbursement.

# Effective Partnership Working: A Case Study of Hospital Discharge

## Introduction

The separation of the health and social care systems which has existed in England since 1948 is widely viewed as problematic. The fissure between the two creates potential difficulties at all levels: from the strategic to managerial and operational. Most important is the impact this has on patients and service users who often fall awkwardly between the two systems, or who fail to understand why their needs are apparently arbitrarily deemed to belong to one domain or the other. In recent years these challenges have arguably become more evident as the boundary between health and social care has shifted, and much of what would have been viewed as health care in years past is now categorised as social care (House of Commons Health Committee, 2005). Many people who previously would have been cared for free of charge by the NHS now find they must meet some or all of the costs of care for themselves.

Many of the difficulties between health and social care are crystallised in the experiences of patients being discharged from hospital. The speed of discharge (too soon or delayed too long) is frequently the result of confused or disputed responsibilities. After years of exhortation for health and social care to work together more closely to tackle such problems, a more radical solution was introduced by the Community Care (Delayed Discharges) Act 2003. This established a system of 'reimbursement' by social services to the relevant NHS organisation where discharge delays are caused by the failure of the social services authority to provide timely assessment or social care services.

This legislation was highly controversial and widely resented prior to implementation. However, since January 2004 when the system became fully operational it is apparent that there has been a significant and positive impact in reducing the scale of delayed discharges. This paper explores the context to the legislation and the effect which it has had both in terms of outcomes for older service users, and on policy and practice in hospital discharge. It also considers the potential implications of these developments for partnership working more broadly.

## Policy response to delayed discharges

Problems with delayed hospital discharges have been evident for at least the past 30 years. This is largely a problem associated with the care of older patients who have on-going needs for care and support following their discharge from hospital. Research throughout the years has consistently identified a range of features associated with poor practice. Glasby has summarised these in terms of: poor service co-ordination; lack of clarity over respective responsibilities; lack of information sharing; inappropriate range of service models; inadequate assessment and planning for discharge; inadequate consultation with patients and their carers; lack of notice of discharge, and over-reliance on the contribution of family carers (Glasby, 2003). The publication in 1994 of the *Hospital Discharge Workbook* (Department of Health, 1994) was an attempt to “improve the consistency of good practice at both individual and management levels”. Subsequent policy developments focused on emphasising the development of ‘whole systems approaches’ across health and social care economies; building the capacity of local services to provide community support, and developing models of intermediate care at the interface of health and hospital and community services (Henwood, 2004).

Specific targets for reducing levels of delayed discharges (still often referred to by the pejorative term ‘bed blocking’) were intrinsic features of both *The NHS Plan* (2000), and the *National Service Framework for Older People* (2001). However, a significant change of strategy emerged in 2002. The publication of *The Wanless Report* which had been commissioned by the Treasury to examine future health trends and the resources required to meet them, recommended that the Government should “examine the merits” of financial incentives (such as had been employed in Sweden) to help reduce the problems of delayed discharges. The immediate response of the Government was in the publication of *Delivering the NHS Plan* (2002a). Far from following the Wanless advice to examine this case, the Government announced its intention “to legislate therefore to introduce a similar system of cross-charging”. A system of incentives and penalties would accompany the legislation with additional funding allocated to cover the associated costs:

*“If councils reduce the number of blocked beds, they will have freedom to use these resources to invest in alternative social care services. If they cannot meet the agreed time limit they will be charged by the local hospital for the costs it incurs in keeping older people in hospital unnecessarily. In this way there will be far stronger incentives in the system to ensure that patients do not have to experience long delays in their discharge from hospital.”* (para 8.10)



The way in which this development was announced did nothing to win support. It appeared to be an ill-thought through announcement which cast local authority social services departments as the villain of the piece, when there was considerable evidence to suggest that the causes of delayed discharges are actually complex and multi-layered and often out of the hands of social services. Moreover, the failure of the Government to follow its own mantra of adopting an evidence-based approach to policy and practice when these proposals had not been the subject of any piloting or evaluation, added further to the hostility with which the announcement was received.

An inquiry into delayed discharges undertaken in 2002 by the Health Select Committee (House of Commons, 2002) found “some cautious support” for the model of cross-charging, but:

*“(...) the predominant reaction was that the proposals constituted a blunt instrument that, rather than improving partnership, would be likely to reinforce a negative blame culture.”* (para 162).

Several witnesses to the inquiry identified “perverse incentives” likely to be associated with the cross-charging measures, and the lack of enthusiasm for the approach was evident not only among social services and local government representatives, but also within the NHS Confederation:

*“We talk to our members. What they say is that it is right to have incentives and we need joint incentives between the two organisations, but the majority view we are getting back is that people do not believe it is an effective incentives and that in places which have worked hard to have good relationships it could bring contesting back rather than partnership (...) It could be counterproductive.”* (para 164).

While there was acceptance by many witnesses that the right incentives *could* be helpful, there was a view that these needed to be positive rewards rather than simply negative sanctions, and that they needed to work across the system not just at one point of it. The Health Committee also followed this path and recommended “the development of positive incentives that reward good practice.”

The criticisms made by the Health Committee and repeated across virtually the entire health and social care community appeared to have little effect. The Bill received Royal Assent on 8<sup>th</sup> April 2003. However, changes *were* agreed to the implementation schedule which meant a ‘shadow’ period of operation would take effect from October 2003, and the arrangements would become fully functional from January 2004. This extended timetable provided a

window of opportunity for preparatory work to be undertaken. In particular, local capacity could develop, drawing upon the resources provided under a Delayed Discharge Grant (transferring £100 million from the NHS to local authorities for each full year of the operation of the reimbursement scheme).

A practice guide on hospital discharge issued in January 2003 (Department of Health, 2003) followed the whole system model and set out some key principles for effective discharge and transfer of care, in particular:

*“The avoidance of unnecessary hospital admission, good clinical outcomes and effective discharge planning is facilitated by a ‘whole system approach’ to the commissioning and delivery of services.*

*Organisations should work proactively, separately and together to review and improve performance and final solutions.”* (Department of Health, 2003, P.15).

The timing of the publication of the Guide was curious in view of the imminent developments around the Delayed Discharges Bill, and while the principles and good practice that it restated remain relevant, they were of little direct help to authorities needing to prepare for the implementation of new requirements around reimbursement.

The establishment of the Health and Social Care Change Agent Team (CAT) in the Department of Health was announced in October 2001, and the team became operational in March 2002. It was developed to support local change and implement contingency arrangements where there were particular problems in tackling delayed discharges of older people from acute hospitals. CAT was assigned responsibility for developing implementation support for the introduction of the Act. This can be seen as a critical turning point both in the acceptance of the policy and in the operation of the arrangements in practice (Henwood, 2004). The Reimbursement Implementation Team developed a range of support products directed towards those people who would be responsible for implementing the new arrangements. The approach that was adopted was one that focused on supporting local partnerships, by revisiting and strengthening local discharge planning arrangements, particularly through the development of templates and suggested model processes and protocols. By the end of 2003 the reimbursement team concluded that there was clear evidence emerging of “some early positive experience of implementing reimbursement” (Health and Social Care Change Agent Team, 2003).

What was especially significant in the work of the reimbursement team was the shift that they achieved in securing wider recognition that reimbursement was an issue not just for councils

with responsibilities for social services, *but also for the NHS*. This was certainly *not* evident in the original features of the Bill, nor in Ministerial comments about the underlying issues surrounding the need for a cross-charging mechanism. However, the Act also brought new duties and responsibilities for the NHS (see Box 1), which located the issues *within* the partnership agenda for health and social services, rather than driving a wedge into it as had been feared initially.

In the preparations for implementation the reimbursement team was able to identify factors that were likely to reinforce poor partnership practice and strain relationships. Typically these included familiar patterns of mutual blame and recrimination, and focusing on the problem rather than seeking solutions. The reimbursement arrangements would only succeed in tackling delayed discharges if there was, at minimum, a whole systems approach to investment (which was facilitated by the Delayed Discharges grant). However, there were also a range of other factors associated with more mature inter-agency relationships that were likely to be associated with success. Health and social care economies that have moved to this higher level have resolved the basic requirements around reimbursement and have established a higher level of understanding which makes linkages between delayed discharges and other processes and practice across acute, primary and social care systems.

**Box 1**  
***New Duties and Responsibilities around Delayed Discharges***

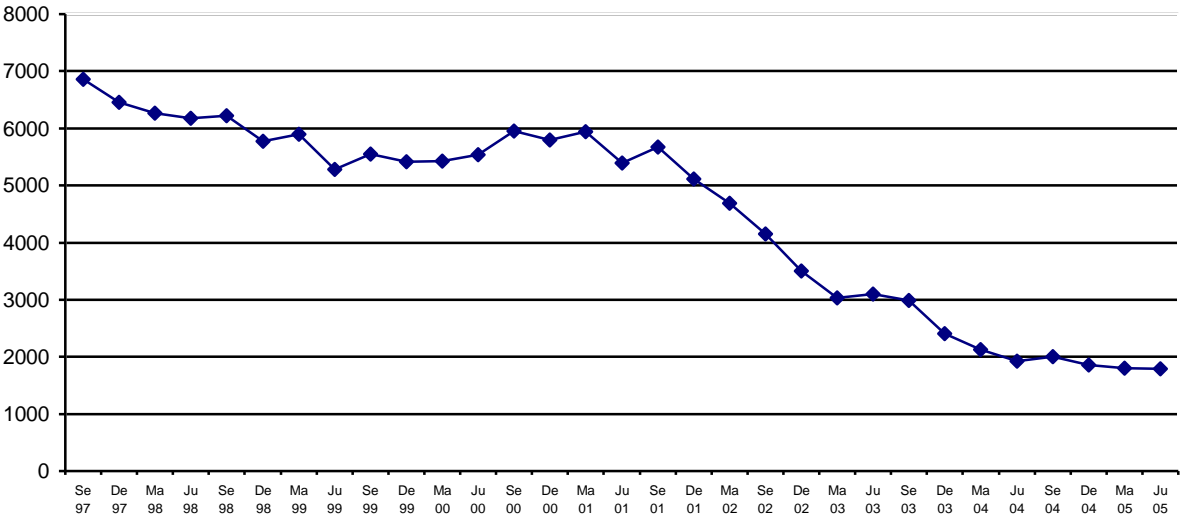
- NHS bodies have a new statutory duty to notify social services of a patient's likely need for community care services (referred to as an '**assessment notification**' or '**Section 2 notification**.')
- There is a defined timescale (**the 'minimum interval'** of at least three days) for social services to complete the individual's assessment and provide appropriate social care services.
- A second notification ('**Discharge notification**' or **Section 5 notification**) follows completion of the multi-disciplinary assessment and gives notice of the proposed day on which discharge will take place (minimum of 24 hours notice).
- A reimbursement charge of £100/£120 per day is paid by social services to the acute trust if the fact of social services not having met their obligations is the *sole* reason for the delay in discharge from hospital. If any element of the delay is related to NHS areas of responsibility then reimbursement does not apply.
- NHS bodies have to make both of the notifications to social services if a claim for reimbursement is to be triggered. Liability for payment begins on the day after the three days of the assessment notification, or the day after the proposed discharge date **whichever is the later**.

**What difference has reimbursement made?**

A special study report on leaving hospital was published in October 2004 by the Commission for Social Care Inspection (CSCI, 2004). The study provided the first evidence on the implementation of the reimbursement policy, “and the impact it appears to be having on people and services.” At the time that the reimbursement arrangements were introduced there was already evidence of a downward trend in the numbers of delayed discharges. However, this trend has accelerated since implementation.

Figure 1 charts the decline in the numbers of patients over 75 occupying an acute hospital bed and whose discharge is delayed. From a high point of 6,854 in September 1997 (15.7% of patients in this age group) these numbers had declined to 1,792 in June 2005 (less than 4% of the patient group). Latest data indicate a 64 per cent reduction in delayed discharge from acute hospitals between 2001 and September 2005 (Secretary of State, 2006).

**Figure 1**  
**Number of patients aged 75+ in acute beds with a delayed discharge**  
**Quarterly figures 1997 to 2005**



As the CSCI study noted, numbers alone do not tell the whole story and “behind these encouraging statistics lies a much more mixed picture, in terms of the quality of the person’s experience” (CSCI, 2004, p.4). While the principal objective of the reimbursement mechanism was to reduce the numbers of delayed discharges, it was also about improving the quality of practice and the outcomes for individual patients. There is some evidence that improvement has *not* always occurred across the board, and in some instances a reduction in numbers of delays has been at the price of undermining the potential of older people to benefit from rehabilitation and improvement simply in order to get them out of their hospital bed quicker. The CSCI study did *not* find gross risk as a result of premature discharge or inadequate support, but *did* find large proportions of older people moving directly from hospital to permanent residential/nursing home care (up to a third in some councils). Concerns about just such situations with people being pressurised into making life-changing decisions from a hospital bed had been expressed in much of the debate around the reimbursement proposals.

Where intermediate care and rehabilitative services were well developed the CSCI study found good evidence of these being effective in facilitating discharge *and* “getting people back on their feet and into their own homes.” However, access to such services was still inconsistent and lack of capacity particularly limited the opportunities for people with confusion or mental health needs.

While the numbers of delayed discharges have been falling (and continue to do so), the CSCI review found worrying evidence that emergency admissions of older people to hospital continue to rise. The fragility of some local systems is apparent and a focus on speeding up hospital discharge can easily lead to reduced attention to expanding community capacity to prevent hospital admissions. This was exactly what the CAT reimbursement team sought to avoid in emphasising the need for whole systems planning. Certainly where this works well there is a synergy across the entire health and social care economy, but this is by no means true everywhere, as CSCI remarked:

*“The best localities are using reimbursement monies to advance plans to extend community-based rapid response services and round-the-clock crisis support. Localities with less well-developed community provision know this is where investment is needed but are pulled towards securing quick fixes to support discharge.”* (CSCI, 2004, p.5).

Whether focusing on delayed discharges would lead to too much haste with discharge and hence to a rise in readmissions was another concern that was raised in the debate around

reimbursement. This was an issue that was also explored by the Health Committee. Age Concern England gave evidence to the Committee and pointed to the problems that can arise when older people are hurriedly discharged home without the appropriate care being put in place because of the need for hospital beds to be freed up quickly:

*“..which can mean that they return to a cold house, with no food, and have to wait for an assessment from social services.”* (House of Commons, 2002, para 72).

Evidence from Carers UK identified similar concerns and highlighted the problem of rising readmission rates. Evidence in the CSCI report indicated considerable variation in readmission to hospital within a few months of discharge (between 8% and 50%), and advised caution in interpreting the statistics while also indicating the need for more careful monitoring. Readmission data only indicate the worst effects of premature discharge and fail to reveal anything about the qualitative experience of people who may be discharged too soon or with inadequate support and who somehow cope, but whose quality of life could have been considerably enhanced given more measures discharge planning and adequate post-discharge support arrangements (Henwood, 2006).

Encouragingly, CSCI concluded that the introduction of the reimbursement arrangements “seems to have brought health and social services together rather than pulled them apart as feared.” While there was still considerable variability in the degree of integration achieved locally (as evidenced by the use of arrangements such as pooled budgets), “on the whole partnerships were improving.”

At the time the reimbursement Bill was being debated it was clear that the remit extended *at that time* to delays in acute care. However, the guidance subsequently made clear that there was scope for extending the arrangements to other types of provision in the future, and regulations could *“gradually extend the reimbursement mechanism through the whole system, where this would be appropriate and beneficial to do so”* (Department of Health, 2002b). The possible extension of arrangements to other areas of in-patient care (such as mental health and palliative care) is still under active consideration. The 2006 health and social care White Paper (Secretary of State, 2006) stated an intention to build on investment in intermediate care and related community services “so that more people benefit from supported early discharge.” There is some obvious learning that needs to inform such development. CSCI highlighted the following:

- The twin-track approach of investment alongside policy change does help implementation.

- Extending reimbursement to older people with mental health difficulties needs to be aware of “the serious service shortfalls that exist in the community”.
- Pressures on intermediate care and community facilities should reduce as more home-based preventive services develop.
- A longer lead-in time to any extension of the scheme “would help to prevent inappropriate, short-term fixes.”
- Incentives to tackle gaps and capacity pressures are needed in respect of community health care (CSCI, 2004, P.7).

It is impossible to know what levels of delayed discharges would now exist if the reimbursement arrangements (and associated investment in intermediate care) had *not* been introduced. The fact that numbers were already falling certainly prompts speculation about what might have developed in any event. However, the low levels of delay which have been achieved *and maintained* suggest that there has been a significant shift in both the understanding of the problems and the means of tackling them. In place of years of repeated exhortations for health and social services to improve their joint working and find solutions, arguably there is now a more coherent strategy which has addressed the causes of delays (in terms of community-based service capacity), identified shared responsibilities for making change happen, and provided leverage to ensure that it does.

### **Wider implications for partnership**

In addition to the specific lessons that the reimbursement experience has for future policy development in the area of hospital discharge, it is also evident that there are more significant conclusions to be drawn for partnership working more generally. These conclusions are of two main types:

- Understanding the *process* of change management and support; and
- Understanding how partnership can best be nurtured and grown.

With the benefit of hindsight the introduction of the reimbursement proposals was initially a textbook example of *how not to manage policy change*. The announcement of the policy was made far in advance of the development of thinking that was required to support it. The lack of detail that was contained in *Delivering the NHS Plan* served to fuel speculation and

anxiety and took little account of local approaches to partnership. The hostility and resistance to the ideas was virtually guaranteed by the 'gung-ho' approach that was adopted by politicians. As CSCI has also observed, the proposals caused "widespread alarm at a local political and professional level" (CSCI, 2004, P.14). There were real risks that the system would:

- Exacerbate tensions and recriminations between local hospitals and social services.
- Encourage premature discharge with inadequate safeguards.
- Be administratively burdensome.
- Be regarded as an income generation scheme by hospitals.
- And divert money away from already hard-pressed social services and investment in community-based solution for the benefit of the acute sector.

The Change Agent Team proved to be enormously helpful in helping with local implementation efforts, but clearly had considerable damage-limitation work to do in redressing the initial hostility and suspicion that had been stoked up. It was notable that the implementation guidance that was issued avoided using the language of 'blame', 'fines' or 'penalties' – all of which had unfortunately coloured initial presentation of the policy. The development support that was provided to bolster local preparation indicated considerable understanding of the partnership agenda which also needs to be addressed in the relationship between central government and local health and care economies. A new model of working is required, particularly in the context of devolution and earned autonomy which the Government continues to advocate for health and local government services, in place of past models of heavily centralised and top-down command and control.

In these new circumstances a better understanding is needed of the motivations and dynamics of local partnership relationships. The life of the CAT was extended and its focus considerably broadened to address key issues around commissioning (particularly in relation to intermediate care and housing) and to engage with the implementation of the National Service Framework for Older People. The model of working (focused on providing practical support and addressing implementation needs in the field) has been particularly beneficial. The continued work of the CAT is now being undertaken within the aegis of the Care Services Improvement Partnership (CSIP, established in April 2005) which brings together the Change Agent Team and a number of work streams in order to address changes in services and in the well-being of:



- People with mental health problems.
- People with learning disabilities.
- People with physical disabilities.
- Older people with health and social care needs.
- Children and families with health and social care needs.
- People with health and social care needs in the criminal justice system.

The specific experiences of CAT in working to tackle the problems of delayed discharge for older people will therefore have wider and more far-reaching influence across the health and social care arena. The importance of CAT in engaging with practitioners and legitimising new work practices cannot be over-stated, and there are considerable implications for the work of CSIP and how it addresses service improvement strategies across the board as well as through targeted work with particular health and social care economies. The wider partnership agenda is of increasing significance. In March 2005 the Government published a Green Paper on adult social care (Department of Health, 2005a). The partnership theme and the need for 'joined-up' working were key dimensions of the document and its vision for strategic integrated services. However, this model of partnership working arguably belongs to a previous era and appears to have learned little from recent experience. The years of exhorting health and local authorities to 'work together' has, in itself, had limited impact. What *does* work (and what the recent experience around reimbursement has underlined once more) is a combination of the following features:

- Clear and specific requirements.
- An appropriate balance of incentives and sanctions.
- And close monitoring of performance.

Without these elements there is little leverage to change practice across the board, and no incentive or reward for those authorities that *do* pursue successful partnership strategies. The subsequent White Paper (Secretary of State, 2006) appeared to have recognised the importance of these dimensions. Future integration of health and social care is to be driven by common outcomes reinforced by a newly aligned approach to performance assessment, management and inspection regimes.

While there is a need for central direction, this has to be balanced alongside the reality that precise models of partnership *cannot* be directed centrally but need to have regard to local circumstances. Trying to find a way of balancing these requirements has exercised the Department of Health for years. *The NHS Plan (2000)*, for example, had relatively little to say about partnership working, but what it *did* say indicated a fundamental lack of understanding about the dynamics of collaborative endeavour. The Plan announced the intention that the ‘flexibilities’ introduced by the 1999 Health Act (which removed legal obstacles to joint working by allowing the use of pooled budgets; lead commissioning and integrated provision) would cease to be optional. Alongside this it was announced that integrated ‘Care Trusts’ would become possible for health and social care authorities wishing to work more closely together sat uncomfortably alongside the threat that where partnership working was poor, authorities would have such models imposed on them:

*“Where local health and social care organisations have failed to establish effective joint partnerships – or where inspection or joint reviews have shown that services are failing – the Government will take powers to establish integrated arrangements through the new Care Trust.”* (Secretary of State, 2000, para 7.11).

Both of these requirements were short lived. It was self-evident that a model of collaborative behaviour that was so reliant on mutual trust would simply not work if imposed from above (Henwood and Hudson, 2000).

The social care Green Paper avoided falling into this trap and recognised the folly of trying to impose solutions, but was apparently uncertain of what alternative strategy to propose other than noting that “we are clear that doing nothing will not be an option” and local health and social care communities would be expected to work together, alongside other voluntary and statutory agencies “to take a community-wide approach to commissioning” (Department of Health, 2005a, para 8.14). It is highly unlikely that such ‘expectation’ will be sufficient of itself to bring about the scale and nature of change that is required.

In July 2005, just prior to the end of the consultation on the Green Paper, the then Care Services Minister Liam Byrne announced that a joint White Paper would be developed to take forward the reform of social care together with changes in the NHS associated with care ‘outside of hospitals’. This created an unprecedented opportunity to address health and social care in a genuinely integrated model. However, there were considerable challenges to be confronted, and particular concerns were expressed about how competing medical and social models of disability would cohere, and the dangers of the White Paper being developed as an NHS document with lip service paid to the wider social care agenda

(Henwood and Hudson, 2005). In practice the White Paper was generally welcomed (particularly for restating the social care vision of the Green Paper). However, the extent to which much of the debate and coverage of the White Paper focused on improving hospitals, introducing NHS 'life checks', and improving patient choice points to the difficulties in tackling a fully integrated health and care agenda in which social care issues are not marginalised.

What is also apparent is that the partnership agenda is now increasingly about a much wider range of relationships than simply those on the health and social care interface. The wider 'well-being' agenda is one that extends across the local authority. The need for the health and social care agenda to be tied into newly emergent Local Strategic Partnerships and Local Area Agreements is a key challenge. The review of responses to the consultation on the Green paper (undertaken by the Care Services Improvement Partnership in conjunction with the Department of Health) found strong support for the objective of promoting partnership working (Department of Health, 2005b). However, beyond this broad consensus there were reservations about *how* partnerships might be strengthened and become more inclusive.

The future of partnership working depends critically on the capacity for policy learning, particularly within central government. Local partnerships are built and sustained within an environment that to a large extent is shaped by central government. That environment can be more or less supportive of partnership developments and the experience in the field of hospital discharge in particular, and from partnership working more broadly, indicates that a constructive environment is likely to be characterised by a number of features. These include the importance of financial and other incentives; the coherence of policy streams across local government and the NHS (and across Government departments); and recognition that while structural reform is not of itself a solution, it can be an important contribution to a more integrated approach.

## **Conclusions**

The reimbursement system introduced to tackle delayed discharges was focused on changing processes and practice between health and social care agencies. The apparent success in reducing the numbers of patients experiencing prolonged stays in hospital appears to have delivered improved outcomes both for the service system and for individual patients and service users. Such conclusions must be tentative at this stage since the prime concern in monitoring has been with the *numbers* of delayed discharges rather than with the effect of this on patients. However, there is also at the very least some anecdotal evidence

which points to the potential risks of poor outcomes for some service users (characterised by overly hasty discharge and consequent risks of readmission). This raises some very significant issues about the clarity that is needed in outcome specification, and awareness of the possible unintended consequences of policy interventions. A pre-occupation with numbers of delayed discharges in isolation could too easily divert attention from addressing other vital outcomes. Reducing delayed discharges cannot be judged as wholly successful without clearer information and longer term evaluation which addresses the impact not only on the service system, but also – and more importantly – on service users and their families.

The development of effective partnership working to tackle delayed discharges provides a case-study on improving partnership developments more widely. This paper has reviewed recent experience in responding to the requirements of the Delayed Discharges Act and has identified the factors that are likely to encourage and support partnership rather than reinforce traditionally adversarial relationships.

These issues will be of increasing relevance to the on-going work of the Care Services Improvement Partnership, and in the development of an integrated agenda across health and social care subsequent to the publication of the 2006 White Paper. Future and sustained success will be contingent upon the operation of the appropriate framework of clarity of objectives; incentives and support; and accountability against the management of performance. Hospital discharge delays provide a significant indicator of the state of partnership across health and social care economies. The specific experiences in tackling delays since 2003 demonstrate the necessity of genuine whole systems approaches, an understanding of the service outcomes that are sought for service users, and the necessity of central Government developing an improved understanding of the complexity of local partnership endeavour and recognising that long-standing partnership problems are not amenable to a 'quick-fix', nor to the crude threats of blunt and punitive policy instruments.

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*Continuing Health Care:  
Review, revision and restitution*

2004

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## Executive Summary

Following the publication of a report on long term care in February 2003 by the NHS Ombudsman, the Department of Health requested all Strategic Health Authorities (SHAs) to establish an integrated set of eligibility criteria for NHS continuing health care to operate across each territory, and to undertake a process of retrospective review of cases where people may have been wrongly denied continuing care, either because the criteria operated by predecessor health authorities were unlawful, or because they were incorrectly applied. All SHAs were originally required to complete this review process by the end of December 2003; this was later revised to a completion deadline of 31 March 2004.

An independent review was commissioned by the Department of Health in order to explore local progress with these tasks. This is the report of the review which was conducted in 9 SHAs throughout the country. The review was undertaken on a confidential basis and it is not intended that the participating agencies should be identified. Visits took place to all the sites and meetings took place with SHA, PCT and local authority social services representatives. In some sites additional meetings or interviews took place with stakeholders from the voluntary sector, with independent sector care providers, and with legal representatives. In total more than 120 respondents were consulted in the course of this work.

NHS continuing care has become a more significant issue since the formalisation of eligibility criteria in 1996. This can be seen as a reflection of a wider debate about the separation of health and social care, the difficulties of managing the boundary between these, and the implications for individual service users who will either receive a 'free' service from the NHS, or a means-tested one for which they will be charged by social services.

The difficulties with continuing care arise particularly because the 1999 Coughlan judgment does not provide a hard and fast distinction between NHS and social services responsibilities and because of the extent to which the boundary between these appears to have shifted over time. In addition, problems have arisen for the health service in applying criteria consistently, and explaining them meaningfully to the wider public. In all 9 SHAs considerable irritation and hostility to the reports from the Ombudsman was encountered. While there was some welcome for the focus that had been provided by the Ombudsman's intervention, there was also a widespread belief that this had often made a difficult situation considerably worse, and that misinterpretation of the reports' findings had contributed to the general confusion surrounding this area of policy.



One consequence of the attention that had been forced by the Department of Health's response to the Ombudsman was the significantly greater profile for continuing care, and a greater prominence on local NHS agendas. This was welcomed, but it was also believed this could be short-lived and that continuing care remained marginal to the concerns of SHAs which are dominated by performance management in respect of the acute hospital sector.

### ***The integration of criteria***

The requirement for SHAs to review and integrate their criteria for continuing health care was the latest in a series of reviews that have been required since 1996. The eligibility criteria have been revisited in the past in the wake of various legal judgments (notably the 1999 Coughlan judgment), and more recently following the consolidating guidance issued in 2001. What this repeated return to the criteria indicates is the failure of some health authorities to establish legal criteria, and to apply them correctly. However, it is apparent that since the Ombudsman's report in 2003 there has been considerable activity and local efforts have been concentrated on remedying this situation.

As the discussion in Section 2 demonstrates, it was apparent across the 9 sites that there had often not been a good record of consistent application of criteria, or any clear consensus about the nature and content of those criteria. In many cases local authority partners had never previously signed up to the criteria developed by the health authority. It was also clear that there was considerable commitment on the part of SHA, PCT and local authority partners to securing agreement and establishing workable arrangements once and for all. However, few respondents were confident that there would not be a requirement to revisit these issues yet again at some time in the near future.

Practical difficulties were greater in those localities where predecessor health authorities had operated widely divergent criteria, and where multiple PCTs were used to following a range of disparate practices. Constraints were also evident in the particular legacies of past provision. Anecdotally at least it was believed that health authorities that had historically provided very little long term care had been able to manage this situation by correspondingly higher rates of placement of patients at the top band of the RNCC in nursing homes. Conversely, those authorities with a considerable inheritance of long stay beds in community hospitals were seen as more generous in judging eligibility for continuing care, but were increasingly recognising the inflexibility of provision that had been developed under an inappropriate ethos of 'a bed for life.'

In all the sites visited a recurrent theme concerned the wish to see national criteria for NHS continuing care. This is a view that has been expressed since criteria were first introduced in 1996, and it was reiterated once more. While it was recognised that there is potential for reducing variation of criteria by locating responsibility for strategic coherence with SHAs, it was still remarked that there remained problems with variability between SHAs and issues therefore arose about equity for patients.

Even if criteria were to be established nationally (in a similar way to the approach followed with the determination of RNCC), it was acknowledged that there would remain challenges of implementation and interpretation of criteria (not least because of the uncertainty about the boundary between health and social care which the Coughlan judgment failed to resolve). The quest to ensure greater consistency in practice had led several of the SHAs to explore the applicability of an assessment tool. Such matters were generally approached with some caution, and it was recognised that a tool should be an aid to decision making, rather than providing a definitive answer. Many of the sites would welcome greater leadership from the Department of Health in recommending the use of validated assessment tools. There are some obvious tensions between the wish to see greater national leadership and guidance in a context in which devolved responsibility and local autonomy are being promoted.

It was evident that in the past local implementation support around the introduction of eligibility criteria for continuing care had tended to be weak in many authorities. In particular, front line staff were reported to have been poorly engaged and to have failed to understand or follow the requirements of guidance. Many sites recognised the vital importance of developing and cascading training programmes throughout the territory. In most sites progress with this task had been slow and had taken second place to the more immediate concerns of finalising the revised criteria, and undertaking the retrospective reviews. It was typically the case that the same core of people was involved in all these tasks and there were major issues about capacity to deliver. Most sites had resolved to move ahead with the roll out of training and awareness raising as soon as they were able to.

The eligibility criteria developed across the 9 SHAs are very similar to the extent that they repeat large sections of the Department of Health guidance. Differences are apparent in the extent to which this is elaborated and illuminated; many have added to a core document by the development of more detailed guidance and explanatory text. The need to reflect the precise wording of national guidance in criteria reflects the local concerns of SHAs to safeguard themselves against legal challenge. However, it is precisely because the specific meaning of much of the wording of the Coughlan judgment is believed by the sites to be

unclear or disputed, and because Departmental guidance cannot offer further interpretation of the legal decision, that a lack of clarity is often reproduced in local policies and protocols.

It is evident that the understanding and conceptualisation of continuing care has undergone a significant evolution in most localities since guidance was issued in 2001. There is now a much wider acceptance that:

- Eligibility for NHS fully funded care should be determined by needs and not on the basis of a diagnosis.
- Continuing care can take place in a range of different settings and is not restricted to care in an NHS hospital.
- Eligibility for continuing care is not a static state, and as people's needs change so may their eligibility for fully funded care.
- Continuing care should not be seen as part of a hierarchy of care, and it is *not* the next level above the top band of RNCC determination.

These developments reflect the intention of the 2001 guidance; ensuring that this shift in understanding flows through all organisational levels will require continued attention.

### ***Investigation and Restitution***

The Department of Health had issued an outline of a suggested procedure that might be followed by SHAs/PCTs in developing their process for retrospective investigation of past decisions that resulted in financial injustice for patients. The analysis in Section 3 demonstrates that the 9 sites followed broadly similar approaches, although these differed in detail and complexity. There were also variations in the role assigned to review panels; while most sent all cases investigated to panel for final decision, others used them only where there was doubt or where patients and their families were unhappy with the refusal of restitution.

The process of review and restitution was generally treated as a high priority and was actively project managed, typically involving the same personnel that had been engaged in work around the revision of eligibility criteria. Considerable anxiety surrounded the process and many respondents expressed concern that their approach would prove to be insufficiently robust and further intervention from the Ombudsman would require them to

repeat the exercise. It was recognised that there was a 'core' of cases in all the sites where it would be impossible to satisfy people that their case had been properly handled unless it overturned an earlier judgment denying them fully funded care. These cases typically involved articulate and well informed individuals who were usually the relatives of a patient who was often now deceased. The involvement of solicitors was increasingly evident.

The approach to case finding in most SHAs had relied in the first instance on cases presenting themselves for review, and on those that had come forward as the result of advertising and publicity of the restitution exercise. It was widely recognised that there could be a further task still to be completed that would entail seeking out cases. There was a concern that many of the most disadvantaged cases might have been overlooked by a process that had favoured the articulate and well-informed population.

In a number of sites, social services authorities were also beginning to recognise that they might need to challenge past decisions which had left them meeting the costs of care that it was now believed should have been the responsibility of the NHS. Such awareness was set alongside a recognition that many health economies were facing financial challenges and there might be little purpose in pursuing this issue particularly at a time when there is an increasing emphasis on developing whole systems approaches and partnership working.

The process of review was extremely arduous and demanding for those most closely involved, and carried significant emotional costs both for staff and for claimants. Staff often expressed their concern for the well being of relatives who had their expectations raised by reporting of the issues but had no realistic prospect of restitution, and underwent an often distressing review for no purpose.

There were also substantial logistical difficulties associated with the task. The scale of response to requests for cases to be brought to the attention of SHAs and PCTs took many by surprise. None of the 9 sites would have been in a position to meet the original deadline for completion of reviews, and few would fully meet the revised deadline (although all were well on the way to doing so). The number of cases reviewed ranged from less than 200 to more than 1,600. The proportion of these cases awarded restitution varied from 4% to 15%.

The sheer volume of work that was involved in investigating each case was clear, and many staff commented on the difficulties of managing these tasks alongside their normal commitments and without any additional support. In fact, substantial additional resources were made available by the Department of Health to meet the costs of restitution. Particular problems were encountered in the course of investigations, and these were most acute around locating and applying relevant information.

The poor quality of documentation and of assessment data featured throughout the sites. Sometimes this was simply a reflection of the passage of time, more often it was indicative of a lack of base line assessments, failure to continue any care management, and a casual disregard for the importance of record keeping. These challenges were often greatest with nursing home records which in many instances were poorly maintained or non-existent (especially when home closures had taken place and care records had disappeared). It was also recognised, however, that some examples of record keeping were excellent. Many respondents were surprised by the minimal regulations on record keeping that do not require files to be kept more than three years. Worryingly, in one or two localities some of the files that were examined appeared to record abusive practices that had gone unchallenged, and had clearly not been written in the expectation that anyone would ever read them. A minority of cases were uncovered in which records had apparently been created for the purpose of the review and did not provide a contemporaneous account.

Despite the difficulties that were encountered in undertaking review and restitution, it was clear that many staff involved in the assessments were only too delighted when they were able to tell someone that they would receive recompense for past mistakes. Staff believed passionately that it was morally right to do all in their power to ensure that justice was done.

There were incidental benefits that resulted from the review process; in particular it provided a valuable audit of past practice. Some of the findings confirmed people's worst expectations about the quality of assessment, care management and day to day care practices, while others indicated that practice was generally good. These findings need to provide the foundation for a deliberate strategy to improve practice across the board. For this to occur it will be essential that the raised profile of continuing care will be maintained in SHAs and PCTs.

Overall the decision by the Department of Health to embrace a restitution process was generally accepted as having positive outcomes, both for individual patients and their families, but also in promoting greater understanding of NHS continuing care. However, it is also apparent that momentum needs to be maintained if the benefits that have resulted are not to be lost and if further progress in the clarity and consistency of policy and practice around continuing health care is to be achieved.

# Continuing Health Care: Review, revision and restitution

## 1 Introduction

- 1.1 The responsibilities of the NHS for funding long term or 'continuing care' are the focus of on-going debate and – at times - confusion. Following a report on NHS funding for long term care published by the NHS Ombudsman in February 2003, the Department of Health introduced a requirement for Strategic Health Authorities (SHAs) to establish an integrated set of criteria for NHS continuing care to operate across each SHA territory, and to review earlier continuing care decisions in order to identify cases that had been wrongly assessed as ineligible for funding for continuing health care, and to make appropriate recompense. Since February 2004, patients must also be assessed for continuing care before they are discharged from hospital.
- 1.2 An independent review was commissioned by the Department of Health to explore local progress with the review task, and to provide a snapshot of the current state of play with continuing care. The review was undertaken across 9 SHAs (approx one third of the total) across the country. Before presenting the findings and conclusions from this analysis, it is essential to set this in context and to provide a brief overview of the background to the latest developments.

### ***Policy Background***

- 1.3 The controversy that surrounds NHS continuing care is of long-standing. In the preparation for the introduction of the community care reforms in 1993 there was recognition of the need to control the withdrawal of the NHS from responsibility for continuing inpatient care that was apparently taking place in some parts of the country. Clarifying and agreeing arrangements for continuing health care were one of the 'eight key tasks' identified by the Department of Health in joint letters issued by the then NHS Executive, and the Social Services Inspectorate.
- 1.4 The current debate around respective NHS and local authority responsibilities for long term care dates in particular from guidance issued by the Department of Health in 1995.<sup>1</sup> That guidance provided reaffirmation that arranging and funding services to meet continuing physical and mental health care needs "are an integral part of the responsibilities of the NHS." Moreover, it was stated that "this includes, but is not

limited to, the responsibility to arrange and fund an appropriate level of care from the NHS under specialist clinical supervision in hospital or in a nursing home.” In addition, the responsibilities of the NHS for continuing care also included “equally important responsibilities around rehabilitation, palliative health care, respite health care, community health services support and specialist health care support in different settings.” All health authorities and GP Fundholders of the time were reminded that they must arrange and fund a full range of these services to meet the needs of their population.

- 1.5 The 1995 guidance required health authorities to develop eligibility criteria for continuing health care that would be finalised and operational by 1 April 1996. The guidance had been issued in response to a number of concerns raised in a report issued by the Health Service Commissioner. This had investigated the failure of Leeds Health Authority to make available long term care for a seriously incapacitated patient who no longer required acute health care, but *did* require full time nursing care.<sup>2</sup> The report observed that at the heart of the individual complaint resided “the question of what provision should be made by health authorities for patients like him, who need such care on a continuing basis.” The 1995 guidance can be seen to provide a clear statement of the responsibilities of the NHS in long term care. To some extent it might also be seen to acknowledge that some health authorities had gone too far in moving away from long term care.

### ***The Coughlan report***

- 1.6 The next significant step in the chronology of continuing care came in 1999 with the publication of a judgment by the Court of Appeal (R V North and East Devon Health Authority ex parte Coughlan). The judgment on whether the NHS or local authority was responsible for the continuing care of a patient hinged upon whether the nursing services provided were merely:
- incidental or ancillary to the provision of accommodation which a local authority is under a duty to provide;
  - of a nature which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide;
  - and where a local authority is excluded from providing services where the NHS has in fact decided to provide them.

- 1.7 This led to further guidance being issued in 1999, requiring health authorities to satisfy themselves that their continuing health care policies and eligibility criteria were compliant with the judgment and existing guidance.<sup>3</sup> More guidance followed in 2001.<sup>4</sup> Following the Coughlan judgment and until the implementation of Section 49 of the Health and Social Care Act, removing from local councils the responsibility for providing nursing care by a registered nurse, NHS eligibility criteria for arranging and funding nursing services in nursing homes were required to address three situations:
- Where all the nursing service is the responsibility of the NHS because somebody's primary need is for health care rather than accommodation.
  - Where responsibility for care can be shared between the NHS and local councils, because nursing needs in general can be the responsibility of the local council, but the NHS is responsible for meeting other health care requirements.
  - Where the totality of the nursing service can be the responsibility of the local council and there are no other health care needs.
- 1.8 The implementation from October 2001 of NHS funded nursing care introduced new arrangements making the NHS responsible for funding care in nursing homes provided or supervised by a registered nurse. This applied to self-funding residents in the first instance, and to all residents from April 2003.
- 1.9 The 2001 guidance effectively provided consolidating guidance on NHS continuing health care responsibilities in the light of the judgment ex-parte Coughlan. Health authorities, in conjunction with Primary Care Trusts, and working very closely with local councils, were required to ensure their continuing NHS health care policies complied with the guidance by 1<sup>st</sup> October 2001, and to agree joint eligibility criteria setting out their respective responsibilities for meeting continuing health and social care needs by 1<sup>st</sup> March 2002. The guidance also signalled that in view of the merging of Health Authorities into Strategic Health Authorities in the near future, "over time, the new SHAs should align the continuing NHS health care criteria they have inherited and ensure that only one set of criteria exist across each SHA." These responsibilities were subsequently set out in Directions that came into force on 27<sup>th</sup> February 2004.<sup>5</sup> The duties of SHAs are summarised in Box 1 below.



### ***The Health Service Ombudsman's report and DH response***

- 1.10 In February 2003 the NHS Ombudsman published a report drawing attention to four complaints about NHS funding for long term care which had been investigated. The cases highlighted deficiencies in eligibility criteria that were over-restrictive, or were not compliant either with Department of Health guidance or with the Coughlan Court of Appeal judgment.

#### ***Box 1***

##### ***Duties of Strategic Health Authorities in relation to continuing care***

Each Strategic Health Authority must:

- Establish a single set of eligibility criteria for the provision of continuing care by Primary Care Trusts and NHS Trusts for which the Strategic Health Authority is the appropriate Strategic Health Authority; and
- Make arrangements for review of decisions made in relation to such care.
- Criteria must be established by 30<sup>th</sup> April 2004, and reviewed thereafter as appropriate.
- Before establishing or reviewing criteria the SHA must take such steps as it considers reasonable to obtain the agreement of each of the PCTs for which it is the appropriate SHA, and each local authority all or part of whose area is within the SHA's area.

- 1.11 The findings in the Ombudsman's report, together with themes emerging from cases still under investigation, led to the following conclusions:

- The Department of Health's guidance and support to date has not provided the secure foundation needed to enable a fair and transparent system of eligibility for funding for long term care to be operational across the country.
- What guidance there is has been mis-interpreted and mis-applied by some health authorities when developing and reviewing their own eligibility criteria.
- Further problems have arisen in the application of local criteria to individuals.
- The effect has been to cause injustice and hardship to some people.<sup>6</sup>

1.12 A week after the publication of the Ombudsman's report, the Department of Health issued its response. This reiterated the requirement for Strategic Health Authorities to complete their work to agree with local councils one set of criteria for continuing care (in line with the guidance issued in 2001). In addition, the Department of Health requested SHAs to review whether continuing care criteria in use in their area since 1996 were consistent with the Coughlan judgment. Subsequently further requirements were introduced for SHAs and Primary Care Trusts to agree procedures to investigate cases where people may have been wrongly denied continuing care. Where it is established that the NHS *should* have funded a person's care, appropriate recompense is to be made. Initially there was a requirement to complete all the investigations by the end of December 2003. This deadline was later revised to 31 March 2004.

### ***Reviewing local developments***

1.13 This introduction has provided an overview of the context within which the local review of eligibility criteria needs to be understood. It is apparent that NHS continuing care has been the focus of considerable attention since 1995, and that there remains uncertainty over the consistency of eligibility criteria and their application to individual cases. The report turns now to examine how SHAs have approached the requirement to agree a single set of criteria, and to review compliance of past criteria since 1996.

1.14 A review of developments was undertaken across 9 SHAs. These were selected on the basis of a number of criteria. Some were self-selecting and put themselves forward for inclusion in the review. Others were chosen to reflect different variables including geography, scale and complexity, socio-demographic features, and history of continuing care development within the health economy. Together the 9 SHAs provide a good spread around the country and are likely to be fairly representative of all SHAs. All participating SHAs (and their respective PCTs, acute trusts and local authority partners) were given assurances of confidentiality. The sites are not therefore being identified in this report. The purpose of the review was not to conduct an audit or to evaluate those localities that were doing better or worse, rather it was to provide an independent assessment of local practice in NHS continuing care, and to examine the key challenges facing NHS staff locally. A brief descriptive case study of

the 9 SHAs is included as an appendix to the report. The analysis which follows adopts a cross-cutting thematic approach across all the sites.

## 2 Integration of Eligibility Criteria

- 2.1 As the overview in Section 1 identified, two sequences of review of continuing care eligibility criteria followed each other in short succession. First, the consolidating guidance issued in 2001 required Health Authorities to ensure their criteria were Coughlan-compliant and to agree joint eligibility criteria setting out respective responsibilities for health and social care by March 2002. Second, directions were issued in draft form in 2003 and finalised in 2004 requiring Strategic Health Authorities to establish a single set of eligibility criteria by 30<sup>th</sup> April 2004.
- 2.2 In a couple of the SHAs this was experienced as an onerous process; no sooner had one review been undertaken than another one was required. However, the need for SHAs to assume responsibility for continuing care eligibility criteria *had* been made clear by the Department of Health in 2002 and the new directions should not have come as a total surprise (even though this *did* appear to be the case in some authorities). In most of the 9 SHAs it was believed that the two processes were actually mutually reinforcing, and much of the work that had been done in response to the 2001 guidance made the development of a single set of criteria considerably easier than it might otherwise have been.
- 2.3 However, it was also evident that the process of reviewing and agreeing criteria for NHS continuing care was, in most of the SHAs visited, disrupted by the parallel need to undertake a retrospective review of criteria in operation since 1996. These issues will be explored in greater depth later in the report.
- 2.4 SHAs typically established a working group to take forward the work on developing integrated criteria (and subsequently to steer the approach to restitution). This was sometimes referred to as ‘the harmonisation group’ or the ‘continuing care integration group’ and included representation from PCTs and local authority social services departments alongside SHA officers. In situations where multiple PCTs operate across an SHA there have been some attempts to develop an alliance whereby one or more people are empowered to represent more than one PCT.

### ***Challenges of integration***

- 2.5 The process of producing a single set of criteria across each SHA inevitably brought challenges and problems. In particular, where predecessor health authorities had

been operating non-compliant criteria, or where there have been widely differing criteria between health authorities that must now operate under a single SHA set of criteria, there have been difficulties. As a respondent in one such authority remarked:

*“The former health authorities were from left to right of a continuum, and we are trying to bring them somewhere into the middle, but from very different beginnings.”*

- 2.6 Such difficulties reflect the range of histories and practices that have developed locally. Predecessor health authorities had varied in their approach to NHS continuing care for a range of reasons. In localities that had a heritage of large numbers of NHS long stay beds, for example, criteria had tended to be very loose by comparison with those who had little provision of their own and had drawn their eligibility criteria more restrictively. The impact of this was evident as these comments illustrate:

*“We had very few people in high band RNCC because most of those were in continuing care because the criteria had been very generous.”*

- 2.7 Despite the requirements of the 2001 guidance that health authorities (in conjunction with PCTs) should work “very closely” with local authorities, and should “agree joint continuing health and social care eligibility criteria with local councils, setting out their respective responsibilities for meeting continuing health and social care needs”, it was evident that many health authorities had been operating criteria that had never been agreed or signed-up to by social services partners, and that disputes had been on-going.

- 2.8 The integration of criteria was often far more challenging than might appear on first sight. While in principle criteria could appear very similar, in their presentation and interpretation they were in fact quite different.

- 2.9 In many sites it was recognised that there was now an opportunity to get political agreement and to ensure there was – often for the first time – sign-up by all health and social care partners. Respondents acknowledged that practice in the past had often been ‘fudged’ and in the absence of any clear agreement over policy, decisions were inconsistent. Despite a much stronger emphasis on trying to secure consensus with the integrated criteria, and demonstrating a willingness to compromise over the wording of criteria that partners viewed as overly-restrictive, many SHA respondents nonetheless acknowledged that continuing care remained a very minor issue on their overall agenda:

*“It is seen as marginal; it is on the fringe of strategic health concerns. It is only the financial risk that has driven this forward. We recognised early on that there was no forum in health and social care economies where continuing health care was central. We’ve tried to change that by having a joint strategic approach informed by the experience of operational staff.”*

*“There are lots of reasons why it has remained a marginal issue that haven’t been addressed, but the retrospective reviews have really forced SHAs and PCTs to focus. The Ombudsman has given us an opportunity to address this, albeit that it has been very irritating.”*

- 2.10 A similar comment was made in another SHA where it was acknowledged that the Ombudsman’s intervention had provided an opportunity to get the issue on the agenda and force change, as this comment illustrates:

*“From 1<sup>st</sup> April it means that there will be no more decisions under the old protocol. We need to spend a lot more (on continuing health care), but there is now a much better recognition that we are talking about a spectrum of provision rather than yes or no.”*

- 2.11 Despite this acceptance, the difficulties of trying to implement the requirements without any additional resources were frequently remarked. A similar issue that was identified repeatedly was the lack of support that had been provided compared with other areas of service modernisation. Many respondents lamented the missed opportunities for shared learning and experience between SHAs, and the consequent uncertainty over local developments, for example:

*“We just didn’t know where we were with this – whether we were ahead, or behind, or whether our criteria were more restrictive or not!”*

And

*“Every area must be dealing with exactly the same issues we are; why couldn’t that have been approached consistently?”*

- 2.12 In some areas the review of criteria provided an opportunity to tackle patchy implementation. Too often there had been reliance on the variable quality of local partnership arrangements and informal relations to ensure that continuing care assessments could be handled on a case by case basis. Where relations were not of such quality, there was concern that people were then reliant solely on criteria which

were inadequate for the task and were applied inconsistently within and between PCTs.

- 2.13 Health authorities had sometimes been able to continue to operate overly tight criteria, for example, in one instance where their local authority counterpart was perceived as “weak” and unwilling to challenge such practices. A change at chief officer level in social services had been accompanied by a very different climate and much less tolerance of perceived cost-shifting by the NHS to the local authority.
- 2.14 Most SHAs were anxious to ensure that their revised criteria met the legal requirements of the Coughlan judgment, Section 21 of the 1948 Local Assistance Act and Department of Health guidance, and sought legal advice on their approach. Social Services often forced this process by seeking counsel advice on whether existing criteria were Coughlan-compliant. The prospect of illegal criteria and the likelihood of continued challenge, review and possible involvement of the health service Ombudsman, has provided important leverage in securing agreement over criteria which all partners are prepared to sign up to.
- 2.15 The documentation presenting each SHA’s criteria typically emphasises that this is a joint policy developed by the SHA but with involvement of representatives from the local health economies and from local authority social services departments. In all the SHAs it was acknowledged that the development of the criteria was only part of the task, and that the real challenge would arise in ensuring consistent implementation across PCTs. To this end, considerable emphasis was laid on the importance of training for health and social care staff as the key to bringing about not only a thorough understanding and knowledge of the criteria, but also in contributing to a cultural change that needs to take place within both health and social services. However, much of the development of training programmes had yet to get underway.
- 2.16 In some SHAs it was recognised explicitly that within a framework of shared criteria there would be local implementation differences, including the use of different assessment documentation and methodologies. As one SHA states in the eligibility document, while offering guidance based on current best practice on the interpretation of the criteria, it is the responsibility “of each PCT in discussion with social services and local NHS trusts, to define and agree operational procedures within the agreed framework and in the context of local circumstances.”

### ***Training and implementation***

2.17 In all SHAs visited there was an awareness of the importance of training and awareness raising to support the implementation of the revised eligibility criteria. It was apparent that in many localities this had been an area of weakness in the past. For example, this respondent with a nursing background described how there had been very poor implementation locally following the 1996 criteria and their revision following the 2001 guidance. The result was poor awareness, particularly among the very front line staff who need to understand continuing care:

*“There was no awareness at all. Personally I feel that I let a lot of people down because I didn’t know about their entitlement to continuing care. There is still a lack of knowledge; many clinicians don’t understand what they are signing.”*

2.18 This person went on to indicate that there were some grounds for hoping that awareness was improving:

*“I think that reimbursement has strengthened practice and improved awareness, as has the Discharge workbook, but it is essential that each acute ward has a copy available. We have to bring these issues into focus at each level. We have gone from having a huge document (for continuing care eligibility criteria) to one which is much shorter and splits the policy and the implementation guidance. That is good, but there is still a lot to do around the guidance.”*

2.19 A history of poor implementation in some localities appeared also to have been indicative of wider issues including an absence of care management of continuing care cases in the past.

2.20 The inclusion of illustrative case studies in guidance material had been followed in several of the SHAs. This can be of value, but equally some people were concerned about the risks of using examples which were still open to interpretation and therefore failed to provide the sought after clarity. In some sites (such as SHA 2) the SHA had taken the lead in appointing a trainer to facilitate roll-out and implementation for a limited period, and to ensure as far as possible that PCTs were following similar approaches locally. While such developments were welcome, it was also acknowledged that this needed to be a rolling programme and “really should be a full time job”, particularly if all partners (including independent sector providers) were to be adequately involved.



- 2.21 One finding that arose in many of the sites was the unexpected value of the retrospective review process in informing approaches to training in support of the revised continuing care criteria. Because training had been developed around the review process and training packs had been produced for assessors to ensure consistency in reviews, it was recognised that there would be added value in using the same material in support of staff training in the approach to current cases.
- 2.22 Some SHAs had been able to test their criteria while they were developing them and had applied them to case study material in order to check consistency of interpretation. A similar approach was being applied in rolling out awareness raising and training across local health economies.
- 2.23 The pace of roll out of training was slow in all the SHAs visited, and while the experience from the restitution process was being used to inform other training and implementation support, it was also recognised that while people were focused on restitution, they had ‘taken their eye off the ball on training’. Because the same people were typically involved in both restitution investigation *and* implementation of the revised continuing care criteria, real issues of limited capacity had arisen. In some localities training was still being approached separately by health and social services, but it was increasingly recognised that this needed to be shared and more fully integrated.

### ***Assessment tools***

- 2.24 In an attempt to reduce or eliminate such inconsistency, some SHAs had chosen to utilise an agreed assessment tool in determining eligibility for continuing care. Such approaches were evident in four of the SHAs, and the possibility of using standard assessment tools was under discussion in others. Two SHAs were using a similar tool that provided assessment across a number of Care Domains (breathing, communication, cognitive impairment, behaviour, seizures, mobility, continence, skin care, drug therapies, and food and drink). In one of these SHAs the tool was applied to allocate a weighted score to each of the domains. Eligibility for continuing care was then indicated by a range of ‘threshold scores’ (see Appendix 1, SHA 3). A guidance document issued by the SHA made it clear that the final decision must be made in accordance with the eligibility criteria and not simply on the basis of the score of an individual. Moreover, individuals who do *not* fall within the weighting range may still be entitled to NHS continuing care “where the overall scale of the

individual's needs is such that their primary needs are health care needs and they should therefore be regarded as wholly the responsibility of the NHS.”

2.25 There had been an on-going debate between the SHA and one of their partner local authority social services departments over the use and application of this tool. In particular, there had been disagreement over the threshold scores. The trigger of 5 or more care domains scoring 60 or more is believed by some to be over-restrictive in its application. The objection from social services was *not* to the use of a tool *per se*, indeed there was support for a tool that would assist in making decisions both more transparent and more consistent. However, the issue was about the level at which the threshold is established, and the extent to which a scoring approach can reduce the need for professional/clinical judgment in decision making. The SSD had proposed that 4 domains scoring 60 was “a fair reflection of where we should draw the line” and indicated considerable convergence with professional judgment.

2.26 SHA 7 was using a similar tool and again this highlighted some tensions between health and social care partners. As this social services respondent commented:

*“I accept the issue about striving towards greater consistency, but from the local authority perspective I am still not convinced that the decisions are right, even if they are consistent! We are trying to ensure that the SHA doesn't give social services responsibilities that go beyond their powers and duties, and I'm not convinced that is the position. (...) There is a lot of debate around the legitimacy of weighting different domains, and that leaves us (social services) in the very difficult position of challenging clinical judgment.”*

2.27 SHAs making use of assessment tools were generally explicit in seeing these as a device to *assist* in the decision making process. In SHA 7, for example, work was on-going around the application of a health and social care Assessment of Care Need tool. Guidance produced by the PCT alliance clearly states:

*“The assessment tool is designed to assist in determining whether a patient is eligible for NHS funded continuing care. The tool should not be used in isolation. It will be necessary to identify supporting clinical evidence as the tool will only identify the nature of health needs not complexity or unpredictability or whether the patient's condition is unstable or deteriorating.”*

2.28 Based on the information gathered from the assessment tool and the supporting evidence, it is then for the assessor to make a judgment as to whether the patient's

need is primarily for health care, or whether the needs can be met through the RNCC for patients in nursing homes, or through community and primary care services for patients at home or in a residential care home.

- 2.29 A slightly different approach was evident in another site (SHA 9) where the tool in use is a 'Case Evaluation Trigger List'. Rather than adopting a scoring approach or providing an assessment tool, this list provides a number of questions that assessors need to ask themselves about the outcome of the needs assessment they have undertaken. This includes three 'tests' of eligibility for NHS continuing care in respect of substantial health needs; substantial health care inputs; and long term or near to death situations. The trigger list should be applied to ensure consistency of assessment and consideration of eligibility.
- 2.30 In one other site (SHA 6) a toolkit had been developed for use in the retrospective reviews. This provided a standardised set of documentation for completion including information in respect of: communication, mobility, personal hygiene, continence, skin condition, pressure risk rating, nutrition, sleeping patterns, discomfort/pain, and emotional and psychological well-being. The experience with developing the toolkit for retrospective application had led to interest in the locality in developing something similar for use with current continuing care determinations.
- 2.31 In sites that had not adopted an assessment tool there was more scepticism about the value of such a methodology. Some respondents believed there was a dichotomy of approaches that either had to be "a tick box approach, or flexible and client-based." It was widely recognised that a scoring system could make it easier for clinicians to explain their decisions to patients and their families, while "the more flexible it is, the more open to interpretation it becomes." Some respondents believed that there is an increased tendency to adopt scoring approaches because of a trend towards more 'defensive practice' that has been forced by the involvement of the Ombudsman. The prospect of further challenge from the Ombudsman can lead people to seek a defence in the evidence of a scoring model. Many respondents recognised, however, that there are risks in "relying on a pseudo-scientific approach to point scoring" particularly with tools that have not been fully validated, and were cautious about adopting a tool without further development and testing.
- 2.32 In other sites there had been experimentation with the use of tools but scoring approaches had been rejected when they were believed to "devalue professional

judgment.” It was recognised that allowing people to use their skills should not entail widely diverging opinions, as this respondent observed:

*“We have tried not to put anything in place that will remove professional judgment. We didn’t want to have to make people’s needs fit into a framework. In giving people the freedom to use their professional judgment, **and** driving the process with clear criteria from the centre, we are controlling the inputs to the process and monitoring the outputs.”*

2.33 One development that was emphasised frequently was that although clinical and professional judgment remained important, new processes were bringing about a shift away from the unilateral decision making that had often characterised past practice. In future, individual clinicians and practitioners would be asked for their assessment reports, but the decisions would be made at the level of a panel where all such multi-disciplinary information would be collated and reviewed.

2.34 In many localities a parallel debate was taking place over the development of the Single Assessment Process (SAP), and the use of particular assessment tools as part of that. There was recognition that continuing care assessment needs to be integrated as part of the approach to SAP, and effectively operate as an integral specialist assessment, rather than as something entirely separate. However, developments have been hampered by the slow rate of progress around SAP. The experience in some localities in developing SAP is believed to indicate the value of using an appropriate and reliable tool that provides greater consistency, as this social services respondent observed:

*“We have learned from SAP that if you have a fairly prescriptive tool, with detailed practice guidance, you can train people up (...) it gives them a framework within which to use their professional judgment.”*

2.35 The attractions of developing a strongly protocol-driven practice lie in the prospects for reducing the variation that is associated with the unfettered use of professional judgment, it was believed that a protocol-led approach would also provide a stability that would withstand the continuing process of organisational ‘churn’ and turnover of key members of staff.

2.36 Some respondents articulated their concerns over having to move ahead with assessment for continuing health care before Single Assessment was properly operational, and that there was (or should be) a ‘logical sequence’ of developments

which it had not been possible to follow. It was also recognised that while criteria for NHS continuing care need to apply to all adult client groups, SAP only applies to older people. In all the SHAs visited there were debates about the extent to which CHC criteria were fully sensitive to the needs of all client groups (particularly people with mental health problems and those with learning disabilities for whom the terminology of criteria may be inappropriate and over concerned with physical needs). It was also recognised that there were further debates to take place over continuing care for children with complex needs.

- 2.37 Some respondents believed that clearer central guidance was needed around the development of assessment tools and ensuring that similar approaches were followed everywhere, as this comment illustrates:

*(...) We need national criteria, but we also need a national tool or tools; why go through the process again and again in all parts of the country when we are all trying to achieve the same thing?*

And

*"I want to be totally honest and transparent in what I do, and people can understand if you talk to them about things like eating and drinking, rather than using terms about complexity and unpredictability where you have to be a lawyer to understand what it means!"*

- 2.38 In this PCT (in SHA 2) there had been interest in trying to use a standard assessment tool and there was an 'informal agreement' to utilise the same model that had been adopted in SHA 3 (although there did not seem to be an awareness of the controversy that has surrounded the threshold scores in SHA 3). The agreement to use an assessment methodology was not one that had been made at the level of the SHA; it was possible therefore that various approaches to assessment would develop across different PCTs in SHA 2.

- 2.39 The debate around the use of assessment tools across the SHAs can be seen as part of a wider issue that reflects underlying differences of approach between health and social care. This was epitomised for many respondents in the contrast between needs-led and service-led approaches. Social services respondents generally believed that they followed a more needs-led model, but that this was relatively alien to their health service colleagues.

## **Eligibility Criteria**

- 2.40 The search for an appropriate assessment tool in several SHAs highlights a more widespread concern about the importance of consistency of application of criteria, and indeed the consistency of the criteria themselves. These are issues that have received on-going scrutiny by the NHS Ombudsman. The report published in February 2003 drew attention not only to the need for eligibility criteria to be consistent with guidance and to have been reviewed in the light of the Coughlan judgment, but also to the significance of *reliable assessment* otherwise inconsistency would result.
- 2.41 A further report from the Ombudsman in December 2003 highlighted another statutory investigation involving continuing care where the complaint was upheld on the basis that “the former Health Authority’s assessment process was flawed, documentation was incomplete and the patient’s family was given no information about the eligibility criteria, nor involved in the discharge process.”<sup>7</sup>
- 2.42 There was a general recognition across the 9 sites that the development of integrated criteria in 28 SHAs marked an improvement on the previous situation where there might have been 95 different sets of policies and eligibility criteria operated by health authorities throughout the country. However, there were still major issues about the differences between the 28 sets of criteria, and the implications of this variation - particularly at the boundaries between SHAs. It was still apparent that most respondents viewed the situation as a compromise, as this individual remarked, “it is still a postcode lottery; there are just fewer postcodes now.” In all SHAs visited, respondents were highly critical of the absence of national eligibility criteria for NHS continuing care. The forceful remarks which follow were typical of those encountered:
- “There has been an enormous, staggering, lack of central guidance! We wanted a framework that we could work within. Such guidance as there has been has largely been informal – such as through meetings of leads with the Department. The worry must be that the Department hasn’t responded to the Ombudsman’s criticisms about insufficient national guidance, and doesn’t that mean that we will be back here in the same position in having to review decisions again in a few years time?”*
- 2.43 A contrast was often drawn between the local approach to be followed with continuing care and the national framework and assessment model that has been specified for

the determination of needs for registered nursing care (RNCC). As this PCT respondent commented:

*“The RNCC framework gave us something that we could hang our decisions on; it encourages understanding and uniformity – it gives you something more tangible that you can use to explain how and why you have reached your decision.”*

- 2.44 Nonetheless, it was also acknowledged, that even were there to be national criteria, there would still be issues about the ways in which those criteria were implemented locally. It was generally believed that this would be preferable to the current inequities that are believed to exist between SHAs. Many respondents expressed their frustration at the considerable amount of time and effort that had been invested in revising the criteria, for example:

*“The Department will have 28 variations in policy and criteria. There is frustration around the energy input to all of this. If we had a common national policy to work to the energy would have gone into that. It has been a very poor use of resource; there should be a national policy. As things are, we are all getting played off against each other by smart clients and solicitors.”*

- 2.45 The fear of further legal challenge was uppermost in people's minds in all the 9 SHAs. There was a conviction that more judicial review and intervention by the Ombudsman was inevitable, and in such circumstances there was a wish for greater clarity in being able to defend decisions. Some respondents believed that the guidance published in 2001 represented an improvement on that issued in 1995, but was still inadequate if the objective was to ensure that all health authorities are consistent:

*“The guidance needs to be more explicit – criteria are still not the same between SHAs, and that means that people who have a boundary with us are not applying the same criteria that we are.”*

- 2.46 In some instances these differences were very stark and were not simply a matter of different application of criteria, but of a fundamentally different approach to conceptualising the basis for eligibility. For example, one SHA referred to a situation where one of its neighbouring authorities automatically confers eligibility to all Huntington's Disease patients, which was contrary to their own needs-based criteria and was expected to lead to challenge. For localities that experience considerable

inward migration to their care homes these matters are of particular significance, and issues around establishing the responsible commissioner are especially pertinent.

- 2.47 The integrated eligibility criteria developed by the 9 SHAs are summarised in Appendix 1. It is apparent that there is considerable similarity (at least superficially) in both the style and content of many of these documents. While most of the documents have been written mainly for the guidance of health and social care professionals, some have attempted to be accessible to, and easily understood by, a wider lay audience and members of the public, and one SHA had sought advice from the Plain English Campaign.
- 2.48 In some SHAs the working groups developing the criteria reviewed as many as possible of the continuing care criteria documents produced by other SHAs. There had been a hope that it might be possible to borrow from the experience of others, but in practice this was rarely the case. As one social services respondent remarked, these documents “were either hugely over-complicated or totally inaccessible, so in effect we ended up starting from a blank sheet.”
- 2.49 Many of the 9 SHA documents repeat verbatim large sections of the text from Department of Health guidance.<sup>8</sup> This might be seen as an indicator of concern to stick closely to the legal basis of the policy particularly given the controversy that has surrounded local criteria since 1996. The nature of the wording of the guidance however is arguably also a direct reason why many of the SHAs and their health and social care partners continue to struggle with clarifying the meaning of the criteria and ensuring consistent application and interpretation. For example, much debate continued in the 9 sites to surround the precise meaning of “the nature or complexity or intensity or unpredictability of the individual’s health care needs”, or of “regular supervision”, and “specialist health care equipment.” Similarly, respondents across the sites emphasised that it can be extremely difficult to explain (or operationalise) the important distinction that the guidance draws “between people who require continuing NHS health care and others with continuing health needs.” A general view expressed by respondents across the sites was that the guidance needed to be updated, and a few questioned why this had not yet occurred given an intended review date of 28 June 2003. While the 2001 guidance was an attempt to consolidate earlier guidance in the light of the judgment *ex-parte* Coughlan, attention was drawn by several respondents across different sites to the need to address significant developments that have taken place since 2001 including:



- The introduction of the RNCC arrangements for nursing care, and the removal of local councils' responsibilities for providing nursing care.
- The development of intermediate care services and rehabilitation.
- The continued pace of medical progress that changes the status of many interventions from specialist to standard or routine.
- The introduction of the Single Assessment Process and Fair Access to Care.
- The introduction of the delayed discharge reimbursement arrangements (although the new assessment requirement for continuing care *had* been addressed in the guidance on reimbursement issued in October 2003).

2.50 Many of these developments have added to the difficulties in understanding how NHS continuing care 'fits' within the total spectrum. Particular problems were identified in all 9 SHAs over the relationship between the top banding of the Registered Nursing Care Contribution (RNCC) determination and eligibility for NHS continuing care. Such problems were believed to be associated particularly with the similarity of wording used to refer both to continuing care and RNCC. The guidance that accompanied the introduction of free nursing care made it clear that it did *not* change the duties of the NHS to arrange and fully fund services for people whose primary needs are for health care rather than for accommodation and personal care.

*"The RNCC tool should be used to determine the registered nurse's contribution as part of a care package. 'Complex' and 'unpredictable' in the context of the RNCC refer to an individual's care needs which require care from a registered nurse, such as fluctuating care needs which require frequent intervention and monitoring from a registered nurse. They should not be confused with similar terminology used to assess an individual's overall health care needs when assessing against continuing health care criteria."*<sup>9</sup>

2.51 However, many of those professional staff involved in assessing people's health needs may be unfamiliar with the detail of the guidance, and clearly the NHS locally needs to address these issues with staff. Equally, while the distinction between nursing needs and overall health care needs may be recognisable to health experts, it is much less obvious to patients and their families.

2.52 Some SHA documents use the guidance as the starting point and go on to provide greater clarity and definition around the application of eligibility criteria within their SHA. In SHA 2, for example, five eligibility ‘conditions’ are identified, any of which may indicate eligibility for NHS continuing care. In each instance there is a brief explanatory text that elaborates the meaning of each criterion. This SHA was also developing accompanying guidance to be used alongside the main continuing care policy document and designed to “assist understanding by either giving examples or setting out more clearly what the policy means in practice.”

2.53 Other SHAs presented examples of clinical characteristics, or combinations of characteristics, which “may indicate consideration for eligibility for continuing NHS health care”). Some SHAs had looked at examples of these approaches elsewhere but were critical of a model that appeared to “go by conditions rather than by need.” In SHA 1 it was remarked that there should not be over-reliance on these characteristics, and that eligibility may come from one condition alone or from the presence of several lesser factors. SHA 3 also referred to particular conditions that determine an ‘automatic eligibility’ for NHS continuing care (examples included patients in a Permanent Vegetative State, patients receiving 24-hour ventilation through a tracheostomy; and people under Sections 2, 3 and 4 of the Mental Health Act 1983). SHA 7 offered an almost identical list of specific conditions that “automatically qualify” for continuing care, and added the further condition of individuals in the final stages of a terminal illness and likely to die in the near future (around 4-6 weeks). SHA 5 similarly identified “persons whose health care needs are such that they are eligible for 100% NHS funded continuing health care without formal assessment.” Others are identified who *may* be eligible for NHS continuing care but *do* require a formal assessment. A wider list of situations is included where patients also might meet the eligibility criteria:

- Evidence of severe pressure sores exposing muscle, tendon or bone or deep tissue.
- Evidence of leg ulcer covering 50% or more of the lower leg.
- Requirement for continuous subcutaneous infusions; continuous oxygen therapy; feeding by gastrostomy; frequent changes of tracheotomy tube.
- Existence of Brittle Parkinson’s disease requiring prompt intervention and frequent medication.

- Existence of convulsions requiring prompt intervention but without the threat of deterioration of the patient's general condition.
- Requirement for disease management of terminal illness/palliative care requiring prompt intervention and frequent medication.
- Evidence of dementia, impaired capacity, mental ill health, confusion, challenging behaviour and complex needs which cannot be managed in the community and requires care in a specialised nursing home and requires supervision of a Consultant or members of the Psychiatric Multi-Disciplinary Team.
- Need for regular therapeutic support deemed essential by a Consultant to be delivered by professionally qualified staff.

2.54 In other documents there was a reluctance to indicate particular conditions or circumstances because of the awareness that whatever examples are given, and however many cautions were issued about these being illustrative rather than exhaustive; there was still a risk that they would be used definitively. Many documents, including that from SHA 5, emphasised that a person's eligibility is determined by their individual health care needs and not by disease or diagnosis. While many respondents agreed that a focus on needs was the right approach, they also felt that it "does make it more difficult to explain and defend" (i.e. particularly when talking to patients and their families who may believe that their needs are the same as those of another person with the same condition).

2.55 Some criteria appeared to exhibit some confusion. For example, one SHA set out the eligibility criteria for NHS continuing care, but went on to observe that where these criteria *are not met* a person would be entitled to NHS continuing care if following an assessment of his or her continuing health care needs, or by reference to the quality, quantity and requirement for continuity of any nursing services provided, the requirement "goes beyond that which a Local Authority can be expected to provide pursuant to its obligations under Section 21 of the National Assistance Act 1948." Or "the services themselves are not merely incidental or ancillary to the provision of accommodation." It seems confusing to present such considerations as something quite separate from the eligibility criteria for continuing care. The implication of the Coughlan judgment was rather that criteria should be such that they meet the requirements around Section 21, *not* that there should be eligibility criteria which

operate in parallel to criteria relating to legal requirements. If a person does not meet the criteria for continuing care, but should do so on the basis of the legal responsibilities of health and local authorities, it is surely the case that there is a shortcoming with the criteria that needs to be addressed.

### ***Health and Social Care responsibilities***

- 2.56 Most of the 9 SHA documents did not present the criteria for NHS fully funded continuity care in isolation. Rather, they indicated the respective contributions of health and social care in providing a continuum of support. Typically, this involves a distinction between what is often classified as ‘Category 1’ (or sometimes Band 1, or Category A) care (NHS continuing care); ‘Category 2’ (often referred to as ‘continuing health and social care’ - a package of health and social care support where the person does not qualify for continuing NHS care but still has health and social care needs but their prime need is for accommodation and personal care rather than for nursing or NHS care); and ‘Category 3’ (where a person has no assessed health needs requiring a service, but they meet the eligibility conditions for social care developed by the local authority under Fair Access to Care – FACS - arrangements, and they receive a package of support arranged by social services). In addressing the criteria for at least the first two of these categories the eligibility criteria set out “to make the distinction between health and social care more explicit” (SHA 1), or “to improve the fairness, public understanding and consistency” (SHA 2). However, some respondents commented on the difficulties of integrating criteria for fully funded care or packages of health and care support because the approach of FACS is concerned with the “seriousness of the risk to independence if needs are not addressed”. This was viewed as a different approach from the harder edged health needs assessment.
- 2.57 Some documents explained the definition of continuing NHS health care in terms of services that are usually considered to be in excess of health care that is “routinely available from primary or secondary care.” All 9 SHAs indicated that NHS continuing care may be provided in a range of settings including hospital; a registered care home providing nursing care; a hospice, or an individual's own home. Whether or not a specific assessment tool is to be used in determining eligibility, all the SHA documents also emphasised the requirement for a person's needs to be assessed through a multi-disciplinary process.

2.58 In the majority of the sites respondents believed that the way forward would eventually be through improved partnership arrangements and the development of pooled budgets. At the present time most were a considerable distance from such practices. There was a strong sense from respondents in SHAs, PCTs and in social services, that in trying to clearly delineate the responsibilities of health and social care there were risks of reinforcing 'tribalism' and constraining rather than facilitating partnership.

### ***Evolution of understanding***

2.59 In reviewing the CHC documents and conducting discussions with respondents in the 9 sample SHAs, it became apparent that despite the ongoing difficulties with NHS continuing care, there *has* been considerable progress in understanding the nature and purpose of such care. The areas in which this evolution appears most significant include the following:

- Recognition that eligibility for NHS fully funded care should be determined by needs and not on the basis of a diagnosis.
- Recognition that continuing care can take place in a range of different settings and is not restricted to care in an NHS hospital.
- Awareness that as a person's health status changes over time, so their eligibility for continuing care may also change; those who meet eligibility criteria may not do so in future, while others who do not meet criteria may become eligible as their needs change.
- Acknowledgement that continuing care should not be seen as part of a hierarchy of care, and is *not* 'the next level up' from the top band of RNCC care.

2.60 Some of these issues have already been explored above. The significance of these changes in conceptualisation cannot be over-stated. Most of the SHA documents include statements acknowledging some or all of these issues. These developments reflect the spirit of the 2001 guidance; many respondents commented on the shifts that had taken place locally in people's understanding of the implications of these subtle refinements that had taken place as a result of being asked by the Department of Health to agree new criteria.

- 2.61 All of these dimensions relate critically to the importance of focusing on the needs of the individual. The acceptance that NHS fully funded care can take place in different settings is of particular relevance in localities that have historically had a low level of provision of NHS continuing care beds. In practice this should not make any difference to the likelihood of a person meeting the eligibility criteria for NHS continuing care since this can be provided in settings other than a hospital. In reality, it is clear that the differing legacies of past provision and practices continue to exert an influence on both the level and nature of continuing care provision.
- 2.62 In some authorities with a long established tradition of continuing care beds provided in community hospitals (such as in parts of SHA 4), it was recognised that this has often led to “decisions being service led rather than needs led.” A review conducted of people admitted to one such hospital over a six month period found, for example that of 50 patients admitted, only 15 had apparently had an assessment for continuing health care and “it is often extremely unclear why they are there and what led to the decision to admit them.” Increasingly it was recognised that such practices had not been in the best interests of patients and had often denied them opportunities for rehabilitation and continued independence. A failure to undertake regular reviews of such patients allowed them to remain in care that was often inappropriate and where their needs did not meet eligibility criteria for continuing care. The mantra of ‘needs first; provision will follow’ was frequently cited as the principle that should drive the approach to continuing care.
- 2.63 If continuing care can be provided in different settings, questions arise about whether beds within NHS facilities should make a distinctive contribution. These matters were under discussion in a number of SHAs. There was increasing recognition that continuing care beds in NHS settings should only be used to accommodate people while interventions or assessment are taking place, or where – such as in the case of palliative care – it would be unwise or inappropriate to move a frail patient. For patients who meet the criteria for fully funded continuing care there is a growing acceptance that this should be provided in environments more appropriate than a hospital ward (typically in independent sector nursing homes, but also in patients’ own homes). However, where there is a long established tradition of NHS continuing care being provided locally, this will usually be fiercely defended by local politicians and members of the public, making it extremely difficult to reconfigure provision more appropriately.

2.64 Similarly, the changing nature of the care home market is having direct consequences for where continuing care can be provided. Some areas reported the local care market experiencing particular problems of reduced capacity with the result that there were insufficient places available where fully funded continuing care cases could be placed, and those places which *were* available became increasingly costly. While social services would seek top up of fees from families, such arrangements could not apply to people fully funded by the NHS, with the result that “homes price themselves out of the market and people end up in permanent hospital care because PCTs won’t or can’t pay fees to care homes at that level.”

2.65 The recognition that people may move in and out of eligibility for NHS continuing care has direct implications for patients and their families. Clearly, this is an issue that needs to be handled with great sensitivity, but in most of the sample SHAs there was a growing recognition of the need to increase public awareness that entitlement to CHC does not provide a guarantee of ‘a bed for life’. Circumstances in which changing eligibility may arise can be a particular issue in respect of palliative care. The continuing care guidance has emphasised repeatedly that care should be taken not to impose ‘rigorous time limits’. However, there remains considerable uncertainty about the interpretation of criteria around patients who require palliative care “and whose prognosis is that they are likely to die in the near future.” Eligibility criteria across the 9 SHAs indicated that some fail to provide any indication of how this likelihood of death is to be defined beyond a general prognosis that “they are near to death, and discharge from NHS inpatient care would be inappropriate.” SHA 9 stated clearly that “it is not possible or appropriate to be prescriptive about a time scale for this.” Others were more explicit, for example SHA 2 stated:

*“A person who qualified under this condition will have been assessed by the doctor responsible for their care and will have been given a prognosis that they are likely to die within eight weeks. They may no longer qualify if they improve and are later diagnosed as being likely to live for some time longer (unless they qualify under one of the other conditions).”*

2.66 SHA 7 suggested that a likelihood of death “in the near future” for a patient with a terminal illness would usually mean a period of 4 – 6 weeks, although this should not be applied restrictively and individual circumstances must always be considered. There *could* be a risk with such criteria that prime consideration is given to the prognosis and expectation of life rather than to individual needs, although in practice it was argued that this was not the case and “if a patient is referred with a terminal

illness, we don't assess them using the 4-6 weeks, but against their particular needs.” SHA 8 similarly acknowledged that “there is no clear definition of what consists a final stage of a terminal illness for the purposes of eligibility for this criterion, but in practice, a time period of between four to six weeks will be taken as a yardstick for this test.” In SHA 3 it was also recognised that the definition should not be prescriptive but the expectation was that death would occur within 12 weeks. SHA 5 referred to a patient being in a progressive state of decline “and life expectancy is likely to be only days, weeks or months.” Other SHAs emphasised that it is not simply that a person is in the final stages of a terminal illness, but also that they require specialist palliative care services, or their health needs are so complex, intense or unpredictable that they need regular supervision from an NHS professional.

- 2.67 This range of interpretation of the circumstances under which people with palliative care needs might meet the eligibility criteria for NHS continuing care highlights the very real difficulties that arise in applying the criteria to individual needs. Respondents commented on the difficulties for them as health care professionals in applying these criteria, particularly when people live longer than originally predicted and the prospect arises of their care ceasing to be fully funded by the NHS. Many feel strongly that they should not become involved in debates about financial issues but should be solely concerned with the health care needs of the individual.
- 2.68 The other circumstance in which changing eligibility for NHS continuing care is likely to be an issue is when people have been receiving fully funded care in an NHS facility or nursing home for a considerable period, but they no longer satisfy the continuing care criteria. There was an acceptance across the SHAs that while it may be possible to be more explicit with new assessments and to ensure that patients and their families understand that their eligibility may change, it is virtually impossible to apply this retrospectively. The result of this is recognition that some people will be receiving fully funded care that technically they no longer require.

### ***Reaction to the Ombudsman***

- 2.69 Much of the detail of local response to the reports of the NHS Ombudsman will be addressed in Section 3 of the report which explores review and restitution in respect of past continuing care decisions. However, it is also relevant to examine the general reaction to the Ombudsman in the context of the revision of criteria across the SHAs.



2.70 In all 9 SHAs there was considerable irritation and even hostility to the Ombudsman's reports, particularly to the February 2003 report on NHS funding for long term care. This was evident in the language used when talking about the Ombudsman, and several respondents referred to having been "derailed" or even "sabotaged" by the publication of the report. While many respondents accepted that the Ombudsman's intervention was helpful in forcing a review of criteria and trying to establish greater consistency in application, there was also a widespread view that the report had in many ways made a bad situation worse and had added to the confusion. Many people were especially frustrated over what they believed to be a failure on the part of the Department of Health to respond adequately to the Ombudsman, for example:

*"The other major irritant is the position of the Ombudsman – there are a lot of difficulties around the implications of the Ombudsman's report, such as whether it qualifies as case law. The Department is not dealing with issues that question their policy."*

2.71 Others commented even more critically and did not feel that their concerns were acknowledged by the Department of Health, or that any change was likely to follow:

*"From the perspective of the SHA, we go to London and have meetings with the Department and tell them the problems, and it just feels as if the Department turns over and rolls on its back for the Ombudsman."*

2.72 Most concern was associated with a report that at the time of the fieldwork for this study had not yet been published by the Ombudsman, but which had been widely reported and publicised by the Alzheimer's Society (the Pointon case). This case was being interpreted by many to indicate that anyone with dementia was automatically entitled to NHS continuing health care, and was seen as unhelpful in focusing the debate on diagnosis and conditions rather than on clinical needs. As Section 3 will examine, this belief was responsible for many of the requests for reviews that had been submitted for consideration for restitution.

2.73 The Ombudsman's office subsequently took the decision to depart "from our usual practice" and to publish "the full text of this investigation earlier than planned in order to amplify the edited version published by the Alzheimer's Society on their website, which may have led to some confusion about the Ombudsman's findings."<sup>10</sup> The Ombudsman also pointed out that, as always, the findings relate to the unique set of circumstances surrounding the case "and do not set a precedent for a class of

cases.” This is an important statement since there is a widespread belief that the opposite situation is true and that findings do indeed set case law.

- 2.74 The Pointon case does *not* indicate that all people with dementia meet the criteria for fully funded continuing care. However, what it does state is that the eligibility criteria must not be biased towards acute care “and make no provision for the assessment of psychological needs of patients with illnesses such as dementia.”<sup>11</sup> Moreover, meeting the eligibility criteria should not be conditional on the setting of care, and in the Pointon case the Ombudsman observed that the patient would only have met full NHS funding for respite care if he had been an in-patient, but not if he was permanently placed in his own home.
- 2.75 The criteria that were applied in the Pointon case (in former Cambridgeshire Health Authority and South Cambridgeshire PCT) were judged by the Ombudsman to reflect the policy guidance from the Department of Health. However, ambiguities in the criteria “caused staff to produce inappropriate assessments that concentrated solely on Mr Pointon’s physical needs.”<sup>12</sup> The Ombudsman also commented that the assessments failed “to recognise that the standard of care provided by Mrs Pointon was equal to that that a nurse could provide.”
- 2.76 Many respondents across the 9 SHAs expressed their frustration with the Ombudsman and queried the basis for her judgments and observations. There was a widespread view that the Ombudsman did not fully understand the nature of continuing care (“she’s making up the criteria as she goes along”), was contradictory in her judgments (“not sure that her reports would be Coughlan-compliant”), and was adding to confusion around the top band of the RNCC and fully funded NHS continuing care.

### ***Overview and Conclusions***

- 2.77 This section of the report has provided an overview of the themes and issues that were identified in the experiences of 9 SHAs in reviewing and revising their eligibility criteria for NHS continuing care. The following key findings can be highlighted:
- The development of a single set of eligibility criteria for continuing health care across each SHA was extremely demanding. The practical challenges were intensified by the presence of multiple health and social care partners, and in

those areas in which the criteria operated by predecessor health authorities were divergent or inadequate.

- SHAs did not start with a blank sheet. While there may be major revisions to their criteria, these have to operate within the context of the legacy of past practices and a varying heritage of patterns of service provision. In those areas in which there has been a tradition of NHS fully funded care ( and a guaranteed 'bed for life'), the challenge to reconfigure services and ensure that provision is needs-led is just as great (if rather different) than in areas in which the predecessor health authorities have been more reticent in funding continuing care places.
- Securing agreement had not always been straightforward and in some localities it was striking that this was the first time that criteria had been agreed with local authority partners (despite earlier requirements that they should be jointly agreed). It was widely recognised across the sites that this provided a much stronger basis for consistent and fair decision making.
- Continuing health care had been given a greater priority on local agendas by the requirement to develop integrated criteria, but for the most part it remained marginal to the concerns of SHAs.
- Partnership between health and social care has often been weak around continuing care matters with the boundary between the services the focus for dispute. There was growing recognition that future developments should probably be built through pooled budgets and other partnership flexibilities, in order to secure seamless arrangements between health and social care responsibilities. In practice, in most of the 9 sites discussions to take such developments forward were in their infancy.
- It was widely recognised that even if criteria *are* agreed, there are risks that local implementation will introduce differences between PCTs. Attempts to minimise such variation were being focused through training and implementation support.
- Poor implementation in the past had often been a reason for front line staff failing to understand or apply criteria in any meaningful way.

- Other attempts to reduce inconsistency had focused in around half the SHAs visited on the application of standardised assessment tools. This work was at an early stage and the dangers of over-reliance on a mechanistic approach were widely recognised. Social services authorities had been especially cautious about the implications of scoring and domain weighting that they believed could set the boundary for continuing care in a way that forces social services to act in excess of their powers and duties.
- While many respondents were frustrated by the slow progress in the introduction of the Single Assessment Process, there were some grounds for believing that over time assessment for continuing care will be properly integrated as part of the SAP process.
- In all 9 SHAs there was a strong view that continuing care would be easier to manage and more consistent in application with *national* eligibility criteria and a national framework similar to that introduced in support of 'free' nursing care (the RNCC determination). This view is of long-standing and had not lost its force as a result of new criteria being agreed across SHAs.
- The desire for national eligibility criteria was indicative of a wish for greater equity (and particularly to resolve inconsistencies between neighbouring SHAs). It also underlined the tensions between desiring greater central direction and operating within a context in which devolved responsibility is increasingly evident.
- The development of 28 sets of criteria for continuing care was generally seen as an improvement on earlier variation between 95 different health authorities. However, variation was still viewed as unacceptable, and was likely to be especially problematic in respect of working across the boundaries of neighbouring SHAs adhering to different criteria.
- Around half the sites were using, or exploring the use of, assessment tools in determining eligibility for continuing health care. There was a strong view across the majority of sites that guidance on validated assessment tools would be of value, and that it would be helpful to address this in the context of the Single Assessment Process.
- Ensuring that criteria meet the requirements of Department of Health guidance *and* address the concerns raised by the Ombudsman has proved to

be a complex and difficult task. The definition and understanding of terminology often remains unclear. Some documents have attempted to provide clarification by further guidance, but there are dangers with some of this that it is either ambiguous or so specific that it suggests a diagnostic approach rather than one based on individual needs.

- Most of the SHAs had attempted to define their responsibilities for continuing health care alongside those of social services, and to indicate where responsibilities are separate and where they are shared. The idea is to present a continuum, and to ensure there are no gaps in provision and responsibility. In practice, however, what is a joint responsibility in some SHAs may be seen as an NHS responsibility in others.
- The local understanding of continuing care has undergone a transformation since 2001. While the level of this understanding varies between localities and between practitioners, it is generally the case that continuing care is now better understood than previously, and eligibility is recognised as a changing rather than fixed situation. It is also the case that continuing care is now viewed less as the top rung of a hierarchy of provision, and there is a shift towards assessing for continuing care as the first step, rather than seeing it as the next tier above the RNCC.
- The Ombudsman was a constant figure present in the background of all discussions around continuing care. Many respondents acknowledged that the intervention of the Ombudsman had forced the revision of eligibility criteria, and had helped in raising the profile of the issue. This needed to be balanced against the considerable irritation that was obviously felt by many, especially over the apparent misinterpretation that has surrounded many of the Ombudsman's reports, and the consequences this has had for local policy and practice. Many respondents felt undermined and demoralised by these events and were not confident that in the absence of clear national eligibility criteria they would have done sufficient to ensure that their revised policy and criteria are robust, fair and unlikely to be challenged by judicial review or further scrutiny from the Ombudsman.

### 3 Investigation and restitution

3.1 The main focus of the work in reviewing and revising the eligibility criteria for NHS continuing care has been to improve the quality and consistency of assessment of people's needs. Few people would argue that this was not a vital area of work that was needed. However, as one respondent remarked, "I can see how we can make things better for the future, but we can't change what has gone before." However, it was precisely to try and change some of the consequences of past decisions that the restitution arrangements were introduced, but it is also clear that these processes will be unable to fully redress the balance.

3.2 As Section 1 indicated, the report on NHS funding for long term care published by the Ombudsman in 2003 recommended that in addition to reviewing the criteria used by predecessor health authorities, SHAs and PCTs should examine the way those criteria had been applied locally since 1996, and should:

*"Make efforts to remedy any consequent financial injustice to patients, where the criteria, or the way they were applied, were not clearly appropriate or fair. This will include attempting to identify any patients in their area who may wrongly have been made to pay for their care in a home and making appropriate recompense to them or their estates."*

3.3 This recommendation was immediately accepted by the Department of Health requesting SHAs to undertake just such a review, and directions were subsequently issued. A 'suggested procedure' for local approaches to review was also outlined by the Department of Health. This procedure suggested a combination of publicity to raise public awareness of the review process and to invite submission of cases, alongside a case finding approach where criteria were not consistent with the existing law and the Coughlan judgment "to identify any patients who asked for review and were turned down, so that their case can be re-examined."

3.4 It was also recommended that standard letters should be employed seeking relevant information and acquiring necessary written consents. The Department suggested that an initial sift should be undertaken of cases coming forward that would distinguish the following three groups:

- Cases that are not to do with continuing care but are around NHS funded nursing care.

- Cases where it is clear from the information provided that the person would not meet Coughlan-compliant criteria of the time.
- Remaining cases where there is a possible case for review.

3.5 The procedure template also outlined an approach to follow where individuals wished to pursue cases further, and the special review process to follow with all other cases. It was clear in the experience of the 9 SHAs that this template had provided a guide which had generally been adhered to. However, the precise approach followed differed in detail. While the guidance on the overall approach was clearly of value, some SHA respondents commented that it would have been helpful if there had been greater clarity over the minimum data set of information that was required for processing cases.

### ***The review process***

3.6 Section 2 commented on the extent to which respondents identified concerns over inconsistent criteria for continuing care operating across different SHAs. Similar worries surfaced in respect of the approach to review and restitution. While the advice from the Department of Health provided a guide for *process* it was still the case that reviews would be undertaken against different sets of criteria. For some of those involved in carrying out paper-based assessments this raised doubts about how confident they could be in their own approaches, for example:

*“I am concerned that we might not be doing it right; and we will end up doing it all over again. The goalposts keep moving.”*

3.7 The processes followed in the 9 SHAs were similar and featured the identification of cases (and attempts to find cases through publicity around restitution); collection of all relevant notes and material; review of material by assessors; sifting of cases; referral to panel for decisions. Beyond this basic process, arrangements also existed in all SHAs for responding to appeals. The development of a protocol for the restitution work was typically managed in the 9 SHAs by the same group that had been established to develop the integrated criteria for continuing care (or a sub-group of this). Clearly this offered the benefit of continuity of approach and expertise. However, there were also problems that arose around the sequence of work. The

review of past decisions had to be made against appropriate Coughlan-compliant criteria; until those criteria were themselves agreed in each of the SHAs, there were practical difficulties in moving ahead with reviewing past decisions. One impact of this was that the debates that were taking place around the agreement of revised SHA-wide criteria were being paralleled by similar discussions among those most closely involved in the reviews. Thus, assessors were being confronted with explaining the meaning of continuing care to relatives, and trying to define how it might differ simply from nursing care, and why it might not apply to the care of someone with dementia, while these issues were still unresolved across the SHA. As this respondent commented:

*“We find it hard to understand what is health and what is social care within our own organisations, and yet we expect the public to understand it!”*

- 3.8 In many of the SHAs there was confusion over any initial screening-out of cases. While the advice from the Department of Health was, for example, to screen out cases such as self-funders in residential care or in their own homes without any significant NHS input (i.e. where it was clear from the information that the cases would not meet criteria), in practice assessors were concerned about the implications of excluding cases, and tended to include all rather than exclude any cases from full review. This sometimes reflected confusion over the interpretation of the principle that the location of care should not be the sole or main determinant of eligibility.
- 3.9 Many of the 9 SHAs visited had gone to considerable lengths to develop a consistent and well-understood protocol for dealing with retrospective cases, and had trained assessors (and panel members) to ensure as far as possible that the same model was adhered to. In some places, however, it was evident that people were interpreting the process in slightly different ways. For example, a minority of assessors viewed the restitution panel as little more than a rubber stamping exercise and were inappropriately notifying patients of their recommendation prior to its consideration by the panel. It was also evident that the 9 sites varied in their use of review panels in terms of the stage at which they were introduced in the process and whether they were used to examine assessors' recommendations, or solely as a first level of appeal against a refusal of restitution.
- 3.10 In all the 9 SHAs visited, the process for managing review and restitution was treated extremely seriously and was actively project managed. People were acutely aware of the importance of the process being clear, fair, transparent and credible. As far as



possible the processes which were established avoided bureaucracy, and this was underlined by the importance that was attached to including face to face contact wherever possible with those bringing their cases for review. While respondents were generally confident that they had gone about things in the right way and established the necessary procedures, the price of this was seen in terms of the time taken and in the sheer weight of cases going through to panels for decision. Many had encountered difficulties in managing complaints and dissatisfaction and had sought further clarification from the Department of Health over whether these should be dealt with by the PCT or SHA. While the Department had indicated that the PCT complaints procedures should be used, and that all efforts should be made to resolve cases locally and speedily, in many areas it was apparent that people would not be satisfied with local procedures and there would be further escalation of cases to the Ombudsman, as this comment indicates:

*“Originally we thought that if we said ‘No’ (and people wanted to pursue things further) it would go down the usual complaints route. But if they then appeal against that as well, we will probably offer a ‘special review’ of the case. Otherwise we will get into a situation of cases just going round and round.”*

- 3.11 There was considerable anxiety across all the sites about the implications of managing the scale of complaints and appeals that were likely to arise following the completion of restitution reviews. It was recognised that there would be a significant proportion of cases that would want to go through the appeals process in order that they could then progress to the Ombudsman, and the continuing knock-on effects were likely to be enduring.
- 3.12 The approach to review panels in all the sites drew on the experiences that had been gained from operating similar panels dealing with current (rather than retrospective) cases. In many instances the same people would be involved in sitting on both panels. However, it was recognised that there were some significant operational differences that needed to be understood fully by panel members and Chairs, and that they should have clinical input to their decision making. In particular, while reviews and appeals on current cases are concerned with *ensuring that the process was followed and the criteria properly applied*, in the retrospective reviews it is the judgment itself that is being challenged and which can be overturned.

### ***A demanding process***

3.13 The process of review was extremely arduous and demanding for those most closely involved. Quite apart from the work demands (which are explored below), the emotional costs were significant. These were acknowledged by staff across all 9 sites not only to have had an impact on their own experiences, but many were also concerned over the impact that the process had on patients and their families. The responsibility which nurse assessors felt for making decisions was clear; this was seen not simply as a mechanistic process that flowed from gathering the evidence, but at the end of the day a critical judgment had to be made. Where cases clearly met the criteria for continuing care (or indeed did not), this judgment was easier than for the many cases that were believed to be 'borderline'.

3.14 Some of the problems were greatest where the case was brought by the family of a deceased person. Inevitably this stirred up some very difficult emotions for relatives who needed to go back over the detail of an experience which they had been trying to put behind them. The following comments were typical of those encountered throughout the 9 sites:

*"There is an awful lot of emotional baggage that people bring with them, and the staff have to deal with that. People can also find the whole process (of the panel) overwhelming and intimidating. We are involving people in the review as fully as possible; it is important that they know that at the very least they have had a fair hearing."*

3.15 Similarly, others observed that "it takes a lot of tenacity to go through with a case" and quoted cases they had been involved with that had clearly been extremely upsetting for the relatives involved. While some relatives became angry and abusive with review staff, these were a minority and "mostly they just want a sympathetic ear and want to be able to tell their story." While the importance of listening to relatives and giving people the opportunity to put their case was recognised in all the 9 sites, it was also apparent that this was "emotionally draining and time consuming." However, it was believed that the approach paid dividends in reducing the acrimony of a difficult process, and in minimising the number of cases that would go on to appeal after the review process was complete.

3.16 Many respondents expressed concern over the consequences for patients and their families who had had their hopes raised, particularly when there was no realistic prospect of them receiving restitution. The process followed in the SHAs typically

tried to address and dampen expectations at an early stage, but it was evident that many members of the public were receiving false hopes from misleading reporting of the facts around continuing care. It was apparent that people felt (and expressed) considerable anger if they believed they (or their relative) had been wrongly denied something to which they should have been entitled. Many respondents expressed their anger and distress over the way in which the media had reported continuing care. Misleading coverage by *The Daily Mail* was cited frequently, and even publications from organisations that should be better informed (notably SAGA) were believed to have misled their readers into thinking that anyone with a diagnosis of dementia would automatically qualify for restitution.

- 3.17 It was evident from the letters written by relatives that many were basing their cases on such reporting. The reports of the Ombudsman were frequently referred to in such correspondence, as was information from the Alzheimer's Society. In many of the SHA sites respondents referred to voluntary sector bodies that were unhelpfully 'spinning' information around continuing care and restitution. It was not uncommon for solicitors to be involved in the process, and some companies have clearly established themselves in this field and were being used by a number of claimants who were submitting similar letters. The tendency for the process to become increasingly inquisitorial was viewed with concern, and there was a strong sense that nurses would not want to be involved in a process that was highly adversarial and legalistic. Many repeated their commitment to their patients and a prime concern to ensure that their health needs were addressed; they had kept themselves clear of decisions about financial issues (such as around means testing) and did not want to become embroiled in these discussions in the course of review.
- 3.18 For the assessors most closely involved in the process there was often a strong sense of isolation and concern that most people in the PCTs had no understanding of the issues or complexity of the situation. It was apparent that the regular meetings of continuing care lead officers across the SHAs served an important role. In addition to providing a forum for reporting on progress and identifying difficulties, there was a secondary purpose of the groups in providing tangible support for the members involved in this demanding and often distressing work.
- 3.19 It was evident that in the course of investigating cases and organising panel hearings, PCT staff were the focus for a lot of discontent over the policy of continuing care that was actually directed at the government. Many resented their exposure to this hostility and the fact that they were forced to defend a policy that was not of their

creation. It was frequently stated that “the Department should be defending the situation” and that it should not have been left to local resolution. Many respondents had considerable empathy with the situation of patients and their relatives and shared their sense of injustice at the consequences of the political boundary between health and social care.

### ***Operational difficulties***

3.20 In all the 9 SHAs it was apparent that managing the review and restitution process had been problematic to a lesser or greater degree. The two most significant issues were concerned with the sheer scale of the operation and the numbers of cases needing to be investigated, and the limitations posed by inadequate or non-existent case information. In addition, a range of issues were identified around restitution and RNCC determination.

#### ***a) Scale of response***

3.21 In many of the sites respondents wondered whether the Department of Health had any idea of the scale of the exercise that would be involved in undertaking the reviews. Some SHAs were taken by surprise at the level of public response to the announcement of review of past decisions. In others, it was expected that there would be considerable interest because of the nature of local history and experience with NHS continuing care. Many of the former health authorities now replaced by the 9 SHAs had attracted the scrutiny of the NHS Ombudsman, and the profile of continuing care was high. None of the 9 sites would have been in a position to meet the original deadline of completing all their reviews by the end of December 2003. This timetable clashed with parallel demands around the introduction of reimbursement arrangements for delayed hospital discharges, and in many instances the same people were responsible for leading the work in both areas. Many of the 9 SHAs had struggled to meet the revised deadline of 31<sup>st</sup> March 2004, but were well on the way to completing their investigations, albeit in an atmosphere that has been experienced as stressful and highly pressurised. However, there was a growing recognition in the sites that although deadlines were being applied to the completion of reviews, the issue would not simply go away when this date was reached. PCTs in

particular would have to accept that they would continue to need to respond to requests for reviews for the foreseeable future.

- 3.22 The number of cases reviewed in the 9 SHAs ranged from less than 200 to more than 1,600. The proportion of cases receiving restitution varied from 4% to 15%, reflecting the variety of past practice and of eligibility criteria.
- 3.23 The expectation that assessors would undertake the work 'alongside their normal day job' was identified time and time again by respondents who had felt over-stretched by a major task that was to be undertaken on a cost neutral basis, and frustrated that they were distracted from their other work (in fact, substantial central resources had been made available to SHAs to cover the costs of restitution). The need for nurse assessors to be able to draw on appropriate expertise for particular cases was also a difficulty. A lack of mental health expertise was identified in several sites, and people described having to "call in favours" from mental health colleagues to assist with assessments of patients with dementia for example, and in learning disability cases. While general nursing expertise was usually sufficient, when people had particular needs (such as challenging behaviour) there was a clear need for specialist assessment. Relying on 'favours' from colleagues to provide this input was clearly unsatisfactory and could lead to inconsistency in outcomes. In addition to the poor decisions that might arise, the assessors were aware of the challenges that might result, their own exposure to seeing their decisions raked over once more, and the need to conduct further reviews at some point in the future.
- 3.24 A lack of administrative support was identified in many localities and it was evident that this could be a significant impediment to processing the reviews. Assessors who should have been using their technical and professional expertise to best effect were often getting caught up in processing cases, talking to relatives, organising panel hearings and preparing photocopies of case notes. Where administrators had been appointed there were considerable benefits, as they have been able to undertake a great deal of the routine preparation of cases, but had also been invaluable in spending time talking through issues with patients and relatives.
- 3.25 In several sites it was remarked that continuing care was "not an attractive area" in which to work, particularly in terms of career development. There were believed to be significant risks of assessors "burning out" and leaving "unbelievably stressful" workloads. At the same time, it was also acknowledged that there *were* considerable satisfactions in cases where the assessors were able to see a positive outcome from

their involvement and were successful in getting restitution awarded. In all 9 sites respondents repeatedly emphasised that they “didn’t want to have done people out of something to which they are entitled”, and many went to considerable lengths to do all they could to see if restitution could possibly be applied. In one of the SHAs an assessor spoke of her enormous satisfaction in being able to do “a really great job” that could have such direct and tangible results for patients.

- 3.26 In addition to responding to the volume of cases for review that were being identified locally, in a couple of the sites continued pressure was being experienced from the Ombudsman’s office. In one of these SHAs it was recognised that many dissatisfied relatives were pursuing their cases with the Ombudsman’s office rather than going through the review process that had been established for the purpose. The PCTs were sticking to a position that they would “not be bullied into queue jumping cases”, and they were prioritising cases for review where a patient was still alive. Elsewhere, however, it was remarked that in the climate that had been created around retrospective investigation, people felt highly exposed and vulnerable. The prospect of the Ombudsman ‘dropping in’ on cases led to some assessors “giving in.” It was also remarked that the Ombudsman’s office had clearly expanded its own staffing to deal with the issues arising around restitution, but one consequence of this appeared to be that some of the staff with whom the SHAs and PCTs had dealings over the telephone had apparently little knowledge of the issues and poor understanding of the context to the latest developments. An example was cited of a conversation where the person from the Ombudsman’s office had apparently asked “what is Coughlan?”
- 3.27 Many of the sites identified concerns over the ‘responsible commissioner’ and were concerned about the lack of clarity for arrangements. The approach that was being followed was to review patients “in the area where they had been placed or died in order to avoid trooping around the country.” For localities that had considerable inward migration to their care homes this involved them in additional review work.

**b) Past practice and poor information**

- 3.28 The costs and benefits of the restitution process were remarked on by many. In all 9 sites there was an awareness of the costliness of undertaking the labour-intensive reviews, and several respondents expressed the view that “we have probably spent more on investigating the cases than we will spend on restitution payments. “ Investigation of cases could take a considerable amount of time. It was estimated in

one SHA for example that cases never took less than 8 hours to review, and the norm was closer to 16 - 24 hours per case. Legal scrutiny of complex cases (particularly when dealing with a deceased estate) could account for a further 8 hours. This was all before a case reached a panel hearing, which was likely to require at least another 4 hours. Respondents were adamant that they could not do process cases in less time, partly because of the logistical difficulties, but also because of their awareness that their processes *must* be seen to be thorough and robust if they were not to be knocked down by judicial review. Because of the complexities and demands around individual cases it was often argued that the deadline for completion of reviews by the end of March 2004 was inappropriate and that the only way some SHAs would meet it would be by proceeding with “unseemly haste”. However, the Department of Health had made clear to SHAs that investigation should be accurately carried out, and not compromised simply to meet deadlines. It seems likely that this message was not passed down to staff as effectively as it might have been.

- 3.29 At the same time, there was also clear acknowledgment of the “huge lessons learned” in the course of the process, and many respondents were anxious that there should be opportunities to reflect on these experiences and ensure that the issues they raise were addressed and fed back into training materials. As this respondent commented:

*“There have been some very interesting learning points particularly from trawling through records. We have just **got** to improve our practice and ensure that it becomes more person-centres and multi-disciplinary.”*

And as another remarked:

*“What this process has done is help us to realise just how badly we were doing things before (...) having a clear auditable trail is just so important.”*

- 3.30 The poor quality of documentation was a feature of experience in all 9 SHAs. In part, the difficulties were a reflection simply of the passage of time, often compounded by the impact of reorganisations that had changed structures and seen major turnover of personnel who had been the guardians of local knowledge and information.
- 3.31 Comments were made time and time again about the impossibility of reviewing past decisions when the original baseline assessments apparently contained no meaningful information that could be revisited. It was also clear that many patients had not been reviewed on a regular (or even annual) basis as they should have been.

People described having to conduct reviews of cases where patients were still living but had not been reviewed by any one for six years or more. Where self-funders had come forward the data deficiencies were often greater; people who had placed themselves in nursing homes had often done so with no involvement at all from the local authority social services department, and any assessment data was therefore relatively sparse.

3.32 Other problems with collecting information arose from the lack of knowledge on the part of various clinicians, including GPs who were often reported as having little awareness or understanding of why the retrospective reviews were being undertaken and were seeking legal advice before they would share records.

3.33 Further practical difficulties concerned the sheer problems of locating relevant files. This was a particular issue with independent sector care homes. In all the sites respondents expressed surprise at the national regulations that care records must be retained for “not less than three years.” Indeed, some respondents were under the impression that regulations required records to be kept for only one year, which may indicate some practices are falling considerably short of the standards. Where homes had gone out of business it was often impossible to trace the relevant records.

*“No one knows what happens to records of deceased residents of less than three years duration when a home has closed down. There is no apparent procedure for transferring files of live residents or for those who have been dead less than three years. There is a lot of confusion about how long records have to be kept.”*

3.34 Assessors remarked on the difficulties in making decisions in such cases where there was no information on which to make a judgment. Relatives were seen to be quite rightly challenging decisions in such situations, as one assessor observed “it isn’t the relatives’ fault if notes are destroyed.” As another remarked, “we may have made the right decisions, but we can’t evidence that.” In such situations it was recognised that there were questions over the application of “clear, robust and transparent processes that can stand up to scrutiny.”

3.35 When patients had died in care homes there was apparent variation in the extent to which files were archived and available for inspection. Where records *did* exist assessors often reported problems in either achieving access or in obtaining copies of files. One such assessor described the situation in which an average of three letters and telephone calls were required to gain access to records. It was not uncommon for homes to be charging for access and copying of files (at around £80-



£90 a case). Far fewer difficulties were reported over the sharing of information between health and social care partners, although there *had* been debates over confidentiality of information. Some social services departments also indicated that they routinely destroyed files one year after a client's death. The general difficulties with information retrieval were summed up by one SHA respondent who remarked:

*"In general it is difficult to access information outside the NHS, and it can be difficult within the health service even where people are willing. We've had to be pragmatic and move cases along."*

- 3.36 The quality of individual case records varied from very bad to excellent. It was acknowledged that some people are just poor record keepers and always will be, but this was increasingly unacceptable. It was hoped that the implementation of the Single Assessment Process would help to drive up standards and to make examples such as this increasingly rare:

*"There will be no dates, or they won't be signed. Or the information will be about the weather rather than anything to do with the resident. Or a daily record will just say 'usual day' for the patient with no indication of what that means!"*

- 3.37 Other care home records included clearly inappropriate judgments – such as referring to residents being “very naughty”; and demonstrating a lack of respect and basic dignity either for the resident or their relatives.

- 3.38 It was also clear that in a minority of instances “we are getting records that have been created for the purpose.” In other words, where records were known to be inadequate, some care homes appeared to have embellished them retrospectively. Files would also be missing or have parts of their notes missing, or would be mis-filed. It was commonplace for other residents' notes to turn up in the wrong file. In one site respondents drew attention to records that had been found which clearly indicated:

*"Cases of abuse or abusive practices where nothing had been done. These are notes that were written never to have been read. The National Care Standards Commission are supposed to look at care plans – how has this happened?"*

- 3.39 Further elaboration of poor care indicated by case notes indicated a range of practices that were apparently being routinely followed with little or no awareness that

they were wrong. One respondent identified such shortcomings in respect of a range of care practices as follows:

*“Incidents where anal and vaginal plugs were being used for long periods of time with the same patient when quite clearly it was an inappropriate form of continence management that led to fissures and other problems. (...) GP records held in the home clearly documented incidents of abuse which they believed the family were perpetrating whilst visiting. No evidence of this in the nursing home records. No evidence of any sort of action being taken by the GP or the home. (...) Another incident where a resident had lost their dentures and it took a year for the home to action a replacement, and incidents of contractures for bed bound clients and no evidence of passive exercises being carried out.”*

**c)      *Uncertainty over RNCC***

- 3.40 Section 2 highlighted some of the conceptual difficulties that have arisen in distinguishing eligibility for NHS continuing care from that for ‘free’ nursing care under the RNCC arrangements. Another reflection of this confusion was also evident in the approach to restitution. In some of the SHA sites it was apparent that restitution was being made in respect of RNCC payments in some cases which did not qualify for continuing care. This raises a number of issues, not least over how nursing home residents who should all have been assessed under the RNCC arrangements had been overlooked. Where such payments were being made, there were also potential difficulties over the backdating period. While the restitution for NHS continuing care potentially extends as far back as 1996 (when health authorities were first required to have criteria for continuing care), the arrangements for RNCC took effect from October 2001 for self funders, and from April 2003 for everyone else, and do not allow for back-dating of payments.
- 3.41 Those nurse assessors who had developed expertise in both the RNCC and continuing care were much better equipped to understand the inter-relations between these. Many commented on the poor understanding that ward nurses still have of the RNCC, particularly reflecting their lack of awareness of the sort of care that nurses are able to provide to people in the community (which can clearly avoid the need for placement in a nursing home). Comments were also made about some of the difficulties in applying the bandings. For example, a resident might be judged to fit the medium band of the RNCC, but this was *only because of the quality of care they*

*were receiving in a particular home.* If they were to be accommodated elsewhere, it is entirely possible that their needs would be judged as high band because of the poorer quality of general care provided in that setting. Such a situation was viewed as highly anomalous, and clearly introduces questions about the fairness of banding decisions and the consistency of care provided in nursing homes.

### **Case finding**

- 3.42 Different approaches were followed across the 9 sites in relation to case finding. For the most part the response to-date had been a reactive one in which PCTs and their respective SHAs had *responded* to requests for reviews that had been submitted. There were three potential stages to the case finding; first were the cases that identified themselves to the SHA at an early stage; second were those which had come forward as a result of publicity and other processes, and a third potential group of cases could be identified in those sites where the SHA was going further in seeking out cases which case records suggested may have been unfairly excluded in the past. In most of the sites it was recognised that this was likely to involve a further stage of investigation once they had been able to clear the substantial volume of self-selecting cases that had been brought to the attention of the SHA. In a number of the sites social services authorities were also beginning to recognise the need to “trawl back through our data to see where we should be challenging the PCTs” over past decisions that had left social services meeting the costs of care that it was now believed should have been the responsibility of the NHS. At the same time, these issues were set alongside an awareness that many local health economies already faced financial challenges, and there was little point in “pushing them further into the red.” At a time when there is increasing concern to develop whole systems approaches founded on trust and partnership it was also recognised that there were real difficulties and costs associated with pursuing cost transfers of this nature.
- 3.43 A direct consequence of the way in which cases had been collected was that those which had come forward inevitably reflected a bias. As one respondent observed, “the publicity machine has worked extremely well for those who know how to use it and how to write letters.” This was a stronger feature in some SHAs than in others, but to some extent in all the 9 sites it was recognised that there were questions about how well the process had been able to reach all those cases which might potentially qualify for restitution. The following comments were typical of many that were made:

*“I think that lots of people have been missed. We are picking up those who are most able to put their case – typically the white, middle class and articulate who come quoting the Daily Mail or the Ombudsman or the Alzheimer’s Society.”*

And

*“The bulk of the people we are dealing with are not poor; they have the wherewithal to pursue their case.”*

3.44 Some respondents were more direct in their comments and drew attention to the ‘ethical anxieties’ that they had over the way the process may have favoured “a militant minority” while failing to reach others who had suffered a genuine injustice. Similarly, others referred to the review process inevitably favouring “those that shout loudest.” In some sites it was clear that a small minority of aggrieved relatives would never be satisfied, and some were appealing against decisions (even where restitution *had* been approved) because they were seeking reinstatement of the value of an estate.

3.45 In some of the sites the local voluntary sector has been closely involved in ensuring publicity for the review process and where necessary in providing advocacy and support for those wishing to pursue a claim. A Director of Age Concern in one of the sites commented on the general lack of understanding on the part of most members of the public:

*“People don’t know the system, and they don’t know what it is that is being reviewed. That is symptomatic of this whole ridiculous business that isn’t going to be resolved. Most people don’t know the difference between personal care and health care.”*

3.46 The manner in which requests for reviews flowed into the PCTs and SHAs in the wake of national publicity around the Ombudsman’s report was seen as “totally uncontrolled.” There were difficulties in responding to the demands in the early days because systems had yet to be established. While it was recognised that it could be a mistake to deal with cases too hastily, it was also apparent that perceived delays in responding carried their own risks, and further criticisms were made by local media and lobbies over the slow rate of progress.

3.47 In most of the 9 sites once good progress was being made with the cases that had come forward of their own accord, a second wave approach had been adopted with a widespread publicity campaign to do everything reasonable “to ensure that we meet

our obligations.” This reflected the steer from the Department of Health that the wider general public should be made aware of the restitution process.

### ***Overview and Conclusions***

3.48 This section of the report has explored the experiences of the 9 SHAs in organising and undertaking the programme of retrospective reviews of eligibility for continuing care. The similarities of experience across the sites were striking despite some significant variations in terms of the number of requests that were being managed. It is worth highlighting the main features that have emerged from the analysis.

- A broadly similar review process was followed across all sites, although the detail of this varied. The process followed the general template that had been suggested by the Department of Health, but SHAs differed in the extent to which they followed advice on screening out cases judged to be out-with the terms of the review.
- There was considerable anxiety surrounding the operation of the review process, with many respondents worried that they might not be sufficiently thorough in approach and that their processes could be subject to challenge in the future.
- Undertaking the reviews was more difficult when work had still to be completed on the revised criteria. Until it had been agreed what criteria were to operate across the SHA it was practically impossible to move forward with the reviews.
- The approach to restitution was treated as a priority and there was a high awareness of the potential risks that were associated with getting the process wrong. All 9 SHAs were anxious to avoid judicial review or the intervention of the Ombudsman in responding to appeals; at the same time it was also believed that sooner or later further challenge is all but inevitable.
- In all 9 sites it was apparent that the operation of the restitution process had been highly demanding in both practical and emotional terms. Emotionally, it was often distressing for staff confronted with upset and irate relatives on a daily basis. At the same time, respondents felt enormous compassion for the

people they were dealing with and were very concerned that many of them had inappropriately had their expectations raised by a mis-informed media debate when they had little realistic prospect of restitution, and would go through an arduous and often upsetting process for nothing.

- Considerable importance was attached to managing the face to face contact with patients and their relatives in order to explain the process to them and to give them every opportunity to put their case across. It was believed that many of those going through the process simply wanted a chance to 'tell their story' – often for the first time.
- Managing the scale of demand for review was daunting, not least for staff who felt they were expected to manage additional work with no increase in resources, and often without any administrative support. The labour-intensive nature of the work, and the amount of time that it had involved was remarked in all of the sites. The substantial additional resources for restitution that *had* been allocated by the Department of Health did not appear to be evident to many of those on the ground.
- A significant proportion of cases requesting review reflected an awareness of the reports from the Ombudsman, and an often inaccurate interpretation of the implications of those findings. There was some evidence of orchestration of requests by campaigning bodies, and it was apparent that solicitors have also become more actively involved and are promoting their services in this field.
- None of the 9 SHAs would have been in a position to meet the original deadline of the end of 2003 for completion of restitution reviews. Few fully met the revised deadline of March 31<sup>st</sup> 2004, but most were well advanced with their arrangements.
- The background presence of the Ombudsman's office in the course of the reviews was experienced as unhelpful. All SHAs were dealing with cases as they arose, and repeated queries about why they had not yet finished particular cases were resented, particularly when there were doubts about the level of understanding and knowledge of some of the staff from the Ombudsman's office who were making such inquiries.
- All sites experienced enormous difficulties in collating adequate information on which to base their reviews and decisions. Problems included non-existent

care records, or files that had disappeared particularly following care home closures; difficulties in gaining access to case files, as well as the obvious shortcomings of many files that were made available.

- In at least one site case notes indicated disturbing evidence of poor care practices as well as a poor standard of record keeping. It was also clear that some records were created for the purpose of the review and were not contemporaneous accounts.
- The proportion of cases that have been awarded restitution (of those completed thus far) ranged from around 4% to 15%. In addition, in some sites additional restitution had been made in respect of RNCC bandings for those who were not in receipt of such payments but did not meet the criteria for continuing care.
- There was a general recognition that while the task of review and restitution had been very costly in process terms (quite apart from any monies that were awarded in restitution), there *had* also been significant benefits. The principled case for ensuring that people are reimbursed for care that should rightfully have been provided by the NHS was generally accepted. However, many respondents questioned the overall costs and benefits of the major exercise required in order to identify a relatively small proportion of cases.
- For some of those who had not been awarded restitution there had been substantial costs in emotional distress and false expectations. While many people were satisfied that they had been given a fair hearing, a considerable minority remained highly dissatisfied and determined to pursue their case through the appeals process and – if necessary – all the way to the Ombudsman.
- The approaches to identifying cases for review was largely reactive; SHAs and PCTs responded to the cases that had made themselves known. There were considerable concerns across all the sites that the review process favoured those who were best equipped to present their case (typically the middle class and articulate relatives of a deceased older person); that these cases were not typical, and may not include many of those who had been most unfairly treated by past decisions.

- It was clear that the review process has provided an incidental - and perhaps unexpected - audit of past practice. Without the requirement to undertake the reviews many of the shortcomings that were identified would never have come to light. It was recognised that there is an important agenda to be tackled in ensuring these deficiencies are remedied.
- Overall the decision by the Department of Health to embrace a restitution process was generally accepted as having positive outcomes both for individual patients and their families, but also in promoting greater understanding of NHS continuing care. However, it was also apparent that momentum needed to be maintained if the benefits that have resulted are not to be lost, and if further progress in the clarity and consistency of policy and practice around continuing health care is to be achieved.



## Appendix 1

### Strategic Health Authority Case Studies

The following nine anonymised case studies present a concise account of continuing care eligibility criteria and the approach to restitution adopted across the SHAs included in the review.

## **The SHA**

The SHA covers a population of 2.2 million across a territory covered by three former health authorities, and includes multiple PCTs. This embraces a large geographical area with a few major urban centres and significant rural areas.

## **Development of SHA-wide continuing care criteria**

The eligibility criteria document was developed by the SHA, with representatives of the various health economies, and with the respective social services departments. It is presented as a 'Joint policy and eligibility criteria for NHS funded continuing health care.' The document has been written mainly for the guidance of doctors, health and social care service professionals involved in making decisions about individuals' needs for continuing care. A simplified leaflet for wider public use has also been developed. In developing the document it was believed that, with one exception, the continuing care criteria in use by the predecessor health authorities had been compliant with the law and national guidelines since 1996. NHS funded continuing health care is defined in the following terms:

*This is the term used in this document to identify a person who has been assessed as meeting the eligibility criteria for a package of care arranged and funded wholly by the National Health Service (NHS). People who meet these criteria will have complex, unpredictable or deteriorating conditions including continuing and regular specialist clinical supervision by doctors, nurses or other professional staff.*

The policy states that eligibility will be determined following a multi-disciplinary/multi-agency assessment of a person's needs. It is also stated that the interpretation of eligibility criteria "is a matter of clinical judgment using this document, and should be decided by the appropriate NHS professionals in consultation with the multi-disciplinary team (including social workers), the patient and their carers."

The policy is explicit in recognising that eligibility for continuing care can change over time:

*It is important to note that as a person's needs change, then their eligibility for NHS funded Continuing Health Care may also change. A decision that NHS funded*

*Continuing Health Care is needed at a particular time does not necessarily mean that it will always be needed, and vice versa.*

The document is presented as the joint policy of the SHA and social services, and sets out “to make the distinction between health and social care more explicit.”

Eligibility criteria are presented separately for:

- People with physical and/or sensory disability.
- People with dementia.
- Older people with mental health disorders.
- People with learning difficulties/disabilities.
- People who require specialist palliative health care.
- Children and young people.

In addition to the criteria, guidance is also provided through examples of clinical characteristics. It is stated that there should not be over-reliance on these, and that “eligibility may come from one condition alone or from the presence of several lesser factors.”

The criteria for people with physical and/or sensory disability are as follows:

- Requires extensive healthcare support throughout the 24 hour period because of very complex health needs. This healthcare support is of a type which can only normally be delivered by a suitably qualified health care professional.
- Specialist medical/nursing assessment or treatment/management on at least a weekly basis, because of complex, unstable or rapidly deteriorating condition.
- Medical intervention because of instability, frequent or unpredictable relapses.
- Frequent or continually available monitoring or adjustment of medication.
- Clinical management to assist respiration such as ventilation or non-standard tracheotomy.

- NHS funded Continuing Health Care criteria for rehabilitation, short term admission/respite and specialist palliative care can also be applied.

While following the requirement that there should be a single set of criteria operating across the SHA, it is also recognised that patient pathways differ across the previous health authorities. In order to address this, appendices to the document have been prepared on a county by county basis that reflect local implementation issues (and including different assessment documentation). However, it is emphasised within these appendices that eligibility will be determined by the joint policy and eligibility criteria document operated by the SHA.

### ***Investigation of continuing care cases and restitution***

A protocol for managing the review process was established by the SHA-wide steering group which also monitored consistency of approach. An assessment profile is assembled for all cases and all are considered by a Clinical re-assessment Panel. Members of the panel have not previously considered the individual's care, nor are they from the PCT that would be responsible for making any payment. The Panel makes its recommendations to the relevant PCT on whether the individual should have been eligible for NHS funded continuing care for all, part or none of the period. "It is expected that the decisions of the Panel will be accepted in all but exceptional circumstances." Where the patient or relatives are dissatisfied with the outcome of the Panel they can request a review of the process used by the panel in reaching its decision. If they remain dissatisfied with the outcome of consideration by the Continuing Care Review Panel they can use the NHS complaints procedure.

By mid March 2004 more than 620 cases had been identified where restitution reassessment was requested. More than half of these were in the county in which it was known that non-compliant criteria had previously been operating. Around 45% of cases had been to panel for a decision, while the remaining cases were still being processed. Around 8% (22 cases) had been given full recompense and an additional 24 had been judged eligible for a partial refund.

New cases were continuing to come forward. On the basis of experience to-date, the SHA had estimated that 10% of cases would be fully recompensed (at an average of £63,000), and 9% would qualify for partial recompense (at an average value of £25,000).

***The SHA***

The SHA covers the area previously covered by three Health Authorities across a mixture of urban and rural areas.

***Development of SHA-wide continuing care criteria***

Criteria were established in January 2003 following multi agency consultation. It was agreed with all agencies that the criteria would be reviewed after one year. Minor adjustments were made in October 2003 and a small working group was established later that year to revise the January 2003 document. This brought together representatives of the PCTs, Local Authority Social Services departments and SHA officers. The development of integrated criteria across the whole of the SHA area brought particular challenges because a predecessor Health Authority had been operating criteria that had not been agreed with Local Authorities because they were believed to be overly restrictive and not Coughlan-compliant. Considerable effort was successfully put into securing the sign-up of all parties and ensuring that the new criteria were accepted as being compliant with policy and lawful.

Strategic Health Authority officers recognised the difficulties that existed and the poor history (in parts) of engagement with local authority partners. It was acknowledged that significant cost shifting had occurred over time which had pushed responsibilities further towards local authorities e.g. closure of long stay hospitals. It was hoped that progress in future could be achieved through a more explicit partnership approach and the development of budget pooling. The SHA also believed that cost shifting had not all been in one direction.

The document setting out eligibility criteria for NHS continuing care is intended “to improve fairness, public understanding and consistency.” In addition to taking account of recommendations from the Health Service Ombudsman, local health and social care professionals and a range of local partners, advice was also sought from the Plain English Campaign in order to improve the accessibility of the criteria. The document is short and concise and includes all adult care groups. It is recognised that the policy will only be applied fairly and consistently if staff understand it adequately, and a major training programme is underway.

Eligibility for NHS funded continuing health care is addressed around any of five situations, and in each case some explanatory text has been included to illuminate the context. These criteria are set out in the box below.

### ***Eligibility criteria for NHS continuing care***

#### **Condition 1**

A person's health needs are so complex, intense or unpredictable (or any combination of these) that they need regular supervision by an NHS professional.

*Explanation:* These health needs require more intense or specialist care than that provided through primary care services or by a registered nurse in a care home. They need supervision from an NHS professional. The need for supervision by a GP or registered nurse is not in itself a good enough reason to qualify.

#### **Condition 2**

A person has a rapidly deteriorating or unstable physical or mental health condition that needs supervision by an NHS professional.

*Explanation:* A person who qualifies under this condition is likely to qualify for a period during which their physical or mental health care is rapidly deteriorating or unstable. They may no longer qualify if, following a review, their health has stabilised (unless they qualify under one of the other conditions in this documents).

#### **Condition 3**

A person is in the final stages of a diagnosed terminal illness and is likely to die in the near future.

*Explanation:* A person who qualifies under this condition will have been assessed by the doctor responsible for their care and will have been given a prognosis that they are likely to die within eight weeks. They may no longer qualify if they improve and are later diagnosed as likely to live for some time longer (unless they qualify under one of the other conditions in this document).

#### **Condition 4**

A person who needs to regularly use specialist health care equipment that needs to be supervised by an NHS professional (this does not include equipment supervised by a registered nurse or care assistant in a care home).

*Explanation:* This covers the few people who need to use specialist health care equipment regularly and need to be supervised by an NHS professional while using it.

#### **Condition 5**

Where a person's assessed health needs are more significant than their need for personal care, accommodation and meals.

*Explanation:* In these circumstances, a person is likely to need a significant level of nursing and health care. It is likely to include people whose nursing or other health care needs are greater than normally provided for through funded nursing care (for someone living in a care home) or the district nursing service (for someone living in the community). This condition included anyone whose health needs are more than incidental to their need for social care services.

In addition to these five conditions, the policy also addresses “other circumstances where continuing health care may apply” in the following situations:

- Rehabilitation – this applies to a person who has been assessed as needing a programme of treatment to achieve defined goals.
- Programmed care – this applies to a person who has been assessed as needing planned health care so treatments can continue.
- Respite care – this is designed to give temporary relief to carers who would benefit from a break or need treatment for their own health problems. This applies where the person being cared for qualifies for continuing health care (whether or not it is being paid) and is cared for at home or in the community.
- Palliative care – this applies to a person with a condition from which they are not expected to recover **and** whose health needs are so complex, intense, or unpredictable that they need regular supervision from an NHS professional.

The document emphasises the role of a joint health and social care assessment that includes the contributions of everyone involved in a person's overall care. The outcome of the process will be communicated clearly to the person and/or their family, and will set out the reasons for the decision about whether the person qualifies under these conditions for continuing health care.

In addition to continuing health care, the document also defines ‘continuing health and social care’ where a person is assessed as needing a joint package of services from the NHS and social services. This applied “where the person does not qualify for continuing health care but still has health and social care needs.” Eligibility for social care alone is defined where a person has no assessed health needs which need a service, but they meet eligibility conditions for social care and receive a package of services arranged by social services only.

Alongside the SHA Continuing Care Policy document the SHA has also issued detailed operational guidance to assist understanding “by either giving examples or setting out more clearly what the policy means in practice.” In part this is achieved by the inclusion of some detailed case studies and through public information leaflets. This information has been made widely available to partner organisations and via public websites.

### ***Investigation of continuing care cases and restitution***

A process for reviewing past continuing care cases was established to take account of different compliance dates that had been operative across the former health authorities. In two it was believed that eligibility criteria had been legal from 2000 (January in one case and April in the other), while in the third legally compliant criteria had only been introduced in April 2003. The SHA also had concerns about the staff understanding and application of the eligibility criteria, and therefore issued supplementary guidance. It also extended considerably (31<sup>st</sup> October 2003) the date to which retrospective reviews would be considered.

By the end of 2003 the SHA had received 729 requests for restitution reassessment. Decisions were being made at the rate of 30 per week, and by the end of March 2004 just 3 cases were outstanding and awaiting decision. The percentage of these cases being granted restitution was approximately 15%. £940,000 had been paid or committed in respect of 60 cases at the end of April, and agreement had been reached around a further 20 cases where the recompense had still to be calculated. An additional 119 cases had been identified between January and April 2004, and these were expected to be decided within 12 weeks of receipt (i.e. by end July at the latest). It was estimated that overall there were likely to be around 100 successful cases, at a total cost of £1.25 – 1.75m. A small number of new requests for retrospective reviews were received in May 2004 – the SHA expected this to continue for some weeks gradually petering out over the summer.



***The SHA***

The SHA covers the territory of three former health authorities and serves a population of around 2.2 million.

***Development of SHA-wide continuing care criteria***

The integrated criteria have been developed by a 'harmonisation group' drawing representatives from the SHA, local authorities and PCTs. The eligibility criteria are applicable to all adult care groups.

The eligibility document and accompanying guidance for practitioners makes clear that an assessment of need "is an essential starting point for determining whether the NHS has a continuing responsibility to provide a full package of NHS services because the service user's primary need is for health care." Such an assessment is also essential in determining eligibility for other categories of care.

The document identifies three such categories:

**Category 1: NHS Continuing Care** is a package of care arranged and funded entirely by the NHS which may be provided in a hospital, hospice, care home registered to provide nursing care, or in the service user's own home.

**Category 2: Continuing health and social care** describes a package of care that involves services from both the NHS and social care, "where the prime need is for accommodation and personal care rather than for nursing or NHS care." It can be provided in a number of settings.

**Category 3: Continuing social care** is where the service user is entitled to receive community and personal care services provided by social services subject to their eligibility within Fair Access to Care Services arrangements of local authorities.

The document explains that the determination of eligibility for NHS Continuing Care (Category 1) is a top down process. If it is judged that a person's needs do not meet the eligibility criteria for Category 1 care, consideration is then given to whether they require category 2 or 3. Eligibility for Category 1 care is defined by SHA 3 in the Box below.

“The service user will be eligible for NHS Continuing Care when:

- a) The overall scale of the person’s needs is such that they should be regarded as wholly the responsibility of the NHS, taking into account the nature or complexity or intensity or unpredictability of the individual’s healthcare needs.

Or

- b) The individual is in the final stages of a *terminal illness* and is likely to die *in the near future*. (*Terminal illness* is defined by the Department of Health as an active and progressive disease for which curative treatment is not possible or not appropriate or where death can reasonably be expected within 12 months. Whilst not being prescriptive, in this context *near future* means within 12 weeks.

Or

- c) The individual has a rapidly deteriorating or unstable medical, physical or mental health condition and requires regular supervision by a member of the NHS multi-disciplinary team.

Or

- d) Consistent with the above, the individual’s needs may require the routine use of specialist health care equipment under the supervision of NHS staff.

There are a number of other conditions that determine an automatic eligibility for NHS Continuing Care. Examples include patients in a Permanent Vegetative State, patients receiving 24 hour ventilation through a tracheostomy, and people who fall under Sections 2, 3 and 4 of the Mental Health Act 1983.”

The determination of eligibility against these criteria is made with assistance of an assessment tool across a number of Care Domains (breathing, communication, cognitive impairment, behaviour, seizures, mobility, continence, skin care, drug therapies, food and drink. Following the assessment, a scoring device known as the ‘threshold tool’ assigns a weighting score to each of the Care Domains. Eligibility for Category 1 care will be determined on the basis of indicative levels of need on the following threshold scores:

- 3 or more care domains have a weighting of 100
- or**
- 5 or more care domains have a weighting of 60 or more
- or**
- 2 care domains with a weighting of 100, *and* a care domain with a weighting of 80
- or**
- 100 for behavioural problems, 0 for mobility
- or**
- 100 for seizures
- or**
- 100 for behavioural problems and 100 for cognitive impairment.

In reaching agreement across the SHA there have been some disputes with some social services partners about how eligibility criteria are applied in practice, and whether they are too stringent. With the exception of one council, these disagreements were resolved. The SHA reviewed its criteria against those of several other SHAs, and found no significant difference. There has been particular controversy around the role of professional judgment; the extent to which professional judgment forms an essential part of any assessment, and the extent to which the assessment toolkit is able to ameliorate the need to rely to any significant extent on professional judgment.

The SHA commissioned an independent review in order to address a number of key issues around the eligibility criteria, and in particular:

- To confirm that all continuing care panels are operating effectively and consistently.
- To acquire an independent assessment of the outcome of the application of the SHA's criteria.
- To achieve a more complete understanding of the financial consequences of the application of the SHA's criteria.
- And to agree a way of managing a transition from former unlawful shared funding arrangements in each locality and in respect of clients placed under those arrangements.

### ***Investigation of continuing care cases and restitution***

A three stage protocol was established to manage review of previous continuing care decisions. Each case for which records and information can be collated is separately reviewed by two pairs of assessors. If there is disagreement between the two pairs, a third review is undertaken. Cases then go to panel.

In March 2004 the SHA had identified more than 1,600 cases for review. A large number of additional cases had not yet been entered on the data base, and accordingly the SHA estimated that the 'long list' of cases before any screening would be around 2,500. Of the 1,600 on file, investigation had been completed on just under 200. 29 were being recommended to their panel as meeting the criteria for NHS continuing care. The remainder were judged either to have no claim, to be outside the scope of the review, or to have insufficient evidence on which to make an assessment. A number of cases had raised issues about the provision by the NHS of Category 2 care.

To-date the panels had confirmed that restitution was due to 26 clients (some 15% of cases) at an approximate cost of £2.2m. These cases were almost all self-funded clients who had by-passed formal assessment prior to entering a care home. Where restitution was due it often covered a period of several years. The SHA estimated that the future proportion of cases qualifying for restitution would be in the region of 5% (a total of around 150-200 clients eligible for restitution).

***The SHA***

The SHA covers an area of three former health authorities and serves a population of 1.5 million across multiple PCTs. The area is mixed and includes urban and rural aspects in counties that are characterised by both affluence and relative deprivation.

***Development of SHA-wide continuing care criteria***

The review of continuing care policies and procedures was undertaken on a strategic interagency basis. A joint project group was established that brought together health and social services officers “to share areas of good practice, and to agree continuing health and social care eligibility criteria, setting out each agency’s respective responsibilities.”

Criteria for continuing care apply to older people; older people with mental health needs; people with dementia, and young adults requiring health care as a result of illness or accident. Health and social care agencies in the SHA agreed criteria in respect of three bands of care:

- Band 1 – Continuing NHS Care
- Band 2 – Jointly funded care
- Band 3 – Social care

The criteria are summarised in the box below.

Two of the predecessor health authorities had sought a legal opinion on the continuing care criteria they had previously been operating. In the wake of the Ombudsman’s report the SHA also sought legal advice on these criteria.

## SHA 4 Criteria for Continuing Care

### Band 1 - NHS Continuing Care

The NHS will meet the full costs of care when one or more of the following are met:

- A person has complex, intense, unpredictable or multiple healthcare needs that require supervision by a specialist member of the NHS multi-disciplinary team, such as an NHS consultant or other specialist practitioner from a healthcare profession. A requirement for supervision from a registered nurse or GP will not generally be sufficient.
- A person is terminally ill and requires specialist palliative care services.
- The individual's needs require the routine use of specialist healthcare equipment under the supervision of NHS staff.
- A person is under an Order of the Curt to receive treatment or is detained (not merely liable to be detained) pursuant to the Mental Health Act.

### Band 2 - NHS & Social Services Joint Funding

Where an individual does not meet criterion for Band One above, the NHS is responsible for funding the healthcare needs, including equipment, of the individual as assessed. Subject to eligibility, the individual may also be entitled to assistance from Social Services, which may charge for all or part of their services.

### Respite Health Care

Respite healthcare will be funded by the NHS when:

- The individual's needs meet the eligibility criteria for band one;

OR

- Where the individual may otherwise benefit from additional health therapeutic input during the period of respite care.

### NHS Funded Nursing Care

NHS contributions to nursing care for patients in care homes are arranged through the Free Nursing Care System.

It was recognised that ensuring consistency in the application of the criteria would be important. It was believed that the assessment forms in use in one of the counties covered by the SHA were adequate but were often "not completed in sufficient detail to determine whether the criteria have been applied appropriately in reaching decisions about NHS funded

continuing care.” In the other county a proforma had been developed using the harmonised criteria. A common operating manual for staff training was developed but “it was noted that the processes around assessment may be different in the two counties.”

### ***Investigation of continuing care cases and restitution***

The process for review of cases followed a slightly different approach in different parts of the SHA. One area established a second stage of panel scrutiny for all cases judged to be borderline. Another was using one nurse assessor, rather than teams of assessors, to undertake all the initial reviews. Cases were referred to an Independent Review Panel only when the decision of the assessors is not accepted by the client or their relatives.

By March 2004 423 enquiries had been received about eligibility assessment from previous years. Reviews had been completed for almost three quarters of these cases, and around 8% were assessed as eligible. Restitution had been awarded at a total cost of around £570,000 but not all the eligible cases had yet been costed.

**The SHA**

The SHA covers the area of several predecessor health authorities. It is a diverse area including pockets of affluence alongside urban areas and relative deprivation.

**Development of SHA-wide continuing care criteria**

Responsibilities for continuing care have been set out in a document produced through a partnership between the SHA, multiple PCTs and local authority social services departments. Eligibility criteria apply to all adult care groups, while it is recognised that discussions will need to take place between PCTs, social services, and Education authorities over the attribution of shared costs for complex children's cases.

Historically one of the former health authorities is recognised to have operated "very tight" eligibility criteria, which in turn was indicative of a social services partner perceived to have been "very weak." There is now a greater challenge to criteria from social services than was the case in the past. The establishment of an Implementation Group to take the work forward is seen as very helpful in the development of shared understanding. This is reflected in the development of a Continuing Health Care training pack to ensure consistency across PCTs and social services

Continuing NHS health care services are "usually considered to be in excess of health care that is routinely available from primary or secondary care. Continuing NHS health care may be provided in a NHS hospital, a registered care home providing nursing care, hospice or in the individual's own home."

The eligibility criteria for NHS continuing health care in SHA 5 are summarised in the Box below.

The document also states that where these criteria are *not* met, a person will be entitled to continuing care if, after assessment "of his or her continuing health care needs, or by reference to the quality, quantity and requirement for continuity of any nursing services provided:



**The requirement for the meeting of their care needs goes beyond that which a Local Authority can be expected to provide pursuant to its obligations under Section 21 of the National Assistance Act 1948;**

***Or***

**The services themselves are not merely incident or ancillary to the provision of accommodation, which a Local Authority is under a duty to provide to the category of persons to whom Section 21 of the National Assistance Act 1947 refers.”**

***Eligibility criteria for NHS continuing care***

Subject always to the consideration of individual needs, continuing NHS health care will be provided to individuals if, following the carrying out of a health needs assessment (where appropriate), one or more of the following criteria are met:

The nature or complexity or intensity or unpredictability of the person’s health care needs (and any combination of these needs) requires regular supervision by a member of the NHS multi-disciplinary team, such as a Consultant, palliative care nurse/specialist, therapist, or other NHS team member.

The person’s needs require the routine use of specialist health care equipment under the supervision of NHS staff.

The person has a rapidly deteriorating or unstable medical, physical or mental health condition and requires regular supervision by a member of the NHS multi-disciplinary team, such as the Consultant, palliative care nurse/specialist, therapist or other NHS team member.

The person is in the final stages of a terminal illness, whereby medical opinion identified that the patient is in a progressive state of decline and life expectancy is likely to be only days, weeks or months. Regard will be taken of the health care needs and choice of the patient and their family. No patient will be discharged from inpatient care without an individual assessment of their health needs and their expressed wishes taken into account.

In applying the criteria, it is also stated that there are “persons whose health care needs are such that they are eligible for 100% NHS funded continuing health care without formal assessment.” These are:

- Persons in a persistent vegetative state.
- Persons who are ventilator dependent.
- Persons in a coma.
- Persons detained under Section 2, 3, 35, 36 or 327/41 of the Mental Health Act 1983.
- Patients admitted compulsorily to hospital (NHS or independent) under the terms of the Mental Health Act, or patients who would meet the requirements of the Act but are willing to be admitted voluntarily.
- Persons who are terminally ill with severe problems of symptom control.

Those patients whose health care needs are such that they *may* be eligible for NHS continuing health care and who require a formal assessment are identified by regard to the following (which are not intended to be exhaustive or determinative):

- Requirement for the constant attention of a qualified nurse and constant availability and access to medical expertise 24 hours a day.
- Requirement for highly complex or specialist equipment to maintain life and staff trained to maintain the equipment and provide emergency care in the event of equipment failure.
- Existence of a high degree of dependency on nursing care by persons who have a condition that fluctuates unpredictably and which without frequent and prompt intervention by access to a NHS team might lead to death, deterioration or severe distress. Examples of such conditions include brittle diabetes, frequent prolonged convulsions and terminal illness with severe problems of symptom control.

A range of other situations are also outlined which *may* indicate that patients meet the eligibility criteria, and are listed “as a general guide to determining the extent of a person’s health care needs.” However, it is also emphasised that “a person’s eligibility is determined by their individual health care needs and not disease or diagnosis.”

### ***Investigation of continuing care cases and restitution***

In setting out to meet the Department of Health deadline of 31 March for completion of restitution cases the SHA concentrated on responding to those cases where patients or their families had made contact with the SHA to seek a review, however in parallel the PCTs have also followed the Department of Health and the Health Service Ombudsman's office and been actively seeking cases. By April 2004 more than 1,200 cases had been identified for investigation and review had been completed for almost 800. A decision to award restitution had been made in almost 12% of these cases.

***The SHA***

The SHA is an urban authority covering the territory of three former health authorities, and encompassing several PCTs and social services departments. It serves a population of 1.4 million.

***Development of SHA-wide continuing care criteria***

Across the SHA territory it is recognised that different historical provision had led to variations in the restrictiveness of eligibility criteria for continuing care between the former health authorities. The adjustments that will be required will lead to the NHS picking up a larger proportion of funding in part of the SHA than in the past, while in other parts of the authority social services will be making a greater contribution. It is acknowledged that the culture change that needs to occur on both sides will be contingent on the success of training. In particular, there are concerns about ensuring the consistency of interpretation and application of criteria. A 'toolkit' has been developed to assist in the restitution review (see below), and there is now interest in developing a similar tool for assessing eligibility for current continuing care cases.

The SHA published 'joint eligibility criteria for continuing care' developed and agreed with all partner PCTs and social services departments in November 2002. Three categories of continuing care were identified, setting out the different and shared responsibilities of NHS organisations and local authorities for arranging and funding continuing care to meet health and/or social care needs for adult care groups who require a service as a result of frailty, illness, substance misuse, accident, disability or sensory impairment. A separate set of eligibility criteria (for the same three categories) had also been developed in respect of adults with mental health problems.

Eligibility criteria for each of the three categories are presented together with examples of the needs which may lead to eligibility. The criteria are summarised in the Box below.

## ***Joint eligibility criteria for continuing/long term care (SHA 6)***

### **Category A: NHS continuing health care**

Individuals are eligible for continuing NHS healthcare if they meet at least one of the following requirements:

- The nature or complexity or intensity or unpredictability of the individual's health care needs (and any combination of these needs) requires regular supervision by a member of the NHS multi-disciplinary team, such as the consultant, palliative care, therapy or other NHS member of the team.
- The individual has a deteriorating or unstable medical, physical or mental health condition and requires regular supervision by a member of the NHS multidisciplinary team such as the consultant, palliative care, therapy or other NHS member of the team.
- The individual is in the final stages of a diagnosed terminal illness and is likely to die in the near future.
- The individual's needs require the routine use of specialist healthcare equipment under the supervision of NHS staff.

### **Category B: Continuing health care needs jointly provided and funded by health and social services**

Health and social care services have a joint responsibility to arrange and fund packages of care for individuals with complex health needs which need to be considered holistically and whose health needs and social care needs are so inter-linked that they cannot be separately identified and separately met. This will usually mean that a jointly funded care package is required, in addition to any discrete social care or health provision that may be required.

For those individuals placed in a nursing home and who do not meet the eligibility criteria for NHS continuing care, the shared responsibility will be delivered through the 'free nursing care' mechanism to be implemented for all residents in nursing homes from April 2003.

This category includes individuals, the nature or complexity or intensity or unpredictability of whose health needs (and any combination of these needs) requires SOME supervision by a member of the NHS multidisciplinary team, such as the consultant, palliative care, therapy or other NHS member of the team.

### **Category C: Local authority social care**

The local authority is responsible for arranging and funding personal and domestic care for those individuals whose needs are such that they do not meet the eligibility criteria for NHS continuing care (Category A) or the joint eligibility criteria for NHS/social services continuing care (Category B). Eligibility for social care services will be determined by the local authority's eligibility criteria determined within the framework of the guidance on Fair Access to Care Services.

### ***Investigation of continuing care cases and restitution***

A Handbook presenting process & assessor protocols was produced to guide the retrospective review process. A toolkit was developed to provide shared paperwork and information on all reviewed cases. In addition a checklist for supporting documentation was also developed to ensure key medical and social care assessment information is included.

Assessors work in pairs, with no previous knowledge of the case, and review each case against current SHA criteria. Cases are screened out that do not come within the scope of the review. All other cases are reviewed in detail and a recommendation is made to the panel. All cases are automatically scheduled for an independent review panel hearing before the appellant is advised of the outcome.

A total of 162 review cases went to panel for decision, and 9 cases received full restitution and 10 were awarded partial restitution. Currently 12% of all cases will receive some restitution at a total cost of £2.23m (including provision for possible contingencies on appeal).

**The SHA**

The SHA covers an area previously embraced by several health authorities, and relates to multiple PCTs and three local authority social services departments. This is a large territory with significant rural areas and considerable affluence. The territory has a large number of nursing homes and is a popular retirement area.

**Development of SHA-wide continuing care criteria**

Eligibility criteria have been developed jointly between health and local authority social services departments across the SHA. The PCTs have operated as an alliance. The intention has been to ensure that the criteria are “explicit but also simple to apply.” The eligibility document addresses funding responsibility for those people meeting eligibility criteria for NHS fully funded continuing health care (Category 1); or those who require additional health care support but do not meet the criteria for NHS fully funded health care (Category 2); or whose predominant need for accommodation or other services is for personal/social care reasons (Category 3).

**Category 1 Eligibility Criteria SHA 7**

Category 1 care can be provided in a hospital, Registered Care Home, sheltered housing unit or at home. Services funded by the NHS are free at the point of delivery.

**Eligibility** – must be determined by an appropriate multi-disciplinary assessment (which may be under the single assessment process or care programme approach).

An individual may be eligible for Category 1 care when:

1. The nature or complexity or intensity or unpredictability of the individual’s health care needs requires regular supervision of a consultant, specialist nurse or requires input from other members of the NHS multi-disciplinary health care team.

OR

2. The individual has a rapidly deteriorating or unstable physical or mental condition which requires medical or nursing supervision.

The document states that some specific conditions will automatically qualify for Category 1 care:

- Persistent Vegetative State.
- 24 hour mechanical ventilation via tracheostomy.
- Compulsory detention under Section 2 or Section 3 of the Mental Health Act.
- The individual is in the final stages of a terminal illness and is likely to die in the near future. As a guide 'near future' will for these purposes usually be around 4-6 weeks. This should not however be applied restrictively and individual circumstances must always be considered.

The identification of health care needs will be made through the use of the health and social care Assessment of Care Need tool for each of the patient groups (people with a physical disability and/or an organic mental health disorder; people with a learning disability; people with functional mental health problems (the tool is work in progress)). The assessment tool is designed to assist in determining whether a patient is eligible for NHS funded continuing care, but "should not be used in isolation." A document outlining the assessment process makes clear that "it will be necessary to identify supporting clinical evidence as the tool will only identify the nature of health needs not complexity or unpredictability or whether the patient's condition is unstable or deteriorating." The tool addresses seven domains for adults with a physical disability/organic mental health disorder:

- Behaviour
- Cognitive impairment
- Communication
- Dietary intake
- Medication and symptom control
- Mobility – transfer and falls
- Wound/pressure ulcer care



### ***Investigation of continuing care cases and restitution***

The procedure document for the review process observes that “the task of identifying retrospectively the application of the criteria requires a high level of skill and extensive familiarity with the application of the criteria in practice.” In addition to ensuring that a pool of experienced clinicians is identified to undertake the work in each health community, the reviews are to be undertaken “using an agreed format and method.” Standard documentation has been developed and a checklist of supporting documentation to accompany each review is indicated.

Local review teams were established covering each of three geographical health communities. Teams have worked in liaison with a Local Review Officer and were required to complete each review within 12 weeks. Decisions are made by the teams, and where a claim is not upheld claimants can request their case is reviewed by an independent review panel.

Across the SHA in excess of 800 requests for continuing care restitution had been received. By the end of March 2004 reviews had been completed on 17% of cases, and 22 cases (15% of those reviewed) had been judged to qualify for restitution.

***The SHA***

The SHA covers an area previously administered by four health authorities. Several PCTs are responsible for services to a population of 1.55 million. The territory includes some urban development but also extensive rural shire areas.

***Development of SHA-wide continuing care criteria***

A group of SHA Continuing Care Leads was established to agree and produce the continuing care criteria, review procedures and patient information leaflets. The group membership comprised representation from all PCTs and social services departments within the SHA, and also involved representatives of particular client groups.

The SHA published a document in May 2003 setting out the NHS responsibilities for meeting continuing health care needs, and the NHS contribution to continuing health and social care. The policy relates to all adults over the age of 18. The role of SHA is seen in terms of setting the policy and ensuring that NHS organisations across the area adopt and implement the criteria and contribute to monitoring and evaluation. The document also highlighted the positive opportunity the policy offers for closer collaboration between health and social care providers: “the revision of the continuing NHS health care policy is an opportunity to ensure that people get access to the health and social care they need, when they need it and that the NHS pays for the health care components.”

The criteria for NHS continuing care are set out in the Box below. The SHA document also “offers guidance based on current best practice on the interpretation of the criteria.” It is stated that it is the responsibility “of each PCT in discussion with Social Services and local NHS trusts, to define and agree operational procedures within the agreed framework and in the context of local circumstances.”

Standardised training was developed using case studies, and was to be delivered through a cascade across health and social care economies within the SHA. It was recognised that the history of NHS continuing care provision across the SHA differs considerably between the PCTs.

### ***Criterion 1: Continuing NHS Health Care SHA 9***

The test for eligibility for this criterion will be met in the following circumstances where an individual's overall condition means that their primary need is for health care:

- An individual will be eligible for continuing NHS health care under criterion 1 when the complexity or intensity of their medical, nursing or other clinical care needs (and any combination of these needs) or the need for frequent, not easily predictable, interventions requires the supervision of a consultant or other NHS clinician.

**Or**

- Where an individual has a rapidly deteriorating or unstable medical, physical or mental condition.

**Or**

- Where an individual is in the final stages of a terminal illness and likely to die in the near future.

**Or**

- Where an individual's health needs require the routine use of specialist health care equipment under the supervision of NHS staff.

**Or**

- Where the individual requires non registered nursing care to the extent that goes beyond what can properly be described as incidental or ancillary to the accommodation and personal care needs.

### ***Investigation of continuing care cases and restitution***

The Continuing Care Leads Group was also responsible for monitoring the process of retrospective reviews across the SHA in order to ensure consistency of outcome.

By March 2004 around 260 cases for restitution investigation had been identified across the SHA. Investigation had been completed for most of these, and around 11% had been awarded restitution.

***The SHA***

The SHA covers a largely urban territory encompassing an area previously served by several health authorities. There are multiple PCTs and local authority social services departments within the SHA boundary.

***Development of SHA-wide continuing care criteria***

One of the predecessor health authorities had operated eligibility criteria for continuing care that had resulted in challenge and dispute about their legality. Criteria across the remaining health authorities were believed to have been Coughlan-compliant.

Eligibility criteria for continuing health care across the SHA were developed and came into effect from November 2003, although the final agreed documentation was only produced in March 2004. The practitioner guidance published by the SHA was presented as a joint initiative between the SHA and all partner PCTs and local authority social services departments across the territory. The publication of the criteria was the result of a process that began in September 2002 when a group of PCT and local authority officers began meeting with SHA officers to develop common criteria to replace the previous sets of criteria that had been operated by the health authorities.

Two categories of continuing health care are identified:

**Category 1:** NHS fully funded continuing health care – arranged and funded solely by the NHS when a service user meets the criteria specified in the Box below.

**Category 2:** Joint funded continuing health and social care – where the service user is not eligible for NHS fully funded continuing health care and the NHS does not have overall responsibility for the whole package of care. Care is funded by the NHS and social services.

When applying the criteria the multi-disciplinary team should use a Case Evaluation Trigger List. This provides a checklist of questions that need to be addressed in each case.

While the criteria have been agreed across all partner agencies, it is recognised that the real test will be in implementation roll out and on-going training. As yet this process has only just begun.

### **Eligibility criteria for NHS fully funded health care (SHA 9)**

A person will be considered to be eligible for NHS fully funded continuing health care if the following criteria apply:

1. The service user has significant health care needs which means that the overall scale is such that they should be regarded as wholly the responsibility of the NHS. This will usually mean that the individual's condition triggering a comprehensive assessment has resulted in:
  - complex health care needs and/or
  - intensive health care needs and/or
  - unstable/unpredictable health care needs and/or
  - rapid deterioration.

AND

2. The service user requires significant health care inputs. The individual requires:
  - Regular supervision by a member of the NHS health care team – a consultant, palliative care specialist, therapist or other registered health care professional including a registered nurse and/or
  - Has a condition that requires the routine use of specialist health care equipment or medication under supervision of a registered health care professional working in the NHS.

AND

3. The service user's condition is likely to continue over the long term although the timescale of each care input might vary between the remainder of an individual's life and episodes of care.

OR

4. The service user is experiencing the end of a terminal illness and is not expected to live for a long time.

### ***Investigation of continuing care cases and restitution***

A four stage process was developed for investigating requests for reimbursement. The first 2 stages screen out cases that do not fit the review. Cases reaching third stage are the focus of detailed information gathering, and all these cases are referred with a recommendation to a Special Review Panel.

By mid-January 2004 almost 400 cases had been identified for retrospective investigation across the entire SHA. Investigation had been completed in more than half of these cases. To-date restitution had been agreed for 9 cases (just 4% of cases where investigations had been completed).

## References

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<sup>10</sup> Case No E.22/02-03, *Complaint against: The former Cambridgeshire Health Authority and South Cambridgeshire Primary Care Trust. The Pointon Case.*

<sup>11</sup> *Ibid*, para 39.

<sup>12</sup> *Ibid*, para 43.

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## **Part of the problem or part of the solution? The role of care homes in tackling delayed hospital discharges**

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# **Part of the problem or part of the solution? The role of care homes in tackling delayed hospital discharges**

## **Abstract**

As part of current UK policies to reduce the number of delayed hospital discharges, a number of commentators have identified an alleged crisis in the care home market as one of key contributing factors. With local authorities under pressure to cut costs, it is argued, the number of care homes is reducing, and delays in hospital can often result. Behind this diagnosis is a series of assumptions about the role and nature of care home provision, the appropriateness of this form of service for many older people, and the need for more care homes to reduce the number of hospital delays. In order to explore and critique these assumptions, this paper reviews the role of care homes in tackling delayed discharges, and argues the need for fewer and different care home placements rather than more of this type of provision.

## **Keywords**

Hospital discharge

Care homes

Older people

## **Part of the problem or part of the solution? The role of care homes in tackling delayed hospital discharges**

In the second half of the twentieth century, the quality of care provided in institutional settings was the focus of significant debate and concern (see for example, Means and Smith, 1998 for an overview of the development of post-war community care).

Designed initially to impose stigma upon residents and to serve as a warning to others outside the institution, some services focused more on social control than on providing high quality services to older people, people with physical impairments, people with learning difficulties and people with mental health problems (see, for example, Foucault, 1967; Goffman, 1968; Townsend, 1986). Partly in response to this, much of the last quarter of the century was spent developing community-based services and introducing inspection and regulation systems to ensure the quality of remaining provision.

Following this activity, the focus has moved away from care homes, and there has been less attention paid to this issue in more recent years. What is the role of care homes for older people in the twenty first century? This is a fundamental question which raises issues not just about the quality of services that are provided, but also about the purpose and function of care homes as part of a continuum of other services. How many care homes do we need relative to an ageing population? Do we need more care homes (as most debate suggests), or should we be trying to reduce such residential provision in favour of better quality community alternatives, apparently as has been successfully achieved in some Scandinavian countries? This debate is one that has scarcely begun. Rather, much of the discussion around services for older people has focused on two key issues:

1. *The number of older people who are delayed in hospital when they no longer need the services provided there.* While such people are still too often referred to pejoratively as ‘bed blockers’, it is increasingly recognised that most people want to leave hospital and go home as soon as they are able, and that it is often the fault of health and social care services that beds are ‘blocked’ due to a combination of delays in assessment, funding problems, a lack of community services to support

people outside hospital and the failure of health and social care services to coordinate their activities more effectively (see Glasby, 2003 for an overview). The House of Commons Health Committee (2002) estimated that in 2001-2002 around 7,000 people of all ages were delayed in hospital at any one time, occupying six per cent of NHS beds at a cost of £720 million per year (although such figures have since fallen significantly as a result of more recent policy initiatives).

2. *The closure of a number of care homes*, often attributed by the media to local authorities using their position as a near-monopoly purchaser of care home places to drive down costs and force care home owners into bankruptcy. This has led to accusations of “inadequate” fees and a “short-sighted” approach, creating a “dysfunctional market” which is now “at crisis point” (Care and Health, 2003; Salari and Wood, 2003; Glassman, 2004: 11). In contrast, some local authorities and the government have responded by dismissing these claims as scare mongering, accusing care homes of wishing to make excessive profits. According to some reports, this includes the description of the care home umbrella organisation, English Care, as a “cartel” trying to “rig the market” and of care home owners as “dinosaurs” who should become extinct (Care and Health, 2003; Community Care, 2004).

Often, these two issues have tended to become conflated, with an assumption that delayed hospital discharges are caused primarily by a reduction in the number of care homes. While there are clearly a range of factors contributing to delayed discharges (for example, delays in acute care, lack of community health and social services, funding shortages, delays in social care assessment, and service users and carers exercising their right to enter a care home of their choice rather than one with an immediate vacancy; see, for example, Glasby, 2003), many accounts appear to suggest that the main issue has been a decline in the number of care homes (and hence that there need to be more care homes). In 2003, for example, the National Audit Office highlighted “a need to generate increased capacity in the health and social care system in order to resolve the underlying causes of delayed hospital discharges”, adding that “a lack of capacity in long-term residential and nursing care is the main cause of delayed discharge” (National Audit Office, 2003, p.35). In 2004, the annual

report on the nation's health by the Healthcare Commission (2004) indicated that delayed discharge rates can vary from 3.2 to 15.4 per cent from region to region, linking this explicitly to rising property prices in the south and a lack of capacity in care homes. Put crudely, these accounts seem to suggest a simple equation:

- A key cause of delayed hospital discharges is the lack of care home places.
- The answer is therefore more care home places.

Against this background, this paper seeks to explore the role of the care home sector and, in particular, its contribution to tackling the problem of delayed hospital discharge. Whilst recognising that there are a number of tensions in the care home market that need resolving, we disagree fundamentally with the 'more care homes' argument outlined above. While care homes have a key role to play in the spectrum of services available to older people, they also have the potential to be 'part of the problem' rather than 'part of the solution' if used inappropriately. To expand on these views, we explore five key statements which place much of the preceding discussion about delayed discharges and care homes in a wider social policy context and help identify possible directions of travel for the future:

- 1. Care homes have often been used as spare capacity to warehouse older people no longer requiring the services provided in hospital, but with nowhere else to go.*

Although discharging people from hospital has long been a controversial and complex task, discharge has acquired increasing significance following the NHS and Community Care Act 1990. Prior to the full implementation of the Act in 1993, there was a degree of flexibility in the system, with hospital patients who were receiving Supplementary Benefit (subsequently Income Support) able to be discharged directly into residential or nursing homes with funding from the Department of Health and Social Security (DHSS – later the Department of Social Security or DSS). This had been made possible by changes in social security regulations in the early 1980s, with the DHSS beginning to make 'board and lodgings' payments for people in non-local authority homes (see Audit Commission, 1986; Bradshaw, 1988; Laing, 1993; Tinker,

1997). This was initially a discretionary process set up in response to financial difficulties in local authorities and amongst independent residential/nursing homes following the oil crisis and the subsequent economic dislocations of the late 1970s.

To begin with, the DHSS began to make payments for the care of those residents “unable to afford their own fees and for whom local authorities were unwilling to foot the bill” (Laing, 1993, p.25). This practice was later formalised, leading to a massive increase in the number of independent sector homes and the number of residents being supported by the DHSS. As a result, social security expenditure on Income Support for people in independent sector residential and nursing homes in Britain rose from £10 million in 1979 to £2,575 million by 1993, with the number of individual recipients increasing from 11,000 to a peak of 281,000 over the same period (quoted in Tinker, 1997, p.157).

Of course, looking back over a number of years it is difficult to be certain how widespread was the practice of discharging patients directly into residential/nursing care or how appropriate this type of service may have been for the people concerned. Whatever the gaps in our current knowledge, however, three key issues are immediately apparent:

- The number of admissions to private residential/nursing homes increased dramatically following the changes in social security policy described above. By the early 1990s, hundreds of thousands of people were receiving financial contributions to the cost of their care, with no objective assessment of their need for the services they were using. The loop hole in the social security system allowed local authorities to avoid the cost of putting together packages of support for people in the community, and instead allow the costs of their residential placement to fall on the uncapped social security system.
- Many of those admitted to independent sector homes were less dependent than people in local authority homes (for which Supplementary Benefit was unavailable). This has been demonstrated by a host of research studies (see, for example, Bebbington and Tong, 1986), and it is only relatively recently that levels

of dependency have begun to even out between homes in the public and independent sectors.

- Hospital staff may sometimes overestimate the level and duration of support which older patients require, prematurely ‘writing them off’ as suitable only for residential/nursing care (see below and Littlechild *et al.*, 1995).

The conclusion is inescapable that throughout the 1980s substantial numbers of older people were admitted to residential and nursing care, not because they needed the support provided by these services, but because of the relatively easy availability of public funds for this form of care and the under-development of alternative services in the community. It is now widely accepted that large numbers of older hospital patients were prematurely admitted to institutional forms of care by hospital staff, not necessarily because they needed twenty-four hour care, but because they simply did not need to be in hospital and the availability of DHSS funding provided something of a safety valve in the system. This was clearly a disaster in terms of public expenditure management. For many of the older people themselves, it was nothing short of a tragedy which removed from them the option of continuing to live in their own homes and community.

2. *Current financial difficulties are a direct result of the NHS and Community Care Act 1990 and could easily have been predicted.*

By the late 1980s, this state of affairs was recognised as unsatisfactory for a variety of reasons (see Lewis and Glennerster, 1996 for a summary):

- Public expenditure on residential/nursing care was increasing dramatically, seemingly spiraling out of control.
- This was not only expensive, but also diverted resources towards institutional forms of care and away from community services. For the Audit Commission (1986, pp.43-48), the availability of Supplementary Benefit for residential/nursing

care was a “perverse incentive” that hindered the development of community-based forms of support. For Sir Roy Griffiths (1988, p.9), architect of the community care reforms, “the separate funding of residential and nursing home care through social security, with no assessment of need, is a particularly pernicious split in responsibilities, and a fundamental obstacle to the creation of a comprehensive local approach to community care.”

- DHSS support was available on the basis of income alone, for those without sufficient funds to pay for their own care receiving public support irrespective of their health status, their level of disability or frailty or their ‘need’ for residential/nursing care. For Griffiths (1988, p.v), this could easily lead to a situation where “the ready availability of social security makes it easy to provide residential accommodation for an individual regardless of whether it is in his best interest.”

As a result, two of the key aims of the NHS and Community Care Act of 1990 were “to make proper assessment of need... the cornerstone of high quality care” and “to secure better value for taxpayers’ money by introducing a new funding structure for social care” (Department of Health, 1989, p.5). The resultant legislative and policy changes were complex, and have been described in detail elsewhere (see, for example, Victor, 1997; Means and Smith, 1998). However, following the full implementation of the Act in 1993, local authorities were to take the lead in assessing individuals’ needs, designing care packages and securing their delivery within available resources. This was to include those entering residential and nursing care, who would need to be assessed by a social worker prior to admission and whose care would be funded (subject to means testing) by a local authority social services department (SSD) with money transferred from the DHSS via a new Special Transitional Grant (STG). Perhaps unsurprisingly, the latter involved complex calculations, based in part on the social security payments that would have been made to people in residential and nursing care had the pre-1993 system continued (see Glasby and Glasby, 1999, 2002 for a more detailed discussion of social work and local government finance).

**Figure 1** The *Caring for People* White Paper (subsequently enacted in the NHS and Community Care Act 1990)

*“The Government believes that for most people community care offers the best form of care available – certainly with better quality and choice than they might have expected in the past. The changes outlined in this White Paper are intended to:*

- *Enable people to live as normal a life as possible in their own homes or in a homely environment in the community;*
- *Provide the right amount of care and support to help people achieve maximum possible independence and, by acquiring or reacquiring basic living skills, help them achieve their full potential;*
- *Give people a greater individual say in how they live their lives and the services they need to help them do so.”*

(Department of Health, 1989, p.4)

While much of the White Paper (*Caring for People*) emphasised the humanitarian and benevolent nature of the community care reforms (see, for example, figure 1), there is little doubt that the 1990 Act was also primarily a response to pressing financial issues. Public expenditure on residential/nursing care was rising rapidly with no assessment of need (other than financial) and no means of controlling the ongoing increases. Since local authorities have finite budgets and have to balance a host of competing demands, the decision to transfer responsibility for funding residential/nursing care to SSDs meant that the task of restricting the rapidly increasing social security bill would fall to local authorities. As Lewis and Glennerster (1996: 8) observe:

*“[The community care reforms] were not primarily driven by the desire to improve... services for elderly people... They were driven by the need to stop the haemorrhage*



*in the social security budget and to do so in a way that would minimise the political outcry.”*

When local authority SSDs complain of a lack of funds, therefore, it is worth remembering that such financial difficulties are an almost inevitable consequence of the 1990 community care reforms. Put another way, the reforms can be seen as a deliberate attempt by government to transfer financial pressures from a central department to local government in the hope that the latter would be able to constrain the rise in public expenditure. As a result, financial tensions were always going to develop once the Act came into force, and would remain a feature of the social care landscape.

### *3. We need fewer care homes not more.*

In current debates about the role of care homes, the number of home closures has been a key issue, with estimates ranging from 19,000 to 50,000 lost beds in recent years. However, research undertaken by the House of Commons Health Committee (2002) suggests that the true figure may lie somewhere in between these two extremes at around 34,200 places between 1997 and 2001. While this seems like a substantial figure, the statistics mask a change in the balance of provision, with reductions in local authority and NHS care homes partially offset (until recently) by an ongoing expansion of private and voluntary sector places. In particular, the overall number of beds available in 2001 was almost identical to the number available in 1990, the year of the passage of the NHS and Community Care Act (see figure 2).

While the eleven years between these two dates has seen an ageing population, it has also witnessed concerted attempts to develop community-based alternative services. If policy makers and front-line services are genuine in their desire to maintain older people's independence and to support them to live longer at home, then we arguably need fewer care homes than we had in 1990 and therefore need to lose even more beds – not to gain them. As the House of Commons Health Committee (2002, p.46) concluded:

*“The fact that [so many] discharge delays can be attributed to waits for care home placement... might suggest that the obvious solution would be the rapid development of further residential and nursing home capacity. We do not support this conclusion. While we accept that developing capacity in areas where there are shortages has a contribution to make within a wider strategy, we are concerned that too much effort is being put into developing ‘more of the same’, with insufficient attention being paid to focusing on providing the most appropriate care for people, and developing the necessary alternative service models to ensure that the right care, in the right place, at the right time is available.”*

**Figure 2** Care home places over time

<b>Year</b>	<b>Care home places (local authority)</b>	<b>Care home places (NHS)</b>	<b>Care home places (private/voluntary)</b>	<b>Total</b>
1990	125,600	76,700	318,700	521,000
1991	117,400	71,300	350,400	539,100
1992	105,200	66,000	375,800	547,000
1993	94,600	62,200	406,100	562,900
1994	85,900	56,600	425,600	568,100
1995	80,100	53,100	437,300	570,500
1996	77,300	47,900	450,400	575,600
1997	71,000	44,000	457,600	572,600
1998	68,600	39,900	455,600	564,100
1999	64,200	36,600	450,300	551,100
2000	60,000	34,200	444,300	538,500
2001	57,400	31,500	437,000	525,900

Adapted from House of Commons Health Committee (2002)

With regard to delayed hospital discharges, moreover, there is a danger that older people are admitted to care homes, not because they need the services provided there, but because such provision is easy to fill once it exists and because older people can be ‘written off’ too quickly by health and social care professionals. While official statistics suggest that some 28 per cent of delayed hospital discharges are due to people awaiting a care home placement (or a care home placement of choice) (House

of Commons Health Committee, 2002), there is also some evidence to suggest that some older people may be inappropriately assessed while in hospital and prematurely admitted to permanent care home placements. This is difficult to prove as it is hard to know what would have happened to the individuals concerned had a different course of action been pursued. However, an early study from Herefordshire provides an important insight.

In 1992, a rehabilitation project was established in Hereford General and County Hospitals to prevent unnecessary admissions to residential and nursing home care (Littlechild *et al.*, 1995). With the support of local health and social care workers, the project appointed a care manager to work with people aged at least 65 who were on the point of discharge from hospital and who had been assessed as needing residential or nursing home care. Significantly, the care manager had a small budget (in addition to the normal budget for services available to older people) to provide facilities beyond those currently available and was able to employ the services of an OT. Of the 34 cases assessed during the first six months, 76 per cent people were able to avoid the permanent entry into residential or nursing care predicted for them when they were referred to the project (see figure 3). This success was achieved by a combination of methods, with some users returning home with additional support and others undergoing a period of interim care out of the home. In all cases, the emphasis was very much on rehabilitation and convalescence, thereby preventing those users who entered residential care for short periods deteriorating and becoming permanent residents. Techniques for retaining this focus on rehabilitation included frequent home visits with key workers and care plans orientated towards regaining practical living skills. Overall, the implications of this study are clear: for whatever reason, front-line services got it wrong in the case of 26 out of 34 (76%) of these older people and, without the project, these individuals would have been prematurely and inappropriately admitted to permanent long term care.

**Figure 3** Predicted and Actual Destinations

<b>Destination</b>	<b>Number of people (as predicted on referral)</b>	<b>Number of people (actual destination)</b>
Residential home	24	3
Nursing home	10	1
Home with support	0	26
Deceased	0	4
<b>Total</b>	<b>34</b>	<b>34</b>

Source: Littlechild *et al.*, 1995, p. 41

Another example comes from comments from respondents in a national study of hospital discharge, where the absence of local rehabilitation services in some case study areas was believed to lead to inappropriate and avoidable placements in nursing and residential homes:

*“There are such pressures to get people out of hospital, and the effect is that we have continued to place people in residential homes, even if that is not the best option... There should be health purchased rehabilitation.”*

*“People are put in nursing homes instead of in rehabilitation... we don’t provide the time for people to get better anywhere else than nursing homes. We have had people in nursing homes, and we have put in physio and OT support, and the person has gone home. I think the medics tend to write them off.”* (Henwood *et al.*, 1997, pp.38-39)

It is largely in response to issues such as these that the government has latterly invested so heavily in ‘intermediate care’ services to prevent inappropriate admissions to care homes (Department of Health, 2001). The NHS Plan of 2000 provided a renewed focus on services to support older people in making “a faster recovery from illness, encouraging independence rather than institutional care, and providing reliable, high quality on-going support at home” (Department of Health, 2000, para 15.13). The term ‘intermediate care’ is a broad one that is used to refer to a wide range of diverse services (including rapid response, Hospital at Home; supported discharge, and residential/day rehabilitation). However, the essential characteristics shared by such services are summarised in figure 4 below.

In addition, the Department of Health Change Agent Team has also been piloting projects to ensure that no older person is admitted to a permanent care home place directly from hospital (personal communications, Change Agent Team). As an example, Birmingham and the Black Country Strategic Health Authority have explicitly incorporated this into their hospital discharge protocols, stating that “no patient for whom long-term placement in a residential or nursing care home is being considered should be expected to make that decision from an acute hospital bed” (Birmingham and Black Country Strategic Health Authority/Change Agent Team, 2003, p.7).

**Figure 4** Intermediate Care Services

- Are targeted at people who would otherwise face unnecessarily prolonged hospital stays or inappropriate admission to acute in-patient care, long-term residential care, or continuing NHS in-patient care.
  - Are provided on the basis of comprehensive assessment, resulting in a structured individual care plan that involves active therapy, treatment or opportunity for recovery.
  - Have a planned outcome of maximising independence and typically enabling people to resume living at home.
  - Are time-limited, normally lasting no longer than six weeks, and frequently as little as one to two weeks.
  - Involve cross-professional working with a single assessment framework, single professional records and shared protocols.
- Department of Health (2001)

Above all, however, it is important to emphasise that many older people do not want to enter care homes. This has been demonstrated by a number of studies over time (see, for example, Henwood and Waddington, 1998; Harding, 1999; Royal Commission on Long Term Care, 1999), with the vast majority of older people keen to retain their independence and not wishing to leave their homes, community networks, gardens, pets and families if at all possible. Such attitudes are likely to become increasingly prevalent, with subsequent generations of older people thought to be much less likely to opt for care homes as a result of a series of ongoing social and attitudinal changes. According to one commentator, “the generation that spawned

flower power and protested against Vietnam are now, as they approach retirement, unlikely to accept a one-size-fits-all approach”, while Help the Aged argue that “there will be no room for the patronising way people are treated. It just won’t wash. It’s so far from the way we are used to living our lives” (both quotes from Smith, 2004, pp.18-19). According to a MORI (n.d.) poll, moreover, most people under 60 want to stay independent for as long as possible, receiving support in their own homes from friends and families (62%) or from formal services (54%) rather than in care homes.

*4. The problem is not a lack of care homes, but the way in which the market is managed.*

As highlighted above, there are significant concerns about the way in which the government and some local authorities are handling the care home market. According to one estimate, current fee levels are £127 and £83 per week too low for nursing and personal care costs respectively, with an extra £1 billion required to create a fully modernised care home sector (Joseph Rowntree Foundation, 2004). At the same time, care home costs are arguably rising due to the impact of the minimum wage, the requirement to meet new minimum national care standards, the need to carry out Criminal Record Bureau checks, increases in National Insurance contributions and a range of staff recruitment and retention difficulties. While some of these concerns have been voiced by care home providers with a vested interest in receiving higher fees, the furore that has arisen in recent years is sufficient to suggest that there are genuine problems and real substance to some of these issues of under-funding.

This derives from the unsophisticated way in which some local authorities continue to manage the care home market (and the failure of central government to provide sufficient funding for a more proactive approach to care home commissioning). Too often, homes close in an unplanned and unmanaged way, with little apparent notice or time for residents to prepare (see, for example, Community Care, 2003; Dobson, 2003). This can mean that home closures occur in areas with insufficient capacity and that good homes close as well as poor ones (Henwood, 2002). There is also a risk that larger national and international companies are better able to survive current financial difficulties than smaller, more local providers, and that this could lead to increasing

globalisation, greater depersonalisation and a reduction in choice and diversity. As a former Community Care Minister suggests (Ladyman, 2003):

*“Loss of care home capacity where there is a significant oversupply is, I’m afraid, inevitable and need not be a problem, providing that closures are managed sensitively. Of course, in such circumstances there may be distress for individual residents but while care homes are supplied by the private sector, or even in the cost conscious public sector demanded by taxpayers, then some closures cannot be avoided. What is a problem is when these losses occur in an unplanned way in areas where there are few other alternatives. This reduces choice.”*

Instead, a recent government Green Paper on the future of adult social care (Department of Health, 2005) calls for a much greater emphasis on long-term strategic planning, with new Directors of Adult Social Services responsible for assessing the needs of the local area and producing long-term commissioning strategies to meet these needs. To make this proposal a reality, there will need to a much greater ability to plan ahead to identify future demographic changes and social need, stronger and more co-ordinated commissioning across health and social care, and a growth of longer-term relational contracting (so that providers have greater security and are able to develop a closer relationship with commissioning than under current spot- and shorter-term contracts).

*5. Care homes are a key part of the spectrum of services available for older people, but need to play a different role in the future.*

While some older people may always want and need care home places, there is also scope for traditional care homes to operate in new ways in the future to meet demands for more responsive, community-based and person-centred care. While it is beyond the scope of this paper to explore these issues in detail, a key contribution may be for care homes to focus on the provision of short-term accommodation and rehabilitation as part of new intermediate care services. In addition to providing step-up and step-down support for those at risk of hospital admission or about to be discharged from acute care, care homes could also be used to provide interim care for those no longer

requiring acute care, but needing time and support to recover their confidence and self-care skills. Crucially, this will require new ways of working to ensure that care homes retain a genuinely rehabilitative focus, and do not encourage dependence in short-term residents by doing things for people rather than with them. Alternatively, other possible developments might include the development of supported living schemes that offer housing-based services and/or residential apartments where service users have support staff available, but retain their own front-doors and their own properties; outreach services that support people in their own homes; or use of care home facilities for members of the local community (for example, rooms for meetings and for adult education classes, use of dining areas for a community café, use of laundry facilities as a laundrette and/or use of payroll services for voluntary organisations). Whatever the best way forward may ultimately prove to be, we believe that the time is right for a reconsideration of the role of care homes, and that all these (and any other relevant options) need to be considered as part of the process of developing new approaches to and roles for care home provision.

## **Conclusion**

This paper has argued that ‘more care homes’ are not the answer to current concerns about delayed hospital discharges. In the past, care homes have too often been seen as spare capacity to ‘warehouse’ older people needing additional support after discharge from hospital, and this has led to the growth of a form of provision which is expensive and which many older people do not want. Instead, the task is develop a market and models of care in which we need fewer care homes (not more), and care homes that operate in different ways (with more of an emphasis on rehabilitation, working as part of a spectrum of services and opening themselves up more to the local community). The problem is not too few care homes, it is a market that is inadequately managed, partly as a result of the financial and historical legacy of the NHS and Community Care Act 1990 and a deliberate attempt by central government to curb rapidly escalating costs by transferring them to cash-limited local authority social services. That social services departments have succeeded in this task and, more often than not, made the current system work is greatly to their credit and is probably one of the unsung and under-rated achievements of social care in the 1990s.



However, the fact remains that we should now be seeking in the early twenty-first century to move beyond this initial task of bringing budgets back under control to exploring new ways of meeting the needs of older people in more individualised, person-centred ways. Above all, the answer to delayed discharge is not ‘more care homes’ – this was our previous policy, it did not work and it nearly bankrupted us. Instead, we need fewer care homes but a market that is better planned, managed and funded so that care homes can play their rightful role in the spectrum of services available to older people, as a genuinely positive choice for the few rather than the only option for the many.

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# Analysis of Evidence Submitted to the CSCI Review of Eligibility Criteria

A report commissioned by CSCI for the review of  
eligibility criteria

By Bob Hudson & Melanie Henwood

August 2008





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# Executive summary

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This paper reports on the evidence submitted to the Commission for Social Care Inspection (CSCI) review via an online survey and through written evidence. The review asked for views on the current arrangements for Fair Access to Care Services (FACS), and on what might be done in the short and long term to improve eligibility arrangements for social care support. Almost 3,000 respondents completed the online survey, including people who use services (or are in need of social care support), carers, people employed in council social services, people employed in other sectors of social care, and miscellaneous other interested parties. Just over 100 separate written submissions to the review were received.

Our analysis of the evidence is structured around three key dimensions:

- views on the current system
- proposals for short-term change
- proposals on longer-term reform.

Across both sources of evidence the following key points emerged:

- There was a strong underlying acceptance that some means of limiting access to publicly funded support has to be in place.
- There is some support for the current system on the grounds that it is an improvement upon previous arrangements and constitutes a national system of accountability and consistency, but most respondents expressed criticism of FACS at the level of principle and of practice.
- Very few respondents took the view that everything is fine with the current system of FACS. The main criticisms concerned lack of clarity and transparency; lack of fairness; service-led approaches; the limitations of a risk/needs-based model; insularity and fragmentation; neglect of the prevention and inclusion agendas; inadequate diversion and signposting; the dominance of budgetary considerations; and tensions with the personalisation agenda.
  - **Lack of clarity and transparency:** The problem most frequently raised related to the sheer complexity of the FACS framework, such that neither professionals nor users and carers were confident of their understanding. This can culminate in is a system that is too complex and confusing to be open to challenge.
  - **Lack of fairness:** Lack of clarity and complexity of challenge can soon spill over into a perceived lack of fairness in the way criteria are applied and resources allocated. Two dimensions of the allocation process were deemed to give rise to this situation – variations in professional judgement, and the 'postcode lottery' between different councils.
  - **Service-led approaches:** The introduction of FACS can, in part, be understood as an attempt to move practitioners away from a service-led approach to support, but the evidence submitted to the review suggests

that service-led approaches still dominate. The position of carers was felt to be at particular risk in these situations.

- ***The limitations of a risk/needs-based model:*** A risk/needs-based model constitutes the basis of the current FACS regime, with an assumption that a hierarchy of needs can be identified to justify resource allocation. The evidence reveals two main strands of criticism of the risk/needs-based model – that it has resulted in inadequate and unduly standardised assessments, and that it has led to the neglect of ‘hidden’ user groups.
- ***Insularity and fragmentation:*** FACS was not seen to offer a holistic response in the sense that it does not include consideration of important areas such as health, housing and leisure. This in turn had, in the view of some people, resulted in social care becoming an isolated, residual and stigmatising service. This insularity is exacerbated by the fragmentation between FACS and some important parallel processes that are likely to involve the same people. The areas most frequently identified were continuing health care, the care programme approach (CPA) and learning disability services.
- ***Neglect of the prevention and inclusion agendas:*** There is a considerable body of evidence testifying to the importance of ‘low-level’ preventive support and this does appear to be acknowledged in the FACS guidance. However, the overwhelming view in the submitted evidence was that this injunction was being infrequently observed.
- ***Inadequate diversion and signposting:*** The evidence raises several problems with the practice of signposting. Firstly, a concern that in their initial contact with the council, people’s needs and circumstances are insufficiently explored. Secondly, that insufficient support is given to people who are signposted in this way. And finally, that councils showed insufficient attention to what happened to people signposted out of the council system – in other words, unmet need was not being recorded and monitored.
- ***The dominance of budgetary considerations:*** The sources of spending pressure are demographically well established and these were a dominant feature of much of the submitted evidence. For some respondents this situation was simply a reflection of inadequately funded social care rather than any inherent fault with the eligibility framework.
- ***Tensions with the personalisation agenda:*** The two approaches could be seen as complementary, with FACS constituting the decision on eligibility for support, and personal budget holders then determining their own care needs and how these should best be met. Many respondents suggested that there are two different paradigms at play here with very different underpinning assumptions, values and operating procedures. This tension between FACS and personalisation was a recurring theme of the evidence:

**Proposals for interim change** fell into six broad categories: more consistent implementation of FACS; improved support for self-funders; more robust diversion strategies; better information; more sensitive assessment; and modification of FACS criteria. It is important to point out – as many commentators do – that there has to be confidence that any short-term change introduced would be worth the disruption it would bring, prior to any further major change that may be associated with subsequent reform following the anticipated Green Paper on a new care and support system.

- **More consistent Implementation:** The CSCI report *Lost to the system* (2008) highlighted the variable ways in which front-line staff implemented FACS, and the ways in which councils were accordingly seeking to curb this discretion. The call for more consistent implementation of FACS guidance by councils and their staff was also a prominent suggestion for short-term change in the submitted evidence.
- **Improved support for self-funders:** *Lost to the system* found that the situation of self-funders and their carers, in most cases, could be described as one of policy neglect and indifference, and this had resulted in some very poor outcomes in the lives of some people who self-fund. This situation was widely acknowledged in the evidence, and better support for self-funders was identified as an important area for early action.
- **More robust diversion strategies:** Better diversion was a frequent suggestion for short-term change in the evidence. Proposals included more effective monitoring and review systems, better evidence trails for decision-making and the systematic follow-up of ineligible people who have been signposted elsewhere.
- **Better information:** Calls for improved information services as an immediate reform were made in the evidence. These included information about services available, what people will be charged for and how much, signposting to services and support, and a clear point of contact for every client who will be responsible for ensuring that information is provided.
- **More sensitive assessment:** The way in which assessments are undertaken was identified as an issue that could be rapidly addressed. This is about ensuring timescales are more flexible, with sufficient time given for relationship building, about the importance of re-assessment, and about exercising caution in closing a case down.
- **Modification of FACS criteria:** Some evidence supported the idea of amalgamating the existing bands in order to simplify and streamline access to support. Proposals included merging the 'moderate' and 'low' bands into a separate 'prevention' band, with the distinction between the 'critical' and 'substantial' bands then determined by the speed of response required. Another proposal is to distinguish (and separately treat) people with multiple and complex needs from those with less complex needs.

**Longer-term reform:** Although some of the submitted evidence was broadly supportive of the current FACS framework, there was also a very strong view that nothing less than fundamental change would suffice. The following key themes for

longer-term change were prominent: an outcomes-based framework; alignment with the personalisation agenda; transparency of entitlement; prevention and partnership; and reappraising national and local responsibilities.

- **An outcomes-based framework:** In principle, there is no reason why eligibility criteria should not be related to the outcomes established in the 2006 White Paper *Our health, our care, our say*, and there was widespread support for such an approach in the evidence. For practical purposes the key decision to make here would be to determine how much extra support someone would need in order to achieve the outcomes guaranteed by the eligibility criteria.
- **Alignment with the personalisation agenda:** Making personal budgets creative and flexible means focusing on outcomes and not services, and giving people the chance to use money in new and different ways to meet their needs and achieve desired outcomes. There was generalised support in the evidence for re-framing eligibility within a personalisation context, but there will still need to be some formula for linking sums of money with levels of need, with greater amounts going to people in need of greater support.
- **Transparency of entitlement:** Much of the evidence went beyond issues of process and on to broader principles that should underpin access to support. Often this began with the need to ensure 'fairness', with transparency seen as an essential element of fairness. Calls for a clearer, entitlement-based system (allied to frustration with the current tightening of eligibility) led to some respondents calling for a much more serious approach to human rights legislation.
- **Prevention and partnership:** It was common in the evidence to find calls for a new vision of social care that would go beyond the narrow model that currently predominates. Typically this related to the need for a stronger focus upon prevention and inclusion so that councils and their partners know much more about people who currently fall outside of the system. This implies a move towards a more universal model of support. Any such reconceptualisation of social care carries a further implication – that it can no longer be viewed as solely the preserve of the adult social care departments of local authorities. The implication of *prevention* is *inter-agency partnership*.
- **Reappraising national and local responsibilities:** Given that so much of the dissatisfaction with FACS arises from the variable and inconsistent application of the guidance by professionals and councils, it was inevitable that the evidence would include calls for a reappraisal of the locus of decision-making in respect of eligibility. The call for greater national consistency in the determination of eligibility for, and access to, social care support was widespread in the evidence. Typically this involved calls for a national minimum guarantee of support.

**Conclusions:** The evidence submitted to the review came from a wide variety of sources, reflecting different interests, experiences and perceptions. With few exceptions, the evidence accepted that some form of rationing of social care resources is inevitable. While there is some limited support for incremental short-term changes that will make FACS fit for purpose, the bulk of evidence supports more radical reform. While in part this is in response to the perceived shortcomings of FACS, more positively it is also a reflection of the need to move to an alternative

framework better suited to the emerging policy agenda which has developed largely post-FACS.

While relatively little of the evidence included precise proposals for a new framework, the nature of the critique of FACS offered a clear direction of travel for the next stage of the journey. Any new system will need to demonstrate that it meets the requirements of: an outcomes-based approach; compatibility with the personalisation agenda; a focus on prevention and social inclusion; fairness and clarity of access; and a guaranteed basic national minimum entitlement as part of a universal offer.

# 1. Introduction

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- 1.1 This paper arises from, and builds upon, the review of the impact of Fair Access to Care Services (FACS) undertaken by the authors for the Commission for Social Care Inspection (CSCI) in 2007,<sup>1</sup> and which informed Chapter 8 of the CSCI *State of social care in England* report.<sup>2</sup> The report expressed concern about the tightening of the FACS eligibility criteria and the impact upon the lives of people excluded from support, including those who fund their own care. In response to the CSCI annual report, the Care Services Minister, Ivan Lewis MP, immediately asked CSCI to undertake a review of eligibility criteria, to be completed by 15 September 2008, which will look at national definitions of need and their application at a local level.
- 1.2 The CSCI review has a number of components including a national 'sounding board' and a series of consultation meetings around the country. In addition, a call was issued for written submissions, alongside an online survey on the CSCI website. This report analyses the findings from both the written evidence and the online survey. We refer to those submitting written evidence as 'witnesses', while those who responded via the online survey are identified as 'respondents.' The call for evidence and the online survey were launched at the same time and were open from 1 April to 9 May 2008 (with some flexibility over the cut-off date). The call for evidence set the following terms of reference:
- i) Is the current FACS system appropriate in principle? What principles should underpin eligibility for publicly funded social care?
  - ii) Does the FACS system work in practice? If not, why not?
  - iii) What changes would you put in place:
    - a) in the short term, if the overall social care system remained broadly the same?
    - b) anticipating the transformation of social care in implementing Putting People First<sup>3</sup> and the expectation that personal budgets and self-directed support become mainstream?
    - c) if there were to be a radically new approach to the funding of social care?
- 1.3 Just over 100 written submissions to the review were received. Of these, around 20% were from individuals, and whilst some of these tended to be relatively brief and personal, others took a much wider approach. The remaining 80% came from formal organisations of various kinds, split between national provider and lobbying organisations (around half) and local user groups and local councils (about a quarter each). This means that the review has received a very good spread of views from a variety of levels – national policy and strategy, local policy and strategy, and the perspective of individual users and carers and their local organisations.

- 1.4 The online survey (see Appendix 1) received submissions from 2,940 individuals, with fully usable data recorded for 2,884. Overall, 11% of returns were from people who were either using social care services or who had needs for such support (defined in the survey as 'Someone who could benefit from social care'). Carers accounted for the largest group of people responding with 29% of people identifying themselves as carers or ex-carers. Half of all respondents were people who worked in social care, either in council social services (22%) or in another sector (28%). The remaining 10% of respondents were classified as a miscellaneous 'other' group which included a wide range of interested members of the public; journalists; advocates; social care consultants; researchers and trainers; student social workers and nurses; people employed in the health service, and those working in the voluntary sector both in paid posts and as volunteers. As with the written submissions, the online survey therefore reflected a considerable range of views and knowledge, and particularly of people with personal experience of social care (as people using services or involved in their provision). In addition to collecting tick-box responses to questions (which are collated in Appendix 1), the questionnaire included a number of questions with 'free text' areas to capture wider comments, and thousands of such responses were submitted.
- 1.5 Both the call for evidence and the online survey sought views on the current arrangements for FACS, and on what might be done in the short and long term to improve eligibility arrangements for social care support. Given the wide range of responses, it is only to be expected that many different issues and judgements were raised, and the aim of this report is to analyse these responses and identify common issues and themes. It is structured around the three key dimensions of the terms of evidence:
- views on the current arrangements
  - proposals for short-term change
  - views on longer-term change.

## 2. Views on the current system

### Acknowledgement of the inescapability of rationing access to social care

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- 2.1 All governments are concerned to hold down public spending and all societies limit access to social care in some way. As Allen et al<sup>4</sup> note, allocative decisions are made at a number of levels:
- At the macro level, politicians have to decide on the level of welfare funding and how this should be distributed between areas – in the case of social care this is the province of the pending Green Paper.
  - At the meso level, intermediate bodies like local councils make decisions about the resources allocated to different services.
  - At the micro level, the conflicts and dilemmas created by these decisions have to be managed by professionals and other service providers.
- 2.2 Although the concept of rationing is often described pejoratively, there is nothing inherently wrong with allocating resources according to a set of priorities. In setting up such arrangements, eligibility frameworks constitute a key mechanism, serving to regulate service provision in line with available resources and identified priorities. Although some of the written evidence raised the issue of 'entitlements' to social care (which challenges the necessity for professional assessment and judgement on eligibility), there was nevertheless a strong underlying acceptance that access to support needed to be within the context of some basis for eligibility:
- "It is recognised that resources in social care are limited and that there will always have to be some system of deciding who should get what."* (Multiple Sclerosis Society)
- "The broad principle of eligibility criteria as a means to allocate services to those most in need, and ensure a fair and consistent process, is appropriate."* (Parkinson's Disease Society)
- "It is accepted that in a system where there are limited resources, there has to be a tool used to decide who does and doesn't receive support."* (Help the Aged)
- "If one assumes that available resources will never be sufficient to meet all needs, then the principle of allocating those resources according to degree of need is broadly appropriate."* (Crossroads)
- 2.3 These – and many similarly expressed sentiments – constitute an important basis for the rest of this review, in that they acknowledge that some means of limiting access to publicly funded support has to be in place. As we point out in our literature review,<sup>5</sup> rationing access is no easy task, raising dilemmas that moral philosophers have not yet been able to solve. In the case of social care there is no automatic right or entitlement; rather there are 'claims'. Having a claim to 'X' is not necessarily the same as having a right to 'X', but it does constitute a case of at least minimal plausibility that one has a right to 'X'. A claim establishes a right to consideration,



and claims will differ in degree with some being stronger than others. In effect the purpose of this CSCI review is to determine the basis upon which some claims will be accepted as entitlements. It is not considered necessary in this report to describe the current system – Fair Access to Care Services (FACS); rather the focus is upon the judgements made in the submitted evidence about the extent to which FACS serves as a robust framework for the determination of eligibility. For the most part the submissions were critical (often highly so) of FACS, but this was by no means a universal view. Before going on to explore the substantial critiques received, it is important to examine the position of those who see merit in the established framework.

## Support for FACS as an appropriate framework

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- 2.3 Support for the current system came from several quarters and was based upon several grounds. The frame of reference used by some people was the pre-FACS situation and, in this respect, FACS was seen as a distinct improvement. The report on the initial CSCI consultation event, for example, notes that:
- "Some people recalled the situation before the national framework of FACS was introduced, and problems where judgements were too subjective and there was no way in which people using services could hold a worker to account."*
- 2.4 Other evidence also referred to the value of having a national system of accountability and consistency. Again, the consultation event report describes the view that FACS is:
- "...a useful benchmark to compare practice within and between councils...a useful tool with which to challenge councils to scrutinise their practice more closely."*
- 2.5 One carer said that he had successfully made a complaint about the treatment of his disabled daughter, "where I was able to compare their actions and inactions against FACS policy and eligibility criteria...it was extremely useful to have FACS with which to compare the de facto practice".
- 2.6 For some witnesses, the virtue of FACS lies in the way it should encourage a common understanding of people's needs based upon a holistic view of their lives. The Resolution Foundation, for example, could see much value in principle with FACS:
- "A clear assessment of need is vital for the effective delivery of care, and standardised criteria such as FACS enables public, private and third sector care providers, as well as health service staff, to have a common understanding of an individual's requirements."*
- 2.7 There was also support from the Foundation for the view that FACS encourages a 'whole-person' approach to people's needs:
- "The current FACS guidance covering health, personal care, education, work, social and family life, is a positive 'whole-person' approach."*

The mental health charity, MIND, also supported this position:

*"In principle, the FACS system is a fair method of assessing a person's need for services and allocating resources according to that assessed need...The assessment process rightly reflects a social rather than a clinical model of disability. The assessment process is the same for all individuals, so people are not put in boxes as 'older people', 'people with mental health needs' or 'people with a learning disability'. This allows for a holistic approach to need."*

A strong view was also expressed, notably by the Association of Directors of Adult Social Services (ADASS), that FACS could serve a tactical political purpose. The introduction of FACS was seen to have *"provided a powerful means for raising interest in social care at a local level and arguing the case for increased resources"* (consultation event report). One attendee at the consultation event remarked:

*"Let's agree what's good and what's bad, and just change the bad bits."*

- 2.8 This viewpoint attracted other support. Sense, the national charity for deafblind people, stated that:

*"The FACS guidance has worked very well to make the tightening of social care budgets transparent...the introduction of an eligibility system which is less transparent will merely hide this fact."*

- 2.9 The evidence submitted by ADASS queries whether, in the short term, change is wise:

*"In the short term the question has to be – how likely is it that anything different we put in place would be better than what we have at present, and is it worth making a change prior to the Green Paper recommendations?"*

- 2.10 A minority of comments (literally just a few respondents) submitted through the online survey also observed that the system was "working fine" and there was no need for change. The balance of the written evidence, and of submissions through the online survey, however, undoubtedly falls the other way, with most respondents expressing criticism of FACS at the level of principle and practice. A number of issues were regularly identified:

- lack of clarity and transparency
- lack of fairness
- service-led approaches
- the limitations of a risk/needs-based model
- insularity and fragmentation
- neglect of the prevention and inclusion agendas
- inadequate diversion and signposting
- the dominance of budgetary considerations
- tensions with the personalisation agenda.

- 2.11 While respondents to the online survey identified these issues – as we highlight below – it was evident that the survey provided an opportunity for many general remarks about social care which were beyond the specific remit of the review of

eligibility criteria. Equally, many of the suggestions offered for ways forward were at a high level of generality or principle, for example arguing that social care should be available for everyone who needs it; or that social care should be free of charge.

## Lack of clarity and transparency

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2.12 In principle, FACS should serve as a clear form of what we termed '*rationing by directive*' in our earlier report. We described this as the elaboration of rules and procedures to determine who gets what in terms of services and support – in effect the various formal attempts by agencies to locally implement FACS. The key characteristics of rationing by directive are that it is (or should be) explicit and rule-based, resulting in clear, consistent and standardised responses to all of those who fall within the remit of the '*directive*'. Notwithstanding the positive views outlined above, some respondents felt that this was not the way FACS was working in practice. For some people, the issue is lack of information – the National Centre for Independent Living, for example, said that:

*"In our experience of calls to our information line, people applying for, or using, social care are rarely given copies of the eligibility criteria being used by their local authority."*

2.13 Comments made through the online survey made similar points. For example, this respondent (a carer) observed:

*"The general public have little or no understanding of social services eligibility criteria. 'Fair Access to Care' means nothing to the person in the street."*

2.14 Others remarked that, quite apart from information about eligibility criteria not being routinely provided:

*"when Social Services are asked for a copy they will not provide one. People applying for help do not know what they might be able to get because they do not know the criteria."*

2.15 Other respondents remarked that they had no knowledge of local eligibility criteria, even when they have experienced assessment for social care, for example:

*"My Social Services Department have told me in writing that they only provide help to those who most need it, which seems reasonable, but they didn't say what the criteria were."*

2.16 For others, the main problem was a lack of clarity on the purpose of FACS – as one attendee at the consultation event asked about FACS, "*is it about rationing resources or better outcomes?*"

2.17 It was also apparent from survey respondents that there is considerable confusion about the meaning of '*eligibility*', and while some people understood this to be concerned with assessing people's needs for support, others thought that it referred to a determination of people's savings and assets. This comment from a person seeking help from social care makes the point:

*"My experience is that it is means-tested based on savings. One has to do a lot of individual research to ensure you get what you are entitled to."*

As does this from a carer:

*"Even though I have had some contact with the system I am not certain I am aware of the eligibility criteria. It seems to be a mixture of actual 'need' and the amount of savings you have. Some aspects appear to be free (e.g the OT services), but others – the social carers – are paid for."*

- 2.18 The problem most frequently raised, however, related to the sheer complexity of the FACS framework, such that neither professionals nor people who use services or carers were confident of their understanding. Nottinghamshire Council explained that:

*"The FACS guidance is difficult to explain to staff and to people who use services. The words are dramatic, and the danger is that explanations about eligibility are given to people in jargon...We are measuring risks to independence in words that people do not necessarily recognise and which are not 'people friendly'."*

- 2.19 Durham County Council takes a similar line:

*"FACS is a complex system that is not easily understood by service users and staff. The system on the whole does not appear to be very person-centred; it can be confusing, particularly in terms of its definitions around need."*

- 2.20 And for Staffordshire Council, FACS is further complicated by its relationship to means-testing:

*"The process is not transparent. We are not clear with people from the start whether they will have to pay for services."*

- 2.21 The lack of clarity or transparency in eligibility criteria was apparent in the confusion expressed by some respondents over their experiences:

*"I have had help in the past. I don't know why I am not getting it now, my circumstances have not changed."*

- 2.22 For some people the experience of assessment and eligibility were shrouded in mystery. Several respondents stated that they had no idea what the current eligibility criteria were, while some suggested that this information was deliberately withheld:

*"What are the criteria? In a 15 month process to get help for my son I never found a definitive answer. There was a matrix which I obtained via the Freedom of Information Act, but this did not explain at what level support would kick in."*

- 2.23 Other respondents reported similar bewildering experiences of decisions being made in secret and through processes which excluded them, as this carer remarked:

*"There should be transparency in how decisions are made. At the moment my son's support is reviewed annually by a Panel and we and our son do not see the information the Panel considers and we are not allowed to attend the Panel meeting."*

*We are not given reasons for their decision, just told how many hours support he can have a week. There seems to be no right of appeal."*

And as another observed:

*"Most people have absolutely no idea whether their council is acting fairly and in accordance with best practice or other councils' practice. All people want is a fair deal."*

- 2.24 What this can culminate in is a system that is too complex and confusing to be open to challenge. The National Centre for Independent Living (NCIL) claims that *"the lack of clarity and differences in interpretation make FACS criteria difficult to challenge"*, whilst Northumberland Council acknowledges that this can result in some inequity:

*"If criteria are incoherent, the likely result will be that articulate people willing to challenge social services authorities will get high levels of support, while others with greater needs will see a progressive decline in the services we can afford to fund."*

- 2.25 The sense of not knowing how access to social care is determined, or what people need to do to get into the system, was widely reported by people who could benefit from social care and by carers, as the following comment highlights:

*"We don't know what help we are entitled to...what we can expect if we need help...where to get the help or who to contact."*

- 2.26 In some circumstances such lack of clarity could be deliberate, as this respondent implied:

*"I don't think it is at all clear what the eligibility criteria are – I think it is a case of luck and if they have the funds you might get some help."*

- 2.27 The lack of clarity in the system was also acknowledged by respondents working in social care, as this social services employee observes:

*"It should be made simpler and clearer. FACS has on the whole created confusion amongst staff leading to a huge waste of time in briefings, training, debate and discussion. It is poorly worded, inherently contradictory and wooly; consequently it is difficult to apply consistently and is open to different interpretations."*

## Lack of fairness

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- 2.28 Lack of clarity and complexity of challenge can soon spill over into a perceived lack of fairness in the way criteria are being applied and resources allocated. The evidence submitted to the review focused upon two dimensions of the allocation process that were deemed to give rise to inequity – variations in professional judgement, and the 'postcode lottery' between different councils. In the online survey these themes were repeatedly emphasised across all groups of respondents and the lack of fairness was one of the issues identified most frequently.

## Variations in professional judgement

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- 2.29 In our earlier report we used the term '*rationing by discretion*' to refer to the exercise of professional judgement in the rationing process. This bottom-up perspective provides a contrast to the top-down approach of rationing by directive. Whereas top-down models put their main emphasis on the ability of decision-makers to produce unequivocal policy objectives, and on controlling the implementation stage, bottom-up critiques view local 'street-level bureaucrats' (in this case, social workers or care managers) as a key influence upon policy delivery. The key characteristics of rationing by discretion are that it will be informal and individually focused, with judgements potentially varying on a case-by-case basis.
- 2.30 While the FACS process establishes a framework and some degree of clarity over eligibility criteria, it is evident that how this is interpreted and applied in practice is of critical importance. The key activities at operational level take place at the points of referral, assessment and review. Professional judgement is necessary because needs cannot be automatically derived from the descriptions of the FACS bands. The eligibility bands are expressed as risks rather than needs, and councils (through their professional staff) have to make sense of the risks and consider what needs derive from them, and how these can best be met. In the course of any assessment journey, practitioners will be aware of both the limitations set by the organisational policy and resource context, and the needs and concerns of potential service users. The decisions they come to will, to some extent, reflect their own values and personalities, and to that extent will introduce a variable factor that is at odds with the attempt (through frameworks such as FACS) to minimise the postcode lottery in access to support.
- 2.31 Our earlier report identified considerable variation in professional judgement and practice in respect of the application of FACS criteria, and this is confirmed in the written evidence and survey responses submitted to the review. Some councils were surprisingly candid about this issue. Durham County Council stated that "*Staff have different perspectives on FACS. Some keep rigidly to the criteria, others are more flexible...FACS is subject to a wide and varied interpretation, with different custom and practice in different teams and specialisms*". Similarly, Islington Council acknowledged that "*The complexity of the FACS banding matrix and eligibility criteria can result in inconsistent interpretations of FACS eligibility criteria across teams*". Similar issues were identified in the survey, and some respondents acknowledged that staff 'bent the rules' to ensure people got the help they needed, as this person employed in council social care remarked:
- "The current FACS arrangements are in the eyes of the person who is assessing. If it is felt that a service is needed, the assessor will be focussed on where to pitch the eligibility in order that the client meets the eligibility criteria."*
- 2.32 While this *could* work in favour of those people seeking help, inconsistent application and interpretation are unreliable and there is a risk that 'who shouts loudest' is listened to while others are overlooked. Those on the receiving end of eligibility decisions were not happy with this variability. Ealing Mencap complained that "*The four bands are open to massive interpretation...they lay claim to an objectivity that is*

*not present*". Sunderland Carers Centre expressed some despair at the impact upon carers: "The quality of service provision totally depends on the individual social worker's knowledge and creativity on how to assess the 'carer needs' regarding individual choice and supportive services". And Scope, the national organisation that focuses upon people with cerebral palsy, was aggrieved that social workers seemed to be 'upping' existing service users into higher categories (in order to ensure they continue to receive services) whilst rejecting younger and new applicants on the grounds that they fall outside of the eligibility criteria.

## The council postcode lottery

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- 2.33 The cumulative effect of these variations is one of the reasons for the second dimension of a perceived lack of fairness in the application of FACS – the 'postcode lottery'. Although the very *raison d'être* of FACS was to diminish local variations in performance through the introduction of a national framework, the consensus was not only that this had not been achieved, but that in some respects FACS had reinforced the very difficulty it had been created to address.
- 2.34 Some evidence pointed out that the FACS framework only determines *access* to the service – not to the volume or quality of support that might be expected. Staffordshire Council, for example, states: "*The criteria do not set minimum standards for provision and for meeting eligible needs within the threshold bands, thus responses in terms of provision to meet eligible needs are widely variable across the UK.*" Charging systems added to the complexity since rates and prices may vary significantly within and between council areas.
- 2.35 Others were perplexed by the lack of portability of the support they received, should they wish or need to move to another council area – an issue raised at the consultation event and in other submissions. One of the strongest stances was taken by Scope, who described the position as a breach of disabled people's freedom of movement and indeed a breach of their human rights. Scope also notes that despite guidance, councils and primary care trusts use disputes over a person's 'place of ordinary residence' as a means to delay or avoid paying the costs of care. A 'Catch 22' situation is described in which "*people are unable to move until an assessment has been made, but are unable to receive an assessment until they have moved*".
- 2.36 However, by far the most common criticism was the perception that individuals with apparently similar needs receive very different levels of support – there was little or no enthusiasm for the notion that these variations constitute an acceptable consequence of local democratic autonomy:
- Age Concern argues that FACS has had little impact on the postcode lottery and that "*this is unsurprising given the absence of any limitation on the level at which local authorities can set criteria*".
  - MIND concludes that "*essentially, FACS has systematised the postcode lottery*".
  - Islington Council claims that "*The postcode lottery generates confusion and dissatisfaction among service users and carers, who do not understand how a system called 'fair' can result in the same level of need being met by provision of social care in one local authority area and not another*".

- Ealing Mencap observes that *"everyone was aware of people who had 'passed' FACS who were much less in need than others who were being refused...the system lacks any moral credibility"*.

2.37 Criticism of the 'postcode lottery' recurred throughout the comments submitted through the online survey. Respondents emphasised that *"eligibility should be the same across the country"* and defined nationally. Not only was this seen as an argument in favour of consistency between councils, but also for breaking the link between eligibility and local budgetary factors which mean that councils can change local eligibility in line with local resource availability. The following comments are typical of many:

*"...everyone should be given the appropriate help that they are assessed for no matter what area you live in...I know people who live 10 minutes away from me in a different borough that get all the help they need."*

*"Councils currently get to pick and choose the criteria they are willing to meet, and interpret the criteria differently with different people."*

*"Eligibility criteria per se are not the issue; the postcode lottery is wrong. One council may meet critical, substantial and moderate needs, another only critical and substantial. The councils themselves also have the discretion as to the extent that they meet those identified needs."*

2.38 In addition to the removal of variation between councils being viewed as more equitable, many respondents highlighted the fact that consistency would provide *"a clear set of entitlements"* and remove some of the confusion that currently surrounds understanding of eligibility.

## Service-led approaches

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2.39 Service-led criteria have been influential in social care and represented the first real attempt to be more explicit about resource allocation. Typically each service, such as day centres, domiciliary care, and so forth, would have its own complex criteria, and applicants would have to meet these 'service-driven' conditions in order to access specified types of support. Whilst this approach had advantages over implicit rationing, it also had the effect of defining people by a service they might be given, rather than by their individual needs or aspirations.

2.40 The introduction of FACS can, in part, be understood as an attempt to move practitioners away from a service-led approach to support, but in our earlier report for CSCI we identified the continuing influence of such a model. We noted that in some localities we visited, managers and operational staff conflated FACS bands with the allocation of 'band-specific' services, with the accompanying danger that support could be highly standardised and potentially inappropriate. This evidence was also consistent with the findings from our study of the implementation of self-directed support, which we undertook last year for the Department of Health,<sup>6</sup> in which we noted the continuing influence amongst social care practitioners of the 'giving and doing' tradition.



- 2.41 Evidence submitted to this review has provided confirmation of this situation:
- West Lancs Peer Support states that *"social workers still tell people what they can have rather than base the service on the needs of the person"*.
  - Durham County Council acknowledged that local authorities needed to examine personalised services to meet needs *"rather than the traditional links to services which are embedded in the FACS system"*.
  - Staffordshire Council candidly observes that *"The inherent ambition within the FACS guidance is particularly limited when authorities (such as our own) firmly and definitively link eligibility for help to tasks and equipment to be provided in given circumstances"*.
  - ADASS representatives acknowledged that the current system is *"unhelpful"* as it drives councils to address complex needs with complex packages.
- 2.42 The position of carers was felt to be at particular risk in these situations. Hertfordshire County Council, in noting that current funding models *"lean towards the funding of services rather than needs"*, acknowledges that the refusal to offer support for such things as shopping, gardening and pension collection can have a perverse effect. This is particularly evident in supporting carers, where families are prepared to provide high-level personal care, but in order to do so need support to maintain 'lower-level' needs – *"if these are not provided, the caring network is at risk of collapse, with greater cost to the local authority"*. Securing a change of attitude is not easy – Sunderland Carers Centre took the view that *"it is quite difficult to get some social workers to think of more imaginative ways of looking at need, rather than seeing the bands as a hierarchy of services"*.
- 2.43 Comments submitted through the online survey also revealed that a service focus still dominates some understanding of eligibility. This respondent (employed in council social services) remarked:
- "Staff also get confused as to whether being eligible in one category makes you eligible for all services or just the service you scored in."*
- 2.44 Another respondent (working in the voluntary sector) demonstrated a similar confusion about eligibility criteria and services in stating that:
- "I think it seems pretty fair at the moment. Critical and Substantial for residential care, and Moderate for home care."*
- 2.45 Some respondents referred to not meeting eligibility criteria, for example *"because their needs are not acute enough for home care services"*. Other respondents described experiences where they were told, not that they did not meet eligibility criteria based on their needs, but rather that the council did not provide certain types of service. For example, *"we don't do housework"* or *"we don't do baths, only strip washes"*.
- 2.46 Many respondents – particularly carers – were concerned that there should be specific eligibility criteria to address particular needs (such as learning disability, autistic spectrum disorders, etc), rather than assessing eligibility on the basis of 'need not diagnosis'. This led to statements such as the following:

*"All people with a learning disability should be eligible for services regardless of need."*

## The limitations of a risk/needs-based model

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- 2.47 A needs and risks model constitutes the basis of the current FACS regime, with an assumption that a hierarchy of needs can be identified to justify resource allocation – those whose needs have immediate and longer-term ‘critical’ consequences for their independence and safety should be supported ahead of those with needs that have ‘substantial’ consequences, and so on. Policy guidance requires the evaluation of an individual’s ‘presenting’ needs and related circumstances against the risks to his/her autonomy, health and safety, ability to manage daily routines, and involvement in family and wider community life. It is by comparing risks to independence against the council’s eligibility criteria that those needs which are eligible for support are identified.
- 2.48 The written evidence reveals two main strands of criticism of the risk/needs-based model – that it has resulted in inadequate and unduly standardised assessments, and that it has led to the neglect of ‘hidden’ user groups.

## Inadequate and standardised assessments

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- 2.49 The written evidence reveals a lot of discontent with the nature of the assessment process. For some respondents this discontent was general in nature. Newcastle Health and Community Care Forum, for example, stated:
- "HCCF members agreed that the assessment process itself is personal, intrusive and, if it results in a refusal of eligibility for services, very negative...there is concern that substantial numbers of vulnerable people self-select out of the system as they believe that they have low or medium levels of risk."*
- 2.50 Others had more specific concerns. For Carers UK the issue of portability was raised – in this case portability of assessment rather than support:
- "If people move to another local authority area it is ridiculous that the whole process must be started again. There should be a system where assessments can be carried over in such a way that another local authority can make decisions based on the information in the assessment."*
- 2.51 Other pointed to the complex interplay between the assessment of need and the assessment of means:
- "Currently we have two separate processes, one to assess peoples’ needs and then another following this to assess what people need to pay. This has led to social care asking people to accept support services identified through the assessment of need without telling them how much it is going to cost them. This has caused a drop-out rate for services." (Staffordshire Council)*

2.52 However, two issues dominated the written evidence on assessments: rationing-oriented standardisation, and the negative focus upon deficits.

### **Rationing-oriented standardised assessment**

2.53 The main concern being expressed here is that assessments are more concerned with using standardised procedures to screen people out of support rather than to assess their needs – the consultation event reported the feeling that “*assessments were seen as a tick box exercise with staff acting primarily as gatekeepers to accessing services*”. Further difficulties were identified in the evidence:

- that not all social workers have sufficient skill and expertise in using the assessment process to generate a person-centred understanding of people’s requirements (Social Care Institute for Excellence (SCIE))
- that tight target timescales for completing the stages of the assessment process do not allow time for relationship and confidence building (SCIE)
- that social workers have been turned into gatekeepers, with newly qualified staff unaware of the “*true remit*” of social work (Peterborough Council)
- the undue focus in FACS guidance on counting the number of tasks that require support – the difference between ‘an inability to carry out *vital* personal care or domestic routines’ (critical), as opposed to the *majority* (substantial) or *several* (moderate) such tasks, is not simple to distinguish (MIND; Nottinghamshire Council).

2.54 Respondents to the online survey identified similar concerns as the following comments from carers illustrate:

*“The current system feels as though its main purpose is to ration inadequate resources, rather than assess need and ensure that appropriate help is provided.”*

*“Eligibility criteria exist to screen people out not to include them.”*

*“Social workers must be independent...they can not be gatekeepers and do a fair assessment of care needs, when the opening line is ‘we can only offer you 5 hours a week, that is all we can afford’ and we have not started the assessment yet.”*

*“The individual assessment should not be rigid with a yes/no type of question as no one case is the same. Trained people should conduct the interview and allow for the different circumstances.”*

*“From our experience with completing the disability living allowance form, the assessment and eligibility seems to be more about knowing the right ‘magic’ words to use and only if you include these do you qualify for the appropriate support.”*

And this from a person using social care services:

*“when you ask for a needs assessment you shouldn’t have to beg the receptionist to put you through.”*

## The negative focus on deficits

- 2.55 The concern here is that the FACS framework encourages a focus on what *cannot* be done rather than on what could be done with support (NCIL), what outcomes people want to achieve (National Housing Federation) or the promotion of well-being and independence (Staffordshire Council). What this often results in is the undue primacy of personal care above any other achievements or outcomes:

*"FACS is judgemental about the level of risk associated with different situations and therefore leads to discrimination – an inability to carry out certain personal tasks makes a person more likely to be eligible for services than someone facing complete social isolation."* (NCIL)

*"The framework appears to over-emphasise risk and protectionism instead of asking how it can help people have an 'ordinary life'...the way FACS focuses on different areas of risk does not necessarily accord with the way people who use services see their lives."* (Consultation event)

*"FACS is designed in such a way that assessors often focus on the 'risk' individuals might be exposed to if certain services weren't made available. This approach seems inconsistent with the Government's wider ambition to promote independence where the emphasis is on determining the help an individual might need in boosting their physical and emotional wellbeing."* (Royal National Institute of Blind People)

*"Disabled people should be able to make their own decisions about taking risks, and local authorities should support them to make decisions in their own right."* (Scope)

- 2.56 The consequences of focusing on deficits were also identified by respondents to the survey. This comment was made by someone employed in council social services:

*"There is too much emphasis on 'inability' – getting support is based upon the acuteness of a disability or long term illness. This increases dependency on services because statutory assistance is diverted from prevention...Some form of assistance should be made available to all people but which better reflects their actual needs.. based on mainly preventative support."*

- 2.57 While this carer observed that there should be:

*"...a holistic focus upon all aspects of an individuals' life – currently it is too focused upon management of risk and deficits, ie. What people can't do. They need to focus more on support not care and to recognise that they should be about helping people to achieve things in their lives."*

Other respondents also identified the negativity of an approach focused on risk and deficit, and as this person remarked:

*"It should be more person-centred – more about what you **can** do with a little bit of help."*

## **Neglect of 'hidden' user groups**

2.58 There was a considerable volume of evidence drawing attention to certain groups of people currently felt to be marginalised by the FACS system, often to the extent that they were described as “*hidden*”.

*“There are many people with ‘hidden’ disabilities whose needs may become increasingly ignored as social care criteria are reviewed and directed towards those with more obvious or immediate needs.”* (The Disabilities Trust)

A range of such groups was highlighted in the evidence:

## **People with long-term conditions**

2.59 It is argued that the criteria do not currently include sufficient requirement to take account of the long-term impact of a condition. The Parkinson’s Disease Society, for example, stated that it knew of instances of people with Parkinson’s whose file had been closed after the provision of an initial service, such as a one-off respite break or installation of a piece of equipment.

## **People with fluctuating conditions**

2.60 A number of respondents (both to the online survey and in the written evidence) argued that people with fluctuating conditions were not well served by FACS. The Multiple Sclerosis Society said that “*a major problem for people affected by MS is that the current system does not always recognise the needs of people with fluctuating conditions*”. This was echoed in evidence from MIND, which stated:

*“MIND believes that the eligibility framework does not accurately reflect the circumstances of people whose needs fluctuate over time. People with severe depression, bipolar disorder or psychotic illnesses such as schizophrenia may have periods where they can live very independently and experience few or no symptoms.”*

## **Blind and partially sighted people**

2.61 The Royal National Institute of Blind People argues that blind and partially sighted people “are doing very badly out of the current system”, and are “being consigned to an ‘existence’, unable to access the support that would allow them to lead full lives”. More specifically, FACS was said to be contributing to this situation in several ways:

- low awareness among assessors of the impact of vision loss, resulting in large numbers left outside the top two eligibility bands
- assessors treating the needs of this group as uniform, with scant acknowledgement of their range of support needs
- key areas of importance to blind and partially sighted people – such as communication, mobility, practical daily living and emotional support – are not factored into the assessment process.

## Young adults

2.62 At the consultation event the view was expressed that FACS is seen as rooted in the world of adult services, having no links with children's services and the needs of young people:

*"A young person with disabilities who requires continuing support as an adult therefore moves from one world where they are often well supported, into the adult's world where they may find that availability is restricted."*

## Asperger's/high-functioning autism

2.63 A mother of two adults with Asperger's/ADHD described her own views and experience in written evidence:

*"I don't believe that FACS works in practice for people on the autistic spectrum. A large number of [such] adults live at home with parents [and] the parents' support masks the needs of the individual, therefore they will never be considered for services as they will be deemed not to reach 'critical risk'. Often the difference to them and their families will be low level early interventions which presumably will fall into the 'low' criteria. The needs of people with autistic spectrum disorder is well known not to fit into the traditional support environment of learning disability or mental health."*

2.64 This view is in line with evidence from the National Autistic Society, which complains of a lack of understanding of the condition, preventing people's needs from being understood.

## Carers

2.65 By far the most frequently referred to 'hidden' group was that of carers, who were generally felt to have an equivocal and tenuous relationship to FACS. It is not clear whether, and how far, assessors should take into account the support available to people from carers and other networks. The dilemma is summed up in the report of the consultation event:

*"Some councils take the availability of a carer into account in assessing eligibility for FACS, others do not. On the one hand it is argued that the availability of the carer is a fact of life and should therefore be taken into account. Others argue that taking carers' support for granted leads to an underestimation of the amount of support the person requesting social care requires, and does nothing to share the caring responsibilities taken on by carers."*

2.66 There was a wide measure of agreement that the situation in relation to carers was unclear and ill understood. According to Carers UK:

- some councils appear to believe that FACS only relates to service users, while others do not seem to understand that it is policy guidance and therefore mandatory
- some councils are failing to collect adequate information about carers at the contact/assessment/screening stage

- there is a duty to address carers' eligible needs, and discretion about whether to meet these through carers' services or community care services – but some practitioners appear to think the discretion is about whether to help carers at all
- inappropriate assumptions are made about the willingness of carers to care, leading to too low an assessment of their level of need and risk
- too few carers receive an assessment, and follow-up analysis on the family's support needs as a whole is not taking place.

## Insularity and fragmentation

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2.67 The consultation event reported the view that FACS was “*not holistic*” in the sense that it does not include consideration of important areas such as health, housing and leisure. This in turn had, in the view of some people, resulted in social care becoming an isolated and stigmatising service:

*“People who use services said they find the FACS process of having to prove their eligibility stigmatising. Some also commented that they were reluctant to approach a voluntary organisation because of the stigma of having to rely on charity.”*  
(consultation event)

*“FACS has been treated totally in isolation from other policy. This partly results from local attitudes to care services being viewed as deadweight expenditure, and not contributing to the delivery of anything positive.”* (NCIL)

2.68 This insularity is exacerbated by the fragmentation between FACS and some important parallel processes that are likely to involve the same service users. The most frequently mentioned of these were continuing health care, the care programme approach and learning disability services.

### Continuing health care

2.69 The ways in which FACS intersects with continuing health care (CHC) is far from straightforward, and is likely to particularly affect people assessed as being in the ‘critical’ and ‘substantial’ FACS bands. Given that such people will tend to have a complex mix of health and care needs, and be very expensive to support, the danger is that they become the victims of inter-agency wrangling over financial responsibility. CHC refers to a system of NHS-funded care that applies to people who have serious long-term health conditions, and who have their entire care costs met by the NHS. Such a decision is crucial for councils, individuals and their families, since failure to qualify for CHC means that the council may be liable to meet the costs, and the individuals must enter the means-tested social care system.

2.70 In the recent past, each of the strategic health authorities had its own rules, tools and processes for determining eligibility for NHS CHC and this has resulted in wide variations in its availability – Age Concern, for example, claims that people in some areas are 160 times more likely to get CHC than those living elsewhere.<sup>7</sup> The NHS Ombudsman has repeatedly highlighted the ongoing inconsistencies; a series of high-profile judicial reviews (notably the Coughlan and Grogan judgements)<sup>8 9</sup> have challenged the legality of local interpretations; and the House of Commons Health

Committee has criticised the anomalies which beset CHC.<sup>10</sup> In response to ongoing difficulties and the need to improve consistency of approach and ease of understanding, the Government introduced (from October 1 2007) a new national framework for CHC designed to end the postcode lottery, replace regional criteria with a national system of eligibility, and simplify the registered nursing care contribution with a single band of nursing costs. The impact of the reforms is expected to increase the numbers of people qualifying for CHC by about 7,000 per annum, up to a total of 31,000.

- 2.71 Written evidence to the review confirmed the existence of problems at the CHC–FACS interface, but many respondents were attracted to the principle of having a national framework for social care eligibility similar to that for CHC. Arguably this is precisely what FACS currently is, but unlike the position with CHC there is currently more discretion for local councils to determine levels of entry. This issue will be further examined later in the report.

### Care programme approach

- 2.72 The care programme approach (CPA) has been used since 1990 to describe the framework for supporting people with severe mental health problems in secondary mental health services. Currently two levels of support are distinguished:

- *standard* for those people receiving care from one agency, who are able to self-manage their mental health problems and maintain contact with services
- *enhanced* for those people with multiple care needs from a range of services.

- 2.73 From October 2008 CPA will no longer apply to people needing 'standard' support and this 'new CPA' is to be targeted at people with the greatest need as defined in the new best practice guidance.<sup>11</sup> However, the new guidance is cognisant of the changing policy scene in three important respects. Firstly, it is clear that support through the CPA approach should not be service-led: "*New CPA should not be used as a 'gateway' to social services or as a 'badge' of entitlement to receive any other services or benefits.*" Secondly, it is emphasised that since CPA is a process (rather than a measure of eligibility), then it should not be equated with FACS eligibility levels. And finally, it is said that support via CPA should not stop people from taking advantage of individual budgets.

- 2.74 The written evidence suggests that current practice falls some way short of this, and indeed that the pending changes may further complicate access to social care support. Nottinghamshire Council complained of a general lack of fit between the two systems:

*"FACS does not fit easily with the CPA, and it has added an unnecessary level of complexity to decision-making in some areas."*

- 2.75 One respondent with front-line experience emphasised the subservience of social care issues to those prioritised by clinicians:

*"In joint teams such as adult mental health, the clinical culture is so entrenched that social care workers are directed to be involved, generally because of clinical priorities rather than risks to independence. Teams would not accept certain people with certain diagnoses, and thus some people would find it difficult to even get a social*



*care FACS based assessment as their diagnosis would not meet the team's clinical criteria."*

- 2.76 The most substantial (and critical) evidence on the FACS–CPA relationship came from MIND, corroborating the above view that community mental health services are informed primarily by clinical priorities and led by NHS budgeting priorities. This has problematic consequences for those potentially eligible for social care support:

*"Because the health service is usually the first port of call for those needing mental health care, many potential service users are wrongly screened out before they can be assessed for social care because their clinical needs are not acute enough to engage with the health service. Because the route to social care is concentrated within the community mental health service, many people who are treated solely in primary care are never assessed for social care needs."*

- 2.77 Further, according to MIND, "many" councils are complicit in this situation by operating a threshold for service provision based on mental distress that is severe enough to justify CPA-based care. This threshold, it is said, is frequently used as a basis for deciding whether to provide an initial assessment, and "as a result service users are unlawfully denied an initial social care assessment". This situation could be exacerbated by the new guidance outlined above, with the CPA threshold itself about to rise even higher.

### **Learning disability services**

- 2.78 The report on the consultation event includes an extract from the minutes of a senior management team meeting which describe a situation for learning disability services not dissimilar to that given above on CPA:

*"There is a view that FACS has no direct relevance to learning difficulty services since it is effectively the referral criteria imposed by community learning difficulty teams which determines who will receive a service – not the application of FACS, which is a paper exercise having no direct impact on the level of service delivered."*

- 2.79 This ties in with the evidence submitted by the Working Together with Parents Network – a consortium of six national organisations and individual experts working to improve support to parents with learning disabilities and their children so that they can stay together as a family. In contrast to the FACS criteria, the evidence submitted here reveals the widespread use of IQ measurements to determine eligibility for support from adult learning disability teams.

- A cut-off point of an IQ of 70 is commonly used, and this can exclude parents who (although they score above 70 when tested) do have cognitive impairments that impact upon their parenting, and who would benefit from specialist social care support. In addition, IQ tests are fallible instruments.
- When someone is assessed as not needing the specialist input from an adult learning disability team (because they do not meet the IQ criterion), they may still meet FACS criteria, but tend not to be referred to another social care team for assessment. The common situation is that if a person is deemed ineligible for adult learning disability services, they then have no further contact with social services.

- The practice of using IQ tests as an initial 'gateway' to a FACS assessment is unlikely to be lawful as local authorities have a general duty not to 'fetter their discretion' and must consider each individual's circumstances. Local authorities must not operate blanket exclusions from the definition of 'disabled person' and thereby deny an individual an entitlement to assessment without taking full account of individual circumstances.
- Another 'Catch 22' can arise for parents with learning disabilities – too high an IQ to be eligible for adult social care support, yet judged by children's services to have too low an IQ to be competent parents.

2.80 The concern over inappropriate use of IQ as an eligibility criterion was also a significant theme in comments submitted through the online survey, especially from carers but also from some people using services. The situation of people with autistic spectrum disorders (ASD) was also repeatedly highlighted:

*"IQ should **not** be used as a criterion (my Mum was told by CSIP that it shouldn't be; but my LA still uses it). My abilities are very patchy - I am highly literate, but extremely vulnerable and socially challenged. Government guidance has not clarified the situation for people with ASD – too often we are pushed between learning disability and mental health, each saying we are the other's responsibility."*

*"[There should be] a separate category for Autism to include the 'able' who do not have a learning difficulty but who are vulnerable."*

*"Include autistic spectrum disorders (and Aspergers syndrome) in their criteria and not exclude people because they only have a normal IQ."*

*"Assessments are too rigid (e.g. no help from social services if IQ more than 70) even though the applicant may have severe learning difficulties in relation to communication skills and social interaction (as with Aspergers)."*

*"Autistic Spectrum Disorders and Aspergers Syndrome have to be included on the list of 'conditions' that count for getting social services involved – us parents have to beg and get to breaking point before they take any notice of our situations."*

As other carers described, sometimes people in these situations manage to get access to some support but it seems inappropriate for their needs, for example:

*"My son has been receiving some support from the Community Mental Health Team which is not particularly geared up to dealing with people with learning disabilities. This is because he has a high IQ and even though he has very specific learning difficulties this is not taken into account."*

2.81 Moreover, these comments were not all offered by people using services or their carers, but also by people employed in social care who also identified the problems in this area. For example:

*"Adult care should be assessed on the needs of the person and not on IQ for Disability Team as it is at present...Where do people turn to who have Asperger*

*Syndrome or have mental health issues and there is no local service to meet their needs?"*

*"Learning disability services are excluding a significant number of people who do not meet the threshold of an IQ below 70, but have significant needs in relation to their social functioning."*

## Neglect of the prevention and inclusion agendas

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- 2.82 There is a considerable body of evidence testifying to the importance of 'low-level' preventive support and this does appear to be acknowledged in the FACS guidance, which states that councils should develop methods of risk assessment to help them identify those individuals where risks to independence appear relatively low, but which are likely to become more serious over time. Councils are urged to state explicitly in published eligibility criteria how they approach the preventive agenda, and the 'question and answer' guidance expresses concern that too many councils focus on those whose needs are immediate and obvious, to the detriment of prevention.
- 2.83 The evidence in our earlier report, *Lost to the system*, suggested that this injunction was being infrequently observed, and this was certainly also the general view in the submitted written evidence. Southampton Centre for Independent Living commented that:
- "We have met many service users where it appears the long-term effect on service users' independence has not been considered. A common comment from care managers is 'they can always come back to us when things get worse'. This is hardly a constructive way to look at things."*
- 2.84 Similarly, Age Concern felt that the prevention imperative was marginalised in the FACS framework, suggesting:
- "A weakness in the current FACS criteria is that requirements for a preventative strategy are tagged onto, rather than integrated with, the guidance."*
- 2.85 Many respondents to the online survey identified concerns that prevention was being overlooked and that a focus only on higher-level needs was simply storing up problems for the future. The following comments were typical of many that were submitted:
- "Lower priority needs should be met to prevent worsening situations."*
- "There should be more emphasis on prevention of crisis situations rather than dealing with people when their needs are urgent and at crisis level."*
- "The barrier is set so high for people only in the most critical need that those of us who need less expensive or time consuming input don't get any help at all. However, provision of assistance earlier at a lower level could prevent a more costly intervention later."*

*"A little support for people in a moderate state could prevent severe and critical situations requiring heavier input."*

*"I think that the way my local authority prioritises services (only to users who are Substantial/Critical) is extremely short-sighted, as it fails so many people on so many levels, especially in terms of prevention."*

- 2.86 People employed in social care (in both local councils and related sectors) also identified the frustrations in not addressing prevention:

*"It should include provision for preventative needs so that we prevent people going from moderate to substantial or critical due to no provision."*

*"The current eligibility criteria mean only people with critical and substantial needs receive the assistance they need. People with a lower level of need are signposted elsewhere. This leads to the reduction of preventative interventions which if available can minimise the need for larger care packages."*

Other, more specific issues, were raised, all confirming the evidence contained in *Lost to the system*.

### **The futility of tight banding**

- 2.87 For the council already using only the critical band in the *Lost to the system* study, there was a growing acceptance that the tactic was economically self-defeating:

*"When I came in we were at FACS critical so there was nowhere to go, and to stay there was going to restrict us in addressing the future. We had to move away from FACS critical. It was like aeroplanes waiting to land, we were stacking people up waiting to come into FACS critical. That was unsustainable."*

- 2.88 Similar views can be found in the written evidence. It was reported at the consultation event that a lack of preventative services meant that when FACS thresholds were raised there was a short-term dip in the number of people eligible for social care, but this was soon followed up by a longer-term rise.

### **Narrow interpretations of prevention**

- 2.89 Even where councils do pay some attention to the need for preventative services, evidence suggests that this tends to be unduly narrowly interpreted:

*"Definitions of prevention which require the person's needs to deteriorate within a short period of time are not reasonable. Where someone's condition would deteriorate slowly, waiting until they are nearly at the critical level simply makes it too late for prevention to be effective."* (Sense)

*"We are in agreement with the need for preventative services, but the guidance is not clear in defining what it means by prevention. The amount of time authorities 'look ahead' is varied...It is difficult to raise the eligibility threshold whilst at the same time providing preventative services."* (Nottinghamshire Council)

*"Risk assessment must take a long-term approach...Simply waiting for things to get worse is not a solution to managing long-term conditions, and this should be reflected in the eligibility criteria."* (Parkinson's Disease Society)

*"In some cases local authorities are limiting consideration of risks to those that are likely to arise in weeks or even days...a substantial departure from the national guidance."* (Age Concern)

### **Incompatibility of FACS and prevention**

2.90 For a number of respondents the feeling was that, as things currently stand, the FACS and prevention agendas simply could not be reconciled.

*"The system does not help us deal with the needs of people below the eligibility threshold, yet this is preventative services territory and a key part of 'Putting People First'."* (ADASS)

*"The system is too reactive and there is little capacity within social care teams to engage with housing association staff who are in a good position to identify emerging needs...There needs to be greater emphasis on preventive and proactive care rather than a reactive and critical response."* (National Housing Federation)

*"Preventive care and acute care seem diametrically opposed, and the guidance does not provide much help for councils in balancing two very different agendas."* (MIND)

2.91 One issue arising from the focus on critical and substantial bandings is that whilst the health care agenda may be supported, a key social care agenda – around prevention, inclusion and independence – is relatively neglected. Nottinghamshire Council argues that the underlying assumption of the FACS guidance is that people used to manage independently but are now deteriorating due to age or mental and physical incapacity. This goes against the aim of developing independence, for example with young disabled people entering adulthood or people with learning disabilities seeking wider social inclusion.

*"The current system is not fair to people with learning disabilities who need lifelong support to enable them to play a full part in the community rather than crisis intervention. It does not recognise the role of family carers in preventing substantial or critical need, or the need for people with learning disabilities to live more independently. We are constantly frustrated because there is no support for the things people want to do. Not having a community presence, not being able to attend leisure or education, is not life threatening and therefore will not be supported."* (Carer of a 38-year-old son with severe learning disabilities)

*"A learning disability is a lifelong disability, and individuals who need a low or moderate level of support in order to enjoy an ordinary life will continue to lose out because criteria have been tightened."* (Mencap)

*"Adults with Down's syndrome and their carers are often only nominally known to social services...they have no allocated worker and no assessment of their needs."*

*Crisis intervention following a period of illness or even death of an elderly carer is unacceptably traumatic.*" (Down's Syndrome Association)

- 2.92 The prevention agenda is not simply about trying to avoid needs intensifying at a later stage, it is also about addressing wider social inclusion objectives. Respondents to the online survey highlighted concerns that such objectives were being marginalised by FACS. For example:

*"It should be enabling not disabling, by supporting people to live in the community and have great inclusion in society and help to access their rights and choices."*

*"The current system does not allow for people with low needs to access services. This means that many people are missing out on opportunities as they do not fit the criteria for lots of projects. As a result these people are struggling to get by and run the risk of becoming isolated, unemployed and socially excluded."* (Social care employee)

*"There should be a criterion for social and emotional well-being that enables support to be provided for people to be able to access 'normal' social activities of interest. Too many people are being left socially isolated...they are not able to play a full role in their community."* (Social care employee)

*"People who are assessed as having 'low' or 'moderate' care needs often need all kinds of support which is not measured or provided; provision of support to access community facilities and support with independent living...Lack of support makes these people vulnerable and lonely and increases the chances of their support needs increasing to critical if problems build to crisis level."* (Social care employee)

## Inadequate diversion and signposting

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- 2.93 In *Lost to the system* we identified a third form of rationing – by *diversion*. This refers to the attempt to limit demand upon one part of the system by either diverting it elsewhere, or by simply returning responsibility to the applicant. The greater the system demands, the tighter any eligibility criteria will be drawn, and the greater the likelihood that diversionary rationing will be instituted. The key issue here will be the extent to which such diversion is reasonably meeting the needs of applicants, rather than simply diminishing the budgetary problems of the diverting agency.
- 2.94 One of the most common forms of diversion is *signposting*. This 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. The process can be relatively passive (for example, providing people with information leaflets or lists of other organisations), or more proactive in assisting people in gaining access to these other sources of support and being confident that they *are* able to respond to such demands. The growing importance and acceptability of signposting was commonly recognised across the sites in our earlier study, and the term itself was in widespread use. An important issue here is whether people are completely signposted out of council systems (with no follow-up arrangements) or whether they still remain known to the council despite receiving no direct support. In *Lost to the system* we concluded

that signposting had generally been devised as an 'exit strategy', with little or no subsequent support or monitoring.

- 2.95 Not all of the evidence received was critical of signposting. At the consultation event, for example, it was described as "a means of stimulating creative thinking about alternative ways of meeting need", but at the same event it was reported that "many felt it was unfair to have a rationing system whose effectiveness relies on diverting people with unmet needs to other service providers". The written evidence raises several problems with the practice of signposting:

### **Inadequate initial screening**

- 2.96 The concern here is that in their initial contact with the council, people's needs and circumstances are insufficiently explored. Traditionally, the gatekeeping role for determining access to council-funded social care (or at least to an assessment of need) has fallen to professionally qualified social workers based in duty teams, either on a rota basis or as a specialist intake team. In *Lost to the system* we reported that this is now often being done by reception staff without a professional background in social work, or was being done on the basis of a perfunctory telephone conversation. This was further reflected in some of the written evidence, especially that from groups representing people who use services and 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."* (Age Concern Exeter)

*"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."* (Southampton Centre for Independent Living)

*"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."* (Sunderland Carers Centre)

### **Unsupported and unfulfilled diversion**

- 2.97 Sunderland Carers Centre goes on to argue that insufficient support is given to support people who are signposted in this way:

*"When individuals request assistance with home support they are forwarded a list of domestic agencies for them to seek help for themselves... putting the individual into a position of not receiving a proper assessment with the correct advice, guidance or support."*

Others suggest that even when some subsequent support is arranged, it is not always forthcoming. One service user had a simple plea – "There should be more control over voluntary organisations, they should be made to complete the tasks

*they undertake to do”, whilst the broader consultation event reported that “signposting was felt to be of variable quality”.*

- 2.98 Finally, it was felt that councils showed insufficient interest in what happened to people signposted out of the council system – in other words unmet need was not being recorded and monitored. The RNIB, for example, claimed that:

*“FACS is poor at establishing an individual’s needs over time. Once somebody is assessed as having ‘low’ or ‘moderate’ needs (and once a decision is taken that they are ineligible for local authority funded support) that can be the end of their formal communication with adult social services.”*

- 2.99 The online survey specifically addressed the question of signposting and the consequences for people who did not meet council eligibility criteria for social care. The findings are analysed in Appendix 1. 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*. Indeed only 5% of all those responding said that they had both been given information *and* that it had positive outcomes in leading to them getting help. Some respondents also commented on these experiences in the survey, for example:

*“Social services did not tell me why I did not qualify; nor did they suggest any alternative ways of getting help...That was the end of the story! I think I was expected to be able to manage for myself because I don’t fit the stereotype of someone who needs help. Because I am articulate, they made assumptions about my background and expected me to be able to look after myself.”*

- 2.100 People working in social care also acknowledged the need not just for information, but to actively refer people to other sources of help:

*“More reference to voluntary sector schemes and social workers should be aware of how to refer to such schemes when people do not meet current criteria.”*

- 2.101 Some linked this point to the importance of addressing prevention around low-level interventions to maintain independence and support social inclusion:

*“There needs to be more preventative and earlier intervention. This does not need to come from social services directly but can be provided by the voluntary and independent sectors. The current criteria are workable if the low and moderate needs are not ignored because of funding constraints; some people will only need a conversation with someone and to be signposted in the right direction.”*

*“People who are assessed for care but don’t meet the eligibility criteria...should be provided with an information pack on where they can get advice and support, e.g. independent benefits advice, organisations which may be able to provide help or services, e.g. handyperson schemes, a register of approved tradespeople, activities, local community centres and groups.”*



- 2.102 Some respondents emphasised that this information and signposting should be given to everyone, including people who fund their own care but may need information on how to find what they need for themselves. Such practice may certainly be the norm in some authorities, but the experience of the survey respondents suggest it is far from widespread.
- 2.103 Signposting goes beyond merely providing information and directions to other services – it can also be about councils’ responsibilities to ensure those services *exist*, and that where necessary they fund third sector organisations to ensure the availability of affordable and safe services. This council social services employee makes the point:

*"There should be more of an emphasis for Social Services departments to be able to fund organisations to provide lower level preventative support and to make sure that people are signposted to them. It is not feasible for everyone to be able to get a service from Social Services, but there have to be organisations funded who can take care of the lower level cases to prevent them becoming more serious very quickly."*

## The dominance of budgetary considerations

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- 2.104 In *Lost to the system* we noted that the need to set priorities and control expenditure was paramount in all of the sites, and typically served as the catalyst for reviewing FACS policies. The sources of spending pressure (both demographic and socio-economic factors) are well established and do not require repetition here. At the consultation event it was observed that *"tightening budgets are seen as restricting needs as well as having implications for the sustainability of provision"*, and these points were a dominant feature of much of the written evidence, as well as attracting comment through the online survey.

*"Our staff have to balance their desire to meet individual need against the necessity to be prudent with the Department’s budget. This balance means that although assessments can be person-centred, decisions about eligibility have to be made by staff as gatekeepers of finite resources."* (Nottinghamshire Council)

*"The current system is too crude and linked to budgets. It is targeted only at the top end of demand, and as such is used as a budget control tool which does not work...A lot of time is spent keeping people out of the system."* (Staffordshire Council)

*"At present the social care system is geared towards reducing budgets. Too often councils’ overriding ambition seems to be to keep people out of the system."* (Carers UK)

*"The system is overly budget-driven with eligibility criteria being used to save money. People report that they feel social services are looking for excuses to exclude them, not to meet their needs...The word of mouth impact of this is that other potential users are put off even trying to get help."* (Parkinson’s Disease Society)

*"A system that can draw an arbitrary line which is then moved according to other needs, effectively excluding people whose needs should be met, cannot be fair, and does not provide access."* (Down's Syndrome Association)

*"By setting a threshold of need at which people can or cannot expect help, the FACS criteria implicitly endorse the idea that the legitimate needs of some people will go unmet."* (Multiple Sclerosis Society)

*"The problem is the fact that councils can move the bar up and down the scale of eligibility whenever they like. There is no real point to having the criteria if there are no bars set nationally to say who should get a service. If councils haven't got the money to correctly support people in their area, then they don't support them. Full stop. The eligibility criteria are simply the piece of paper they hide behind when breaking the bad news."* (Person employed in social care).

- 2.105 As some respondents pointed out, the primacy of budgetary concerns was evident in the criteria that would be applied at any given point in the financial year, as this council social services employee remarked:

*"I have found that although the local authority I work for may operate at substantial and critical, this moves to critical only at the end of the financial year, and those unfortunate enough to need services at that time are even disadvantaged in comparison to other service users in the locality."*

- 2.106 All of this was thought to bear down heavily upon users and carers. In the case of aids and adaptations, the Parkinson's Disease Society noted a perverse financial incentive on local authorities *not* to address long waiting lists, as people are frequently forced to pay for their own in order to avoid the wait. The Resolution Foundation further draws attention to the growing transfer of financial responsibility from councils to users and carers, noting the increased numbers deemed ineligible for state-funded care with relatively higher needs who will need (but be unable to afford) expensive care packages.

- 2.107 For some respondents this situation was simply a reflection of inadequately funded social care rather than any inherent fault with the eligibility framework. Typical observations were those from the Learning Disability Coalition (*"the fundamental reason for the tightening of eligibility criteria is shortage of funding which has not kept pace with demographic, social and economic trends"*) and Sense (*"Where resourcing is reasonable, a system can be put in place which will be seen by the majority as fair...much of the current feeling that FACS is not fair is because funding is so tight."*).

- 2.108 Comments from people who use services made the point that budgetary restrictions change the definition of eligibility but *not* the needs that people still have:

*"Just because a council doesn't currently provide something, doesn't mean it isn't needed. I'm not asking for a life of Riley, just to go about my normal everyday life as I would do if I didn't have my disability."*

- 2.109 The experiences which many people using services reported of having their eligibility changed from one assessment to another, without any apparent objective change in

their needs, underlined the sense that dominant budgetary concerns lead to a continual "*shifting of the goal posts*" and considerable sense of insecurity for people who fear losing their support, as this carer's comment highlights:

*"There are great fears that vulnerable people will be reassessed to suit current budgets and their true needs will not be met; some will undoubtedly be put at risk."*

2.110 For some respondents the solution lay (as we have previously noted) in the abolition of local eligibility criteria and replacement with a national framework. Others recognised that this would fail to address the underlying issue of inadequate resources to meet all those presenting with social care needs.

## Tensions with the personalisation agenda

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2.111 In *Lost to the system* we highlighted the lack of fit between FACS and the quest for 'personalised' care in the sense of personal budgets and the principles represented by the *In Control* model of self-directed support. FACS is concerned with categorisation, standardisation, consistency of treatment and explicit decision-making, whereas the personalised budget agenda emphasises self-assessment, self-determination, choice, individual differentiation and some arm's-length accountability for expenditure decisions.

2.112 On one reading the two approaches could be seen as complementary, with FACS constituting the decision on eligibility for support, and personal budget holders then determining their own care needs and how these should best be met. In reality, however, there are two different paradigms at play here with very different underpinning assumptions, values and operating procedures. Our report concluded:

*"Overall, there seems to be a danger that the personalisation agenda could end up running on parallel tracks to the FACS agenda, but at some point the two will nevertheless collide. Any serious attempt to introduce an approach based upon the In Control principles will challenge the values and operating processes currently represented in the FACS model, and councils need to urgently understand and address these inconsistencies."*

2.113 This tension between FACS and personalisation was also a recurring theme of the written evidence:

*"The structure is incompatible with the personalisation agenda and increasing choice and control in that it is wholly based on the notion of professionally led assessment, care planning and service provision."* (North Somerset Council)

*"The principle of fair allocation of funding based on equivalent levels of need is partly at odds with the philosophy of personalisation, which allows for variations in responses tailored to people's individual circumstances."* (SCIE)

*"The current system is becoming increasingly incongruous with the increased use of direct payments and individualised budgets...People who receive direct payments can purchase gardening services or even pay a carer to do their gardening, but this is not the type of service that social care traditionally supports. Personal budgets will*

*create even more problems because they are designed to be more flexible than direct payments.” (Staffordshire Council)*

2.114 Some respondents to the online survey welcomed the flexibility that personal budgets could bring and the opportunity for people to buy the services they need which they cannot get access to under the current social care system. Where eligibility would fit within this new system was addressed by relatively few respondents. Some, however, believed that the adoption of a resource allocation system (RAS), as has been used by *In Control* and in the Individual Budget pilots:

*“could remove the needs for FACS altogether by whole heartedly embracing the RAS and using that system to allocate resources. This could remove the role of assessors as rationers of the service or the ability of local authorities to raise eligibility levels to reduce the numbers accessing the services.” (Person employed in council social services)*

2.115 This section of the report has concentrated upon criticisms of FACS. None of the criticisms is new or unexpected, but taken together they do constitute a formidable body of dissatisfaction with current arrangements. The consequences of restricted access to social care on people’s lives need to be understood. It is important to highlight the findings from the online survey, which indicated that most people who had an assessment had largely positive experiences; and of those responding to the survey, around three quarters met the eligibility criteria for help. Almost one in five people identifying themselves as carers, and one in eight of those who said they could benefit from social care, reported that they had failed to have an assessment of their needs when they asked for help from social services. One third of these respondents understood this was because they did not meet financial eligibility criteria for help. As the data in Appendix 1 demonstrate, only 30% of people who met eligibility criteria reported that they subsequently received all the help they needed, while around half got *some* of the help they required. People who failed to meet their council’s eligibility criteria (and those who may not have approached their council for help because they did not expect to meet the criteria) but who still had support needs were asked what they did. Of those who responded, 35% said that they managed without help; a similar proportion (32%) had help from family members; almost one quarter (23%) made private arrangements and just 10% had assistance through a voluntary organisation. A few of the many comments made by people who were asked to describe the impact on their lives of not having help are reproduced below:

*“House became very dirty. Relied on availability of friends for shopping. Eating nutritious and attractively presented food was a rarity. Overall, extremely undignified and stressful.”*

*“Isolation and having to live with inadequate food and the frustration of not being able to keep the house clean and tidy for Mum - this is important as she doesn't see anything else. For us it's about struggling to manage 50 - 60 hour working weeks and travelling and other time. I've thought about giving up work but try not to dwell on it. It doesn't make sense either for someone paying 40% tax to exchange that for a carers allowance.”*

*"The 6 months when my dad was not taken on as eligible for care were very difficult because he could not manage his medication and was misdosing himself and making himself ill."*

*"My father now is doubly incontinent, can only get out of bed with a physiotherapist cannot drink enough, cannot remember his name and is being discharged from hospital. All social services provide for self payers is a fax of the phone numbers of care agencies after being challenged on why he was not being looked after by his family. None of the care agencies except the most expensive had any carers available."*

*"My flat's a tip and I often spend days without washing or dressing as I'm not able to do it myself. I'm limited in when and where I can go out, and what I can eat as I struggle to prepare a meal, and often burn myself when using the oven."*

*"I cannot leave the room I sit in throughout the day"*

*"I feel unsupported and unimportant. Sometimes I have been made to feel that my son's needs are a mix of either not severe enough, too severe or a burden on services. I feel that unless a family is at crisis point then help is not available."*

*"I do not go out socially at all . I have neurological problems wheelchair user part time also care for husband who has cancer, cognitive problems , heart condition. I cannot expect him to push my wheelchair I stay in do internet food shop, housework doesnt get done most of time gardens a mess .We both have a boring monotonous existence which is stressful. Social services placed us on a list for months and after 6 months of not getting an assessment I told them not to bother !"*

*"Feel as if I am putting an extra burden on my already busy family especially as they do not live nearby."*

*"I feel like a prisoner in my own home."*

- 2.116 The frustration and despair which many respondents felt was evident in their comments through the survey. For those people who failed to get access to social care, or who did not get the support they needed, there was often no alternative plan. Without support people still had needs (and often, it appeared, enormous needs that were simply overlooked), and they managed as best they could, but often at great cost in financial, emotional, personal and physical terms.
- 2.117 Both the submitted written evidence and the comments though the online survey tended to have much more to say about the problems with FACS than how these could be tackled, or what an alternative eligibility framework might look like. The survey and the call for evidence explored different issues. The survey was principally concerned with people's perceptions and experience of social care and also asked respondents about the need for change.
- 2.118 A small minority of all respondents – just 4% – strongly agreed that the present system for determining access to social care (ie the FACS eligibility system) is generally satisfactory (see Table 10, Appendix 1). Overall almost one person in five

(18%) agreed to some extent that this was the case. However, almost two thirds (64%) disagreed, or strongly disagreed, that the system was satisfactory. Carers were the most likely to disagree with this view and more than 70% did so. Even among people working in council social services, more than half viewed the current system as unsatisfactory.

- 2.119 If the system needs to change, on what basis should that happen? The survey asked respondents to indicate their agreement with various propositions. At least 50% of all groups of respondents *strongly agreed* with the statement that 'There has to be some way of deciding who can have help from social services' (see Table 11, Appendix 1). If those who 'agreed' with the statement are also counted alongside those in strong agreement, the consensus is even more evident, with 92% of all respondents supporting this position (ranging from 89% of people who could benefit from services and carers, to 96% of people employed in council social services). Earlier in this report we highlighted the dissatisfaction that many respondents expressed over current eligibility criteria, and some remarked that there should be no criteria at all. However, the response to the proposition about determining who can have help indicates a major acceptance of the inevitability of some level of rationing.
- 2.120 The essential dilemma in determining people's rights to support alongside the need to control access was epitomised in the apparently contradictory responses to other survey questions. Despite the overwhelming support for the principle that access to social care must be managed in some way, 88% of all respondents also agreed with the statement that social services 'should be available to everyone who needs support'. Among both carers and people who could benefit from social care, agreement was evident in 93% of respondents. People employed in council social services were the least likely to support the principle of support for everyone needing it, but even so almost three quarters of these respondents indicated their agreement. Squaring the circle of meeting the needs of everyone in need while also having some method of rationing support is the key challenge for any eligibility system.
- 2.121 There was little support for the proposition that one alternative might be that people should do more for themselves and get more support from family members (Table 13, Appendix 1). Only 4% of all respondents agreed strongly with this view, but almost one in five respondents (19%) agreed with it to some degree. Support was highest among people employed in council social services, where almost one third of respondents agreed to some extent (although only 6% were in strong agreement).
- 2.122 A free-text response option was provided for suggestions on how current eligibility criteria might be changed. Many of the comments have been quoted elsewhere in this report. By and large respondents offered suggestions of a general nature across a number of key themes:
- eligibility criteria should be abolished
  - criteria should be established nationally to remove the postcode lottery
  - lower-level needs should be included
  - more signposting to the voluntary sector to meet lower-level needs
  - abolish charges, or significantly review the means-test

- ensure that all people needing support can access care (especially groups that are currently marginalised by specific diagnoses, and people who are self-funding).

2.123 What was overwhelmingly clear from the survey was that there was little support either for leaving things as they are, or for minor revision. Further insight into possible ways forward was provided from the written evidence which invited views on short-term and on longer-term changes. The following two sections of this report examine the evidence submitted.

## 3. Proposals for interim change

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3.1 Six broad proposals for interim change arose from the written evidence:

- more consistent implementation of FACS
- improved support for self-funders
- more robust diversion strategies
- better information
- more sensitive assessment
- modification of FACS criteria.

### More consistent implementation of FACS

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3.2 In *Lost to the system* we highlighted the variable ways in which front-line staff implemented FACS, and the ways in which councils were therefore seeking to curb this discretion. The existence of FACS criteria, guidelines, matrixes and scoring systems was not always proving to be sufficient to ensure professional compliance amongst the councils in our study, and this had led to a search for additional means of ensuring such compliance. We identified four broad techniques being used – training programmes, peer review, supervision and management, and cultural change.

3.3 The call for more consistent implementation of FACS guidance by councils and their staff was also a prominent suggestion for short-term change in the written evidence:

*"Some people felt that many of these [appropriate] principles already exist within FACS, but that there needs to be better adherence to, and implementation of, these principles in practice. This requires improved support for practitioners, especially ensuring continuity of staff, training and guidance...backed up by effective local performance management and supervision of staff."* (Consultation event)

*"If the social care system is to undergo little change in the near future, more work needs to be done to ensure councils are following the spirit of the criteria, and that individuals' ability to access care is not dependent on how the FACS system is interpreted both between and within local authorities."* (Mencap)

*"Many of the negative consequences of the guidance are not necessarily in the guidance itself but in the way local authorities interpret and implement the policy. Many seem to pick and choose the parts of the guidance they adhere to."* (Southampton Centre for Independent Living)

*"A priority in the short term must be that FACS is properly monitored and enforced by inspectorates and local authorities themselves, and is properly communicated and understood by local authorities and frontline practitioners."* (Carers UK)

3.4 Carers UK went further and identified a number of elements of FACS that if felt needed to be "clearly restated and enhanced":



- that policy guidance is mandatory
  - that it relates to carers as well as service users
  - clearer guidance and enforcement about collecting adequate information at the contact assessment/screening stage
  - clearer guidance and enforcement about the discretion to use carers' services
  - more support for people (and their carers) deemed ineligible to receive state-funded services
  - guidance on, and establishment of, feedback systems asking about what happened when users and carers have been referred to voluntary organisations
  - responsibilities for the assessment of everyone who requests it, along with a stronger care management role.
- 3.5 In order to underpin more consistent and proper implementation, Scope further proposes the establishment of an independent national appeals system that users and carers can use to challenge local authority decisions not to provide them with social care support. Scope argues that this would *"help to evaluate how standardised decision-making is across the country, and identify where inconsistencies are greatest"*.

## Improved support for self-funders

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- 3.6 *Lost to the system* found that the situation of self-funders and their carers could be described as one of policy neglect and indifference, and that this had resulted in some very poor outcomes in the lives of some people who self-fund. This situation was widely acknowledged in the written evidence, and better support for self-funder was identified as an important area for early action. At the consultation event, for example, it was recorded that:

*"FACS focuses attention only on those who may be eligible for state support...Self-funders who have the same level of need are provided with inadequate information about services...Any new rationing and care system must enable the tracking of the needs of self-funders and how these are being met. At a minimum this requires improvement in the information made available to self-funders."*

- 3.7 A number of respondents felt that such improved support for self-funders could be developed through use of the Social Care Reform Grant. North Somerset Council, for example, wished to use it to offer continuing review to self-funders where requested – something not thought feasible in current budgetary circumstances.

## More robust diversion strategies

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- 3.8 In *Lost to the system* we concluded that if rationing by diversion was to be anything other than a cheap exit route for cash-strapped councils then it needs to be underpinned by a 'post-diversion strategy' – a systematic way of gauging the effectiveness of the approach and for feeding the findings back into the planning and commissioning process. The councils in our study had taken relatively few steps to

measure and understand the consequences of their policies, the most frequently mentioned approaches being complaints procedures, aggregate monitoring and data on re-entry to the council system.

- 3.9 Better diversion was again a frequent suggestion for short-term change in the written evidence. The consultation event called for *“more effective monitoring and review systems, including better evidence trails for decision-making and the systematic follow-up of ineligible people who have been signposted elsewhere”*. Similar proposals came from others:

*“A monitoring system should be introduced to ascertain if an individual signposted for an alternative service accesses the service at a future date as a critical or substantial need.”* (Croydon Council)

*“There needs to be a greater emphasis on proactive reassessment [of ineligible applicants] by social workers...contacting people at an agreed point in time to see if their needs can now be met. It would stop some people from slipping through the social care net when their needs change.”* (Help the Aged)

*“Local authorities should be encouraged to put systems in place that monitor the health and wellbeing of people who have presented eligible needs but are not able to access services due to tightened criteria.”* (Mencap)

## Better information

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- 3.10 In *Lost to the system* we drew upon evidence from the Picker Institute<sup>12</sup> which looked at how patients, service users and carers found out about health and social care services. The findings were pessimistic:
- professionals do not systematically or proactively provide information about accessing local services
  - it is rare for an individual or an organisation to take responsibility for providing relevant information about the entire range of services available, and there is a lack of coordination across boundaries
  - there is a lack of effective signposting: no shortage of information, but with the individual user left to find it out for themselves.
- 3.11 The report accordingly recommended that each local area should have a central, easily identified information contact point; that this point should be responsible for gathering and disseminating information on all health, social care and voluntary sector services within the local area; and that a new cadre of local ‘information brokers’ should be created who can provide leadership and coordination across boundaries. All of this is very relevant to the ways in which FACS is being implemented, and the ways in which self-funders are treated.
- 3.12 Since our report, further evidence has been published<sup>13</sup> drawing attention to the surprisingly limited role played by ‘information’ in decision-making by adults and older people in need of support. Faced with problems, most people’s normal instinct is to try to deal with them by drawing on knowledge they *already* have, or on intuitive perceptions of the way they think things work. 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.

- 3.13 It is against this problematic background that calls for improved information services as an immediate reform were made in the written evidence:

*"Improve information provision, including information about services available, what people will be charged for and by how much, signposting to services and support, and a clear point of contact for every client who will be responsible for ensuring that information is provided."* (Parkinson's Disease Society)

*"It should be acknowledged and anticipated that some people who will not meet eligibility criteria for social care will be high users of advocacy and information. Advice and representation is in itself a service, not just a means to a service."* (MIND)

*"Good assessment, guidance and information provision is often as valuable as providing a direct service and needs to be seen positively...Support provided to the individual in a crisis is rarely what is right for that person long-term. Better publicity is required to encourage people to seek relevant information, assessment and advice services, before reaching a crisis point."* (SCIE)

## More sensitive assessment

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- 3.14 The way in which assessments are undertaken was identified as an issue that could be rapidly addressed. This is about ensuring timescales are more flexible, with sufficient time given for relationship building, and also about exercising caution in closing a case down:

*"Assessment is a process not an event. Target timescales for completing assessments should be applied more flexibly to allow time to build up trusting relationships and identify more personalised options."* (SCIE)

*"The practice of closing the case file of a person with a long-term condition after a one-off delivery of service must end. Assessment should discuss the long-term needs likely to arise from a condition, and ensure that users and carers know where to go for support."* (Parkinson's Society)

Better access to *reassessment* was also seen by the Parkinson's Society as a further feature needing urgent attention:

*"Reassessments must be encouraged. Staff need to understand that being turned down for support can be a traumatic experience, and reassessment should be actively encouraged."*

- 3.15 And for those cases where users and carers were unhappy with procedures, some of the evidence urged stronger means of redress:

*"Where FACS criteria is deemed not to be met, there should be access to independent advocacy and complaints/arbitration which reflects a fair and transparent decision-making process"* (Gateshead Council)

## Modification of FACS criteria

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- 3.16 Some evidence supported the idea of amalgamating the existing bands in order to simplify and streamline access to support. Nottinghamshire Council, for example, proposes merging the 'moderate' and 'low' bands into a separate 'prevention' band, with the distinction between the 'critical' and 'substantial' bands then determined by the speed of response required. In such a scenario, all people in the 'prevention' band would have access to robust information and advice, and be properly signposted to alternative support. The latter could include short-term case coordination as piloted in some of the Partnership for Older People Projects (POPP) programmes – in effect a form of preventative intermediate care. A related proposal is that of separating out personal care from domestic routines so that priority is given to those domestic routines that are specifically related to personal care by ensuring personal cleanliness, warmth and safety.
- 3.17 Another proposal on separation is that of distinguishing (and separately treating) people with multiple and complex needs from those with less complex needs. This was a point raised at the consultation event as a way of countering the tendency to allocate all of the available resources to the higher end of the needs spectrum:
- "A way round this might be to establish a system that works for the majority of people, and a separate system for people with complex needs, ie: taking the funding for expensive packages out of the current system and finding alternative funding sources for those needs."*
- 3.18 This proposal was supported in evidence from the RNIB:
- "In the short term there is a need to separate preventative from 'heavy end' resources. As long as they are in the same pot, prevention will lose out."*
- 3.19 Some submissions went on to link the funding of complex cases to an entitlement basis (something that will be considered later). The Learning Disability Coalition, in noting that such cases can range in annual cost from £100,000 to £500,000, argues that these users and their families have lifelong needs, and require certainty of funding.

## 4. Proposals for longer-term change

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- 4.1 As has been noted, some of the submitted evidence was supportive of the current FACS framework, and others (whilst less supportive) cautioned against throwing out the FACS baby with the personalisation bathwater. However, there was also a very strong view that nothing less than fundamental change would suffice:

*"We believe FACS should be replaced with a new system for determining eligibility for support with independent living that is more compatible with personalisation, and specifically with the model for self-directed support."* (Croydon Council)

*"Until suitable resources are committed to social care, a fairer and more sustainable mechanism for allocating existing resources should be found."* (MS Society)

*"FACS is fundamentally flawed as it works to ensure that most of the resources available for community care are allocated without any regard towards the objectives of promoting independence and prevention. The system is therefore in need of serious reform."* (Alzheimer's Society)

*"The FACS criteria are used for purposes for which they were never designed, and they are not fit for the system in which they now operate."* (Help the Aged)

*"There would be considerable anger and frustration if the social care system were to broadly remain the same. Tinkering with the system will be to little effect when it is clear what is needed is a system that promotes dignity and wellbeing."* (RNIB)

- 4.2 It is, of course, relatively easy to develop a critique of FACS and call for fundamental reform; it is less easy to say exactly what should replace it and how it will work effectively. In our earlier review of the literature on eligibility<sup>14</sup> we proposed that eligibility should be regarded as a second-order issue that reflects higher-order principles and policies, and that it should be based upon a clear rationale. In other words there should be consistency of approach across principles, policies and prioritisation, without this approach there are risks that eligibility is developed in unintended directions with perverse consequences for individuals.

- 4.3 There was a very strong body of opinion in the written evidence arguing that any new eligibility framework needs to be consistent with the emerging policy agenda laid out in Putting People First. The well-established features of the Concordat are:

- to replace paternalistic, reactive care of variable quality with a mainstream system focused on prevention, early intervention and enablement
- high quality personally tailored services
- enabling people to have maximum choice, control and power over the support services they receive
- the right to self-determination, constrained only by the realities of finite resources
- levels of protection which should be responsible but not risk averse.

- 4.4 The construction of eligibility criteria logically follows the direction set by values, principles and policy. FACS was well suited to a system in which professional judgement determined levels of need and risk, followed by a care plan based around available services. However, it is now being questioned whether it is fit for purpose in the very different policy regime arising from Putting People First. The challenge therefore is to devise fresh eligibility criteria that better reflect the new policy world.
- 4.5 The values and principles underpinning Putting People First were evident in the various proposals for long-term change submitted in the written evidence. The following key themes were prominent:
- an outcomes-based framework
  - alignment with the personalisation agenda
  - transparency of entitlement
  - prevention and partnership
  - reappraising national and local responsibilities.

## An outcomes-based framework

- 4.6 Outcome-oriented policy is now driving developments in children’s services (the *Every child matters* changes) and adult social care (the outcomes articulated in *Our health, our care, our say*). The table below compares the identified outcomes for the two services.

Children’s Services Outcomes	Adult Services Outcomes
<ul style="list-style-type: none"> <li>• being healthy</li> <li>• staying safe</li> <li>• enjoying and achieving</li> <li>• making a positive contribution</li> <li>• economic wellbeing</li> </ul>	<ul style="list-style-type: none"> <li>• improved health</li> <li>• improved quality of life</li> <li>• making a positive contribution</li> <li>• exercise of choice and control</li> <li>• freedom from discrimination or harassment</li> <li>• economic wellbeing</li> <li>• personal dignity</li> </ul>

- 4.7 In principle, there is no reason why eligibility criteria should not be related to these outcomes, and there is widespread support for such an approach in the written evidence:

*"NCIL supports the outcomes set out in 'Our Health Our Care Our Say, moving away from the arbitrary judgements on risk to criteria based on the individual, and an approach that gives people dignity and respect.'" (NCIL)*

*"The process needs to be focussed on outcomes, and move away from a risk-based approach, recognising that people have the right to take risks." (Consultation event)*

*"Any new system must start by identifying the individual’s desired outcomes, together with ways to achieve these using existing support systems." (SCIE)*

*"Rather than the four-band system, RADAR suggests that a key principle to underpin eligibility for publicly funded care should be that of minimum outcomes...to ensure that every disabled person has a clear right to independent living support which meets basic human rights standards."* (RADAR)

*"A new type of criteria must be written in a new social care 'language'...based on fulfilling outcomes, rather than one focused on systems and prescriptive services."* (Counsel and Care)

*"Any new system needs to be focused on enabling people to achieve personalised outcomes rather than mitigating risk...This would need to include a strong focus on self-assessment and self-determination."* (Scope)

- 4.8 For practical purposes the key decision to make here would be to determine how much extra support someone would need in order to achieve the outcomes guaranteed by the eligibility criteria. This could not be determined by allocating people to 'bands' as in the current system – as SCIE notes in its evidence, *"people with similar levels of need might require different levels of input to enable them to attain equivalent degrees of independence"*.
- 4.9 Work is already under way to flesh out the outcomes framework of *Our health, our care, our say*, and this could form the basis for a revised eligibility framework. In 2006 CSCI introduced a new outcomes framework for performance assessment of adult social care by developing a set of 'grade descriptors' built around the seven outcomes, along with the two additional domains of 'leadership' and 'commissioning and use of resources'. It is now proposed to make further refinements to the descriptors for 2008-9:
- closer alignment between the descriptors and Putting People First requirements
  - improving the coherence of the grade descriptors with the outcomes
  - improving the depth and breadth of the grade descriptors
  - making the descriptors clearer so that they are in plain English.
- 4.10 In the meantime the *Model self-assessment questionnaire* developed by the Department of Health for the *Personalisation toolkit*<sup>15</sup> lays out 12 core areas, each of which is then related back to one or more of the seven *Our health, our care, our say* outcomes. All of this means that a considerable amount of underlying work has already been undertaken in the development of an outcomes-based framework, which could then be turned into an accompanying framework to determine eligibility for social care.

## Alignment with the personalisation agenda

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- 4.11 The proposed focus upon an outcomes-based framework goes hand in hand with the development of the personalisation agenda – a shift that poses new questions and raises new challenges. Making personal budgets creative and flexible means focusing on outcomes and not services, and giving people the chance to use money in new and different ways to meet their needs and achieve desired outcomes.

*"The move to self-directed support offers the opportunity to look at support from the state in a different way. The question moves from whether you are eligible or not for social care services, to what support you need to live your life, what can you contribute, and what support/advice you will need from elsewhere."* (Hampshire Council)

4.12 This constitutes a new and radically different model for the rationing of public money. The standard microeconomic model assumes that individuals deal with scarcity by having preferences, and by then trying to maximise their preferences in rank order of priority. However, complications then arise in the case of rationing decisions that are taken *not* by individuals, but by the state acting on their behalf – the typical situation in respect of social care. In their sociological examination of the issues, Light and Hughes<sup>16</sup> reframe such rationing as *"a form of collective planning that suppresses individual choice."* Given the government's agenda on personalisation it could be argued that the prime purpose of any new eligibility framework should be to seek maximum reconciliation between scarcity and user/carer preferences.

4.13 There was certainly generalised support in the written evidence for re-framing eligibility within a personalisation context:

*"Personalisation is perceived as seeking to empower the person who uses services to assess their own needs, plan the supports they require and either directly purchase or pay an agent to purchase them on their behalf. Any eligibility framework will need to fit with this agenda."* (Consultation event)

*"With the development of personalisation policies, some of the principles stated in the FACS guidance come into question. The hard-and-fast distinction between presenting and eligible need is difficult to maintain in a context where people expect, and are encouraged, to identify for themselves, their aspirations and the outcomes they are seeking to achieve wellbeing."* (SCIE)

*"For personal budgets to become part of the mainstream provision of social care, the eligibility criteria must be reviewed. They are currently at odds with one another, as personalisation and greater individual choice do not sit comfortably with the use of FACS."* (Help the Aged)

*"Government must seriously consider how eligibility criteria determined at local authority level fits in with putting users at the heart of the service, and empowering individuals to assess their own needs and level of risk."* (MIND)

4.14 Some respondents were anxious to emphasise that personalisation and personal budgets do not, in themselves, solve the problem of rationing scarce resources amongst competing needs. In the personal budget model there will still need to be some formula for linking sums of money with levels of need, with greater amounts going to people in need of greater support.

*"The underpinning assumption [of the RAS] is that everyone has a need for a service, and it is just the level of intensity that the RAS determines...this is not sustainable."* (Ophira Ltd)



*"It is essential to recognise that individual budgets and direct payments do not in themselves resolve the dilemmas associated with rationing...The outcomes-focused instrument established to determine allocation of funds under a new system of self-directed support could end up functioning in much the same way the current system does."* (RNIB)

- 4.15 For some people the best solution seemed to be to retain FACS as a 'gateway' to a personal budget, but to then allow greater freedom of spending decisions for those who manage to get into the system. However, the overwhelming preference was for a fresh framework that melds eligibility with personalisation:

*"Our suggestion is that the eligibility level should be built into the personalisation self-assessment framework. This could be in the form of a points range which could trigger eligibility for formal community care services, or descriptors of the types of need which would trigger eligibility."* (North Somerset Council)

*"Whilst it is appreciated that current self-directed support practice tends to admit people to the system only after a determination of eligibility has been made (ie: if someone is eligible for public funding), there is an ideal opportunity here to align and integrate determinations of eligibility with self-assessment, and for the same system to determine the indicative personal allocation."* (Croydon Council)

- 4.16 And for another council, running the two systems side-by-side (FACS and SDS) was seen as transitional rather than complementary:

*"We are running two systems...and can see the need for change to enable SDS to become the default setting, and the establishment of one system. The next generation of the RAS will enable FACS to be phased out over the next three to five years."* (London Borough of Barking & Dagenham)

- 4.17 The RAS is central to any such new system. Amongst the key components of a RAS are an outcomes-based self-assessment questionnaire, and a RAS 'calibrator' (often based on a points system) which determines how much money to allocate, based on the person's answers to the questionnaire. As things stand, it is down to each council (in the case of a personal budget) to then manage within current budgets by ensuring that people only begin to attract needs points (and hence funding) when it is affordable. As Staffordshire Council points out:

*"While this is not the same as 'eligibility criteria' as such, the process local authorities will need to go through is very similar, such as defining those levels of need it is able to meet in order to stay within budgetary constraints."*

- 4.18 Croydon Council further observed that:

*"Using a numerical score as the eligibility threshold would also allow authorities to calculate more precisely the impact of raising or lowering the threshold, and hence would facilitate more effective budgetary management."*

- 4.19 Currently councils are at very different positions in developing a local RAS, and some submissions to the review were not happy with the ways in which local councils might use the RAS to determine eligibility:

*"We would strongly resist any move to use the RAS as a rationing mechanism. It is a crude measure of need and some deafblind people are already suspicious that the RAS system is a way to cut services."* (RNIB)

*"A system of individual budgets makes much more use of self-assessment in order to allocate a budget through a RAS...Our initial concern is that this is moving away from the legal framework of Community Care Assessments or Carers Assessments [which] are critically important."* (Carers UK)

*"Version upon version of RAS documentation constantly emerges. There appears to be a reluctance to acknowledge that the numerous amendments are indicative of intrinsic deficiencies...we fear that the total abandonment of proven assessment practice will, in most instances, equate to poor practice."* (Ophira Ltd)

- 4.20 And finally, there was also a view that the problem was not so much the RAS system per se, but the local variations that are beginning to emerge. In this case, the solution was felt to be a *national* RAS:

*"We suggest the need for a national model for supported adult self-assessment, using a single tool to facilitate the determination of eligibility, to identify self-assessed needs, and to calculate the indicative personal allocation."* (Croydon Council)

*"There must be a strong argument that the RAS should be a national system administered by DWP. Local authorities would then be free to concentrate on support planning and care brokerage, and the issue of eligibility criteria would be avoided altogether."* (Staffordshire Council)

*"Although the unit costs may differ between local authorities, the issue of how to allocate a monetary value to a person's needs will be the same. It would be helpful to have a national RAS that follows an application through from referral to eligibility, and on to the allocation of resources."* (Nottinghamshire Council)

## Transparency of entitlement

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- 4.21 Much of the evidence went beyond issues of process and on to broader principles that should underpin access to support. Often this began with the need to ensure 'fairness':

*"Social care provision and the rules that determine who is eligible to receive it, must be seen to be fair. Currently...this does not seem to be the case. It is crucial that people do not feel the eligibility criteria are being applied in an arbitrary or ad hoc manner."* (The Disabilities Trust)

- 4.22 'Transparency' was sometimes seen as an essential element of fairness. The consultation event included the call for "a system that is easy to understand for all, including people who use services, policy makers and professionals. A transparent system is also one that is open to challenge." In similar vein, Nottinghamshire Council proposes that "eligibility criteria should be simple enough for people to

understand readily, so that they can see how decisions are made, and can challenge decisions where necessary". And Help the Aged is clear that "clarity of decision-making should be integral to any system".

- 4.23 ADASS urged some caution in taking a blanket approach, stressing the need to clarify what can reasonably be expected under a reformed system:

*"Clearly there are some services that everyone should be able to access, such as information and advice; some that we might want particular people to access, such as falls prevention; and some that might contribute to preventing social exclusion (such as lunch clubs), access to which should not be constrained by formal eligibility criteria."*

- 4.24 However, whilst some evidence counselled the need for caution in respect of access, many others felt the time had come to put access on to a firmer footing – one based upon entitlement rather than discretion:

*"Receiving help in carrying out the normal activities of daily life are basic human rights which society has a responsibility for addressing."* (MS Society)

*"There was a consensus that there should be a national, consistent 'social care and support offer' which sets out entitlements to social care and support services, backed by a funding system that recognises a continuum of needs and enables the funding of prevention services."* (National Housing Federation)

*"Currently there are too many people who do not qualify for care, but whose needs are nevertheless very high. There needs to be a system in which older people with any reasonable level of need should be catered for."* (Help the Aged)

*"The positive obligation on the state to ensure that every person has the tools and support to live their lives as independently as possible must be the starting principle for any change in the way that eligibility for social care is established...An acceptance that even in a system of limited resources, all disabled people are entitled to a minimum package of support, advice and follow-up from social services."* (MS Society)

*"The outcomes set out in Independence, Wellbeing and Choice should be the basis of a nationally defined minimum level of care and support that all individuals should be entitled to, regardless of where they live."* (Age Concern)

*"Discussions about eligibility need to start with a discussion about entitlement."* (Scope)

- 4.25 These calls for a clearer, entitlement-based system (allied to frustration with the current tightening of eligibility) led to some respondents calling for a much more serious approach to human rights legislation:

*"We believe that local authorities are left to flout human rights standards because Government has failed to clearly spell out what the positive obligations in the ECHR actually mean, and that they cannot simply be dismissed by reference to resource constraints."* (RADAR)

*"Any new approach to assessment of an individual's needs should be based on their human rights...and not solely considered within the confines of the social care system."* (Mencap)

*"Eligibility should be compliant with existing human rights legislation...Any new system must highlight equality and human rights principles and obligations, and use them to underpin a new framework."* (NCIL)

The key legislative levers seem to be:

- The Human Rights Act 1998 which came into force in 2000, and incorporates the main rights and freedoms set out in the European Convention on Human Rights into UK law. It requires all public authorities to act in a manner which is compatible with the rights set out in the ECHR and, if they fail in this duty, people who are affected by the breach may ask the courts for a remedy. Public authorities include central government, local authorities, NHS trusts and most providers of public services. The Government is (at the time of writing) exploring the potential for extending the Human Rights Act to people with publicly arranged care in independent sector care homes, but this would still leave self-funders excluded.
  - The Disability Discrimination Act (DDA) 1995 (as amended) makes it unlawful to discriminate against a disabled person in a range of areas including employment and the provision of goods and services. The DDA 2005, which amends the earlier Act, introduces a general duty on public authorities to promote disability equality – the 'disability equality duty'. This marks a shift from the reactive duties of DDA 1995 towards a positive duty to actively promote equality of opportunity for disabled people by having 'due regard' to the need to:
    - eliminate unlawful discrimination
    - eliminate disability-related harassment
    - improve equality of opportunity
    - take account of someone's disabilities even where this involves more favourable treatment
    - promote positive attitudes towards disabled people
    - encourage participation by disabled people in public life.
  - The UN Convention on the Rights of Persons with Disabilities builds on existing human rights treaties and aims to *"promote, protect and ensure the full employment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity"*. By early 2008, 123 States had signed this treaty (including the UK) and 13 of them had ratified the Convention. The UK Government intends to ratify the Disability Convention by the end of 2008.
- 4.26 RADAR, in written evidence, states that minimum outcomes based upon core human rights standards would include:
- ensuring freedom from physical risk

- ensuring freedom from inhuman or degrading treatment
  - the full enjoyment of the right to personal development, and to establish and maintain family and other social relationships
  - support for participation in the life of the community
  - support to participate in essential social and economic activities
  - support to access an appropriate range of recreational and cultural activities.
- 4.27 Clearly this is far removed from the narrow conception of social care that is currently reflected in the FACS framework. This potential 'reconceptualisation' of social care is considered in the next section.

## Reconceptualising social care: prevention and partnership

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### Prevention

- 4.28 It was common in the written evidence to find calls for a new vision of social care that goes beyond the narrow model that currently predominates. Typically this related to the need for a stronger focus upon prevention and inclusion so that councils and their partners know much more about people who currently fall outside of the system. This implies a move towards a more universal model of support – away from the idea that we give to some but not to others. And for some, this was felt to even require a new language – one focused on 'support' rather than emphasising 'care'.
- 4.29 The most frequent expression of this vision was made in relation to the need for a more preventative and inclusive agenda – an observation made so frequently that only a selection of supporting evidence can be included:
- "Any system of eligibility should recognise that early intervention and support can prevent people from declining to the point where they need much greater and more expensive intervention."* (The Disabilities Trust)
- "Councils should find ways to proactively assist people who, whilst not currently being eligible, may become so in the future."* (Consultation event)
- "The principle of concentrating resources on those in greatest need should be revisited. Its effects, when coupled with the raising of eligibility criteria as a rationing device, can be to exclude people with high levels of need, where application of moderate amounts of resource could be particularly beneficial and cost-effective."* (SCIE)
- "The fundamental issue is that anyone with social care needs should have these met where they are identified, whether these are minor or critical. Emotional support and human contact both have value, and these needs should be considered as critical for sustained independence and quality of life."* (National Housing Federation)

*"The social care system – along with the health service – needs to move towards a greater emphasis on illness prevention and health promotion, with a greater focus on early intervention and identification of needs."* (Carers UK)

*"It is vital that resources are set aside in every local authority for people...whose needs are not in the critical or substantial category, but who would considerably benefit from relatively low intensity, inexpensive support to improve their quality of life and promote their independence."* (United Response)

- 4.30 The submission to the review from CSIP (drawing on the POPPs pilots) outlined a potential model for delivering on the prevention and early intervention agenda:
- the establishment of a case coordination service which addresses the needs of people not deemed to be eligible for mainstream social care 'care management'
  - development of a structured pathway into the case coordination service for those not deemed eligible for a care-managed response
  - the undertaking of proactive case finding to identify people in need of information or support
  - the development of 'face-to-face' models for proactively providing information and advice
  - the implementation of a locality-focused community development model to promote the general well-being of older people in the area.

- 4.31 Some submissions felt that none of this was likely to be achieved without further direction from central government, or even the introduction of a new statutory duty – though there was an acknowledgement that to some extent the new joint strategic needs assessment (JSNA) could provide some impetus:

*"We would like a system whereby everyone is entitled to a level of support. Needs below the eligible level of community care services would be met by preventive, non-assessed services...and the local authority would assume some formal responsibility for linking people to such services. Making this a statutory duty would help with achieving consistency, but would need resourcing."* (North Somerset Council)

*"The existing guidance allows local authorities to ignore the requirements of those at lower levels of eligibility. With the introduction of JSNAs the authority will have to consider the needs of its population as a whole and this may strengthen the case for an inclusive approach."* (SCIE)

*"An adequately resourced preventative strategy is needed. It should have a high profile and be much more coherent than merely a call to look round for other sources of funding. It may be necessary to ring-fence resources for prevention."* (RNIB)

## **Partnership**

- 4.32 Any such reconceptualisation of social care carries a further implication – that it can no longer be viewed as solely the preserve of the adult social care departments of local authorities – the implication of *prevention* is inter-agency *partnership*. Such a shift has some important policy implications for our future understanding of the

nature of social care and its relationship with other forms and sources of support. In general terms a shift from a narrow perception of eligibility (social care) to a wider conceptualisation (independence, health and well-being) raises the need for much more sophisticated joined-up approaches to understanding, assessing and supporting vulnerable people.

- 4.33 In going down this path, social care would need to change from being a relatively stigmatised and narrow service based upon Poor Law principles to be part of a more inclusive and universal response to people's need for support. Broadly this model would be one in which the emphasis switches from deficit, decline, disability and dependency to one couched in terms of well-being, activity and inter-dependence. The further policy question, then, is whether it is appropriate to have separate eligibility criteria for social care, or whether a more ambitious inter-agency framework based upon wider criteria can be envisaged. Such a development would also be consistent with one of the key aims of Putting People First:

*"Ultimately every locality should have a single community-based support system focused on the health and wellbeing of the local population. Binding together local government, primary care, community-based health provision, public health, social care and the wider issues of housing, employment, benefits advice and education/training. This will not require structural changes, but organisations coming together to re-design local systems around the needs of citizens."* )

- 4.34 Support for the idea of a partnership approach to a new social care agenda was frequent in the written evidence:

*"To break out of this downward cycle, all services – not just health and social care – must be geared up to proactively pursue a preventative agenda."* (Consultation event)

*"Low to moderate need should be met within a prevention strategy, and a citizenship strategy should direct the pooling of resources in health, public health, housing, education, employment, leisure and cultural services, to minimise social services intervention."* (Gateshead Council)

*"Care and support for older people is not purely about social care. If we define social care as support that enables one to live a normal life, then we cannot exclude issues such as health and wellbeing, employment, housing, the environment and social networks."* (Counsel and Care)

- 4.35 Observations in the evidence on the mechanics of partnership working tended to be of two types – those concerned with fixing current problematic interfaces, and those looking ahead to more ambitious and sophisticated scenarios. Several problematic interfaces were identified, and in each case it was argued that these needed to be harmonised with social care. Typically these covered the Independent Living Fund, continuing health care, Supporting People and the social security benefits system. Some respondents also warned that the individual budget model should not be downgraded to a social care based 'personal budget'.

- 4.36 Others were even more ambitious in their partnership intent, and pressed for the alignment or integration of a complex range of interfaces:

- **Across families:** Crossroads called for "greater consideration for the needs of the whole family at assessment rather than the separate consideration of sometimes conflicting needs". Similarly the Princess Royal Trust for Carers said that "Where families wish to, they should have the option of being assessed for eligibility as a whole family, rather than having to negotiate separate assessments for each individual".
- **Across a council:** The corporate responsibility of councils for addressing the prevention and inclusion agendas was felt to be in need of strengthening. Carers UK felt that "At present FACS seems disjointed from the corporate aims of local authorities and the strategic goals that many of them have to support independence, choice and a good quality of life for disabled and elderly people as part of their general objectives for their communities".
- **Across wider services:** Hackney Council called for "a more robust and consistent eligibility criteria which can be applied across different service areas" in order to address disputes over responsibility, whilst Durham County Council wished to see "the development of a joint health and social care eligibility criteria at national level".
- **Across localities:** Most ambitiously, there were calls for locality-wide coherence on addressing eligibility for support. Staffordshire Council summed up this position well:

*"We need shared principles if we are to address cross-cutting issues, ensure consistency and meet the challenges of personalisation. Shared performance indicators and LAAs might go some way towards different organisations aligning their principles."*

## Reappraising national and local responsibilities

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- 4.37 Given that so much of the dissatisfaction with FACS arises from the variable and inconsistent application of the guidance by professionals and councils, it was inevitable that the evidence would include calls for a reappraisal of the locus of decision-making in respect of eligibility. The call for greater national consistency in the determination of eligibility for, and access to, social care support was widespread in the written evidence. Typically this involved calls for a national minimum guarantee of support:

*"There should be a national system of basic entitlement enforced through legislation."* (NCIL)

*"Many participants favoured a system based on national criteria, with the same price points across the country, or a more universal system which guarantees a minimum level of free social care for all."* (Consultation event)

*"We believe that there should be one eligibility system with a single threshold for all disabled people nationally...so abolishing the post-code lottery."* (Sense)

*"There should be consistency across local authority boundaries so as to avoid a post-code lottery."* (Crossroads)



*"A fairer system could be a universal points system applied nationwide for accessing care services." (Spinal Injuries Association)*

*"Most people at our focus group were strongly of the opinion that there should be a national system of eligibility criteria where the threshold was set nationally. It would mean that the result of an assessment would be the same in every local authority area." (Help the Aged)*

*"Central allocation of funding based on local assessment of need. Income support does not get cut because resources have run dry!" (Down's Syndrome Association)*

*"Anything short of a national eligibility threshold is likely to further disappoint and frustrate people in need of support. Our view is that it would be infinitely preferable for there to be a national eligibility threshold, and for personal budgets to be calculated with similar consistency, albeit possibly allowing for regional variations in the costs of services." (Croydon Council)*

*"Age Concern is opposed to the view that the basic level of support that every citizen should be entitled to should be a matter for local discretion. A framework of national entitlements based on human rights principles is needed." (Age Concern)*

*"There was strong support for a national 'core offer' for both users and carers to ensure greater consistency." (Local Authority Networking Event)*

- 4.38 In supporting this general position on greater central determination of entitlement, most of the evidence commented on two additional aspects – 'top-up' arrangements and portability of support.

### **Top-up arrangements**

- 4.39 Calls for a national minimum guarantee usually carried an understanding that this would be complemented by individual or local top-up arrangements:

*"If a person needs social care beyond this entitlement then a means test could be put into operation so that those without the means to pay can receive the care they need when they need it." (Counsel and Care)*

*"It would be preferable if everyone had a basic entitlement to social care as of right, with people using a range of private and welfare benefits funding to top up and add to their basic entitlement to buy additional or higher quality services." (Staffordshire Council)*

*"Any top-up to the basic entitlement would be determined by the individual concerned or at a local authority level." (NCIL)*

### **Portability**

- 4.40 One of the most frequently advanced virtues of a national system (or alternatively of some inter-council concordats) is the greater portability of support across the country:

*"A national approach to eligibility would provide an opportunity to ensure that those transferring from one local authority to another could continue to receive the same level of funding."* (NCIL)

*"If people move to another local authority area it is ridiculous that the whole process must be started again. There should be a system where assessments can be carried over."* (Carers UK)

*"The current system provides a barrier to disabled people being able to move between local authorities. RADAR believes care packages must be portable for a transitional period between local authorities. The principle of minimum outcomes would also ensure that this barrier was removed, as the post code lottery that currently exists in social care provision would disappear."* (RADAR)

## Conclusions

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- 4.41 The evidence submitted to the review – both through the survey and in written submissions – has come from a wide variety of quarters, sometimes reflecting very different interests, experiences and perceptions. It is only to be expected that bodies representing councils, for example, will tend to be more cautious about the practicalities of resource allocation than bodies lobbying on behalf of specific user constituencies. Although this did indeed turn out to be the case, it is true that a number of councils, and individuals working in social care, also took the view that current arrangements are unsustainable.
- 4.42 With very few exceptions, the submitted evidence accepts that some form of social care rationing is inevitable, and whilst there is some limited support for the view that FACS could be made fit for purpose (even if only in the short term), the bulk of opinion calls for a radical reappraisal of arrangements. This is partly because of the multiple problems that have arisen in the wake of FACS implementation, but – more importantly – because of the positive desire to move towards an alternative framework which is better suited to the emerging policy agenda.
- 4.43 The key dimensions of this new framework command near universal support, and comprise:
- an outcomes-based approach
  - compatibility with the personalisation agenda
  - a focus upon prevention and inclusion
  - fairness and clarity of access
  - guaranteed basic national minimum support.
- 4.44 The evidence provides strong support for the analysis that we previously offered in *Lost to the system* and confirms the conclusions that too many people are left to flounder outside a narrowly conceptualised eligibility framework which tends to address needs only when they reach substantial or critical levels, and which has little to offer people with needs for support below this threshold (albeit that this was never an intention of the FACS framework; there have been serious unintended consequences). Whilst very little of the evidence includes precise proposals on what

a new framework would look like, or how new rules would effectively operate, it *does* set a very clear direction of policy travel for the next stage of the policy-making journey. What is overwhelmingly clear is that the current FACS eligibility framework performs badly when measured against the template outlined above. Any alternative approach to developing an eligibility framework for social care will need to demonstrate that it satisfies these criteria.

# Appendix 1: Analysis of Online Survey

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In addition to the CSCI's call for written evidence submissions, an online survey was posted on its website. The survey was designed for use by anyone with an interest in eligibility issues, but was aimed in particular at people using social care services (and those who believed they would benefit from social care, whether or not they had approached social services to ask for help); informal carers of people using social care; and people working in social care and other services.

The survey went live on 1 April 2008, and was closed on 9 May. Over this period returns were submitted by 2,940 individuals, with fully usable data recorded for 2,884. We are extremely grateful to everyone who took the time to complete the questionnaire, and especially to those people who provided extensive written comments and shared their experiences. A copy of the questionnaire is included at Appendix 2. The survey was undertaken on a fully confidential basis and did not seek identifiable information about respondents.

## Characteristics of respondents

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Table 1 summarises information about people responding to the survey. The classification of 'someone who could benefit from social care' was chosen to identify both people who were currently using social care services *and* those who had needs where they believed they would benefit from such support. However, this definition was not entirely clear for everyone responding to the survey, and 30 respondents who had initially placed themselves in the 'other' category should have been in the first category as they were already using social care services. Similarly, a number of people who were carers or ex-carers of people using services had placed themselves in the 'other' category because of a misunderstanding of the definition being adopted by the survey. The adjusted figures are shown in brackets in Table 1.

As the table demonstrates, carers (and former carers) accounted for the largest segment of respondents, closely followed by people employed in social care, and in council social services. The further category of 'other' requested people to specify their identity. This revealed a wide range of respondents from generally interested members of the public, to advocates, consultants, researchers and trainers; student social workers and nurses, people employed in the health service, and those working in the voluntary sector (both in paid posts and as volunteers). Some people also chose this category because they crossed a number of boundaries (for example, being both carers and social care employees) and were unsure how to identify themselves.

**Table 1: Respondents to the online survey**

Online survey respondents	Number	%
Someone who could benefit from social care	282 (312)	10 (11)
A carer of a person who could benefit from social care	781 (832)	27 (29)
A person employed in council social care	628	22
A person employed in another sector of social care	818	28
Other	375 (294)	13 (10)
<b>TOTAL</b>	<b>2,884</b>	<b>100</b>

The survey also requested basic demographic data. By no means all the people responding to the survey shared this personal information, but the data that were provided are presented in Table 2. The vast majority of respondents who *did* supply this additional information were either people who were using services (or who could benefit from services), and carers. The breakdown of data across other categories of respondent is not therefore provided.

Of those people who responded, almost three quarters were female, and the largest proportion was middle-aged (45–64). Respondents who could benefit from social care were most likely to be living alone, while carers were most likely to be living with a spouse or partner. Ninety per cent of those providing demographic data identified themselves as white British.

**Table 2: Demographic characteristics**

Characteristics	Numbers	People who could benefit	Carers
<b>Male</b>	179 (27%)	64 (34%)	111 (24%)
<b>Female</b>	486 (73%)	125 (66%)	356 (76%)
<b>Age 16–24</b>	12 (2%)	2 (1%)	10 (2%)
<b>Age 25–44</b>	199 (29%)	77 (39%)	117 (25%)
<b>Age 45–64</b>	363 (53%)	95 (48%)	265 (56%)
<b>Age 65–79</b>	72 (11%)	21 (11%)	49 (10%)
<b>Age 80+</b>	32 (5%)	2 (1%)	30 (6%)

Characteristics	Numbers	People who could benefit	Carers
<b>Household circumstances</b>			
Live alone	138 (23%)	77 (44%)	59 (14%)
Live with spouse or partner	343 (57%)	74 (42%)	264 (62%)
Live with other relatives	101 (16%)	20 (11%)	79 (19%)
Live in social care setting	21 (3%)	2 (1%)	17 (4%)
Other	6 (1%)	2 (1%)	4 (1%)
<b>Sexual orientation</b>			
Lesbian/gay woman	9	2	6
Gay man	12	5	6
Bisexual	23	10	13
Heterosexual	545	158	379
<b>Ethnicity</b>			
White British	573	167	397
Irish	15	2	13
Any other White	16	5	11
Mixed White/Black Caribbean	1	0	1
Mixed White/Black African	2	0	1
Mixed White/Asian	3	1	2
Any other mixed	8	5	3
Indian	6	1	5
Pakistani	4	1	3
Bangladeshi	0	0	0
Other Asian	1	0	1
Black Caribbean	2	2	0
Black African	2	0	2
Other Black	1	0	1
Chinese	1	1	0

## Needs for support

The survey asked people who could benefit from social care and their carers about their main support needs. Figure 1 records the frequency of responses to each of the care needs identified. Considering both groups of respondents together it is clear that help with personal care was the top priority identified. However, if people using social care (and potential users) are separated from carers, there are some clear differences in relative priorities. Nonetheless, both groups generally attached the greatest priority to aspects of practical support.

**Figure 1: Main care needs identified**

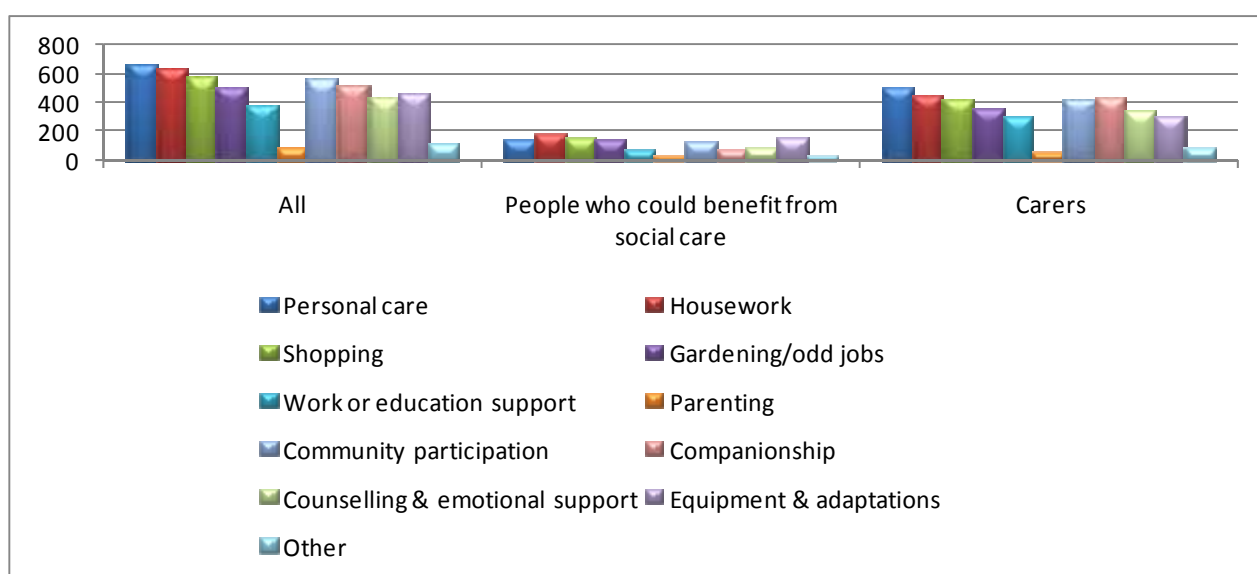


Table 3 below presents the frequency of responses for both groups together with their relative rankings. Some differences are worth highlighting: help with practical tasks such as shopping and gardening or odd jobs, and equipment and adaptations, were of more importance to people who could benefit from social care than to carers. Conversely, carers were more likely to identify a need for companionship, and for support with community participation for the person they were supporting.

The 'other' category of help included a range of specific areas of support with independent living (such as help with meal preparation, medication, communication, transport and managing finances), while some respondents emphasised the need for support in all areas and on a consistent and reliable basis (for example, in supporting a person with Asperger's syndrome). Several respondents also specifically identified the need for respite, particularly where they had experienced the closure of local facilities.

**Table 3: Needs for care and support (numbers and relative ranking)**

Care Needs	All respondents	People who could benefit	Carers
Help with personal care	656 (1)	151 (5)	501 (1)
Help with housework	638 (2)	184 (1)	450 (2)
Help with shopping	579 (3)	156 (2)	419 (5)
Gardening/odd jobs	506 (6)	153 (4)	350 (6)
Support with work or education	380 (9)	80 (9)	298 (9)
Support with parenting	98 (11)	39 (10)	59 (11)
Support with community participation	569 (4)	135 (6)	431 (4)
Companionship	522 (5)	83 (8)	438 (3)
Counselling or emotional support	441 (8)	92 (7)	347 (7)
Equipment & adaptations	471 (7)	163 (3)	304 (8)
Other	123 (10)	35 (11)	88 (10)

## Experience of assessment

People who could benefit from social care, and carers, were asked about their experience of approaching social services for help (at this point other respondents were directed to another part of the questionnaire). Of those people responding, 82% indicated that they had asked for help from social services. This figure was very similar for people who could benefit from social care (84%) and for carers (81%). This high response is important because it underlines the fact that people responding to this section of the survey were basing their responses directly on personal experience, rather than on a general impression of what might happen if they were to seek help.

As Table 4 demonstrates, having asked for help *most people* went on to have an assessment of their needs carried out by social services. This was true of 84% of respondents overall, and was slightly higher for people who could benefit from social care (87%) than for carers (82%). However, some people failed to get access to an



assessment of their needs, and one third of these people reported that they were told this was because they did not meet the council's financial criteria. In other words, they were asked about their financial resources and savings prior to any assessment of their needs for support. Significant numbers of people who had resources of their own were diverted from the system at this stage. Such practice is contrary to policy, but it *is* consistent with the experience we reported in chapter 8 of *The state of social care in England 2006-07*, which documented the fate of people 'lost to the system'.

For those people who *did* have an assessment of their needs for social care support, their experiences were largely positive, with most people reporting that they felt able to express their views, that their wishes were listened to, and that their culture and lifestyle were respected. However, this gives no grounds for complacency given that almost 40% of people felt their wishes were *not* listened to, more than a fifth felt unable to express their views, and more than a quarter felt their culture and lifestyle were *not* respected.

**Table 4: Experience of social care assessment**

	<b>YES (all)</b>	<b>YES (users)</b>	<b>YES (carers)</b>	<b>NO (all)</b>	<b>NO (users)</b>	<b>NO (carers)</b>
<b>Have you asked for help from social services?</b>	786 (82%)	213 (84%)	569 (81%)	173 (18%)	40 (16%)	131 (19%)
<b>Did you have an assessment of your needs?</b>	643 (84%)	183 (87%)	458 (82%)	127 (16%)	28 (13%)	99 18%
<b>Were you told you didn't have an assessment because you did not meet financial criteria?</b>	41 (33%)	12 (41%)	29 (30%)	85 (67%)	17 (59%)	68 (70%)
<b>During the assessment did you feel able to express your views?</b>	464 (78%)	127 (74%)	335 (79%)	133 (22%)	44 (26%)	89 (21%)
<b>During the assessment did you feel your wishes were listened to?</b>	371 (62%)	107 (63%)	264 (62%)	227 (38%)	63 (37%)	161 (38%)
<b>During the assessment did you feel your culture and lifestyle were respected?</b>	427 (73%)	115 (69%)	311 (74%)	159 (27%)	51 (31%)	107 (26%)
<b>Did you meet eligibility criteria for services?</b>	466 (76%)	140 (78%)	325 (75%)	149 (24%)	40 (22%)	108 (25%)

## Eligibility and support needs

As a result of assessment, around three quarters of people met their council's eligibility criteria for services. Table 5 summarises what happened to these people.

**Table 5: Did you get the help you needed?**

	I got all the help I needed	I got some of the help I needed	I did not get the help I needed	I had help for a while, but lost it on review	Total
<b>All respondents</b>	138 (30%)	226 (49%)	75 (16%)	21 (5%)	460 (100%)
<b>People who could benefit from social care</b>	54 (38%)	59 (42%)	19 (14%)	8 (6%)	140 (100%)
<b>Carers</b>	84 (26%)	166 (52%)	56 (18%)	13 (4%)	319 (100%)

Overall only 30% of all respondents who met eligibility criteria for social care reported that they subsequently received all the help they needed, while around half said that they got *some* of the help they required. Despite meeting the eligibility criteria for local social care, around one in six people reported that they did not get the help they needed.

People who failed to meet their council's eligibility criteria (and those who may not have approached their council for help but still felt they needed social care support) were asked what they did. As Table 6 demonstrates, the largest proportion of respondents (35%) indicated that they simply managed without any help at all. While some people might interpret this as evidence that these people did not really need support, the comments made by respondents to the survey in free text (and reported in the main body of this report) offer an alternative view. Many people struggled desperately to cope without help and were at a loss to understand how their needs could go unmet.

Help from other family members was the most likely source of support for people who did not get the support they needed from social care. The comments made by many respondents make it clear that such support was often fragile and liable to break down under pressure. Almost one quarter of respondents reported that they paid privately to try to get the help they needed, while only one in ten had help from a voluntary organisation.

**Table 6: What did you do if you needed help and didn't get it?**

	All respondents	People who could benefit from social care	Carers
<b>Managed without help</b>	145 (35%)	38 (43%)	105 (33%)
<b>Paid privately</b>	94 (23%)	16 (18%)	78 (24%)
<b>Got help from a voluntary organisation</b>	40 (10%)	6 (7%)	34 (11%)
<b>Got help from family members</b>	132 (32%)	28 (32%)	101 (32%)

As we reported in *The state of social care in England 2006-07*, 'rationing by diversion' is commonly used by councils to direct people to alternative sources of help. This 'signposting' can be a way of ensuring that people get adequate support through open access services which are supported through their council, or it can be a relatively passive activity in which people are given leaflets or general information and left to find their own way to other sources of help. Table 7 indicates that almost two thirds of respondents stated that they were *not* given any information about other help that might be available. Only 5% of people reported that they *were* given such information *and* that it led to them getting help.

**Table 7: Given information about other help?**

	Not given information about other organisations that could help	Given information about other organisations but it didn't lead to any help	Given information about other organisations and it did lead to help	Total
<b>All respondents</b>	262 (62%)	135 (32%)	23 (5%)	420 (100%)
<b>People who could benefit from social care</b>	73 (63%)	33 (29%)	9 (8%)	115 (100%)
<b>Carers</b>	186 (61%)	102 (34%)	15 (5%)	303 (100%)

## Help available, and what should be available

The online survey explored all respondents' views about what help they believe is available through social services, and what help *ought* to be available. Tables 8 and 9 summarise the findings. In general terms respondents were *more* likely to indicate that people *should* get certain types of help than they believed is the case in practice. However, there were some clear exceptions to this pattern. In particular, respondents were *less* likely to say that people *should* receive personal care (ie help with washing, bathing, dressing, etc) than they believe to be the case. People who identified themselves as carers displayed the reverse tendency. In the case of residential/nursing care, and day care, people employed in social care (both in councils and other sectors) were also *less* likely than other respondents to indicate that such support *should* be provided. If these responses are considered alongside the pattern of response to other types of support, it appears likely that respondents supporting a reduction in certain types of support did so because they supported an increase in other forms of support (particularly with practical tasks) which could reduce the need for traditional services.

The largest differentials between people's understanding of what support is currently provided and what should be provided for people needing support from social care were evident in respect of help with gardening and odd jobs; counselling and emotional support; and support with participation in community activities.

**Table 8: Help people get and should get: numbers responding**

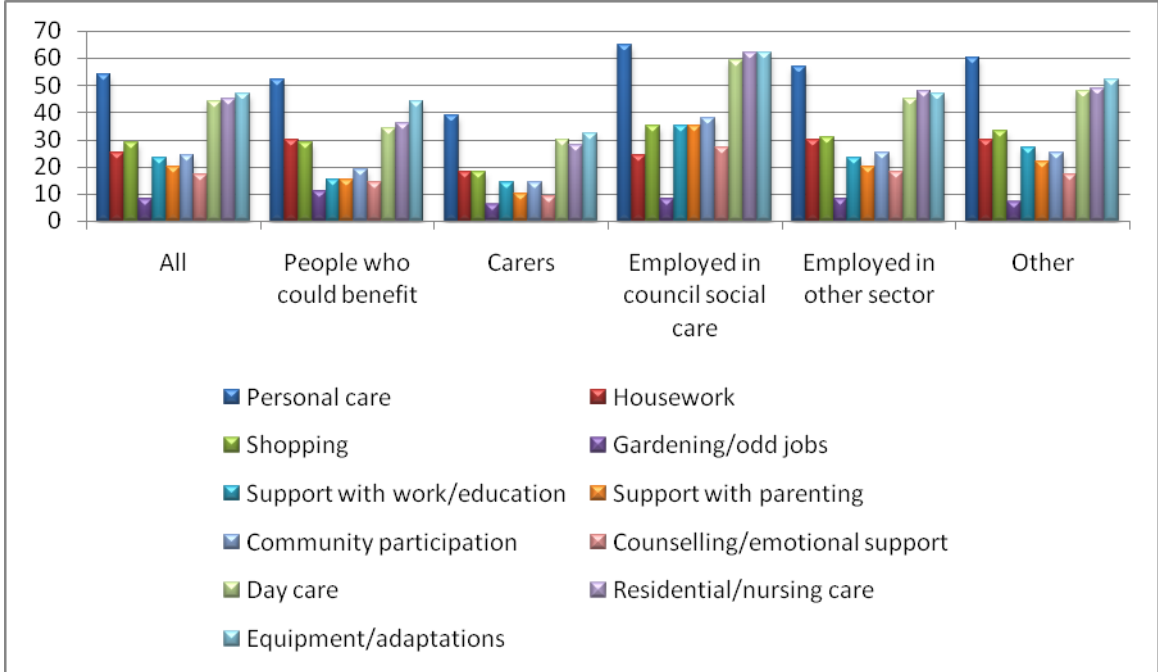
Type of help	All respondents		People who could benefit from services		People who are carers		People employed in council social care		People employed in another sector of social care		Other	
	Help people do get	Help people should get	Help people do get	Help people should get	Help people do get	Help people should get	Help people do get	Help people should get	Help people do get	Help people should get	Help people do get	Help people should get
<b>Personal care</b>	1,567	1,285	147	141	301	366	408	273	471	316	227	175
<b>Help with housework</b>	735	1,408	86	162	137	388	150	269	246	365	113	209
<b>Help with shopping</b>	828	1,409	83	161	143	372	219	291	257	373	125	197
<b>Help with gardening/odd jobs</b>	234	1,238	32	157	50	328	53	202	69	359	29	183
<b>Support with work/education</b>	663	1,263	42	142	109	330	218	264	189	348	101	168
<b>Support with parenting</b>	591	1,257	41	131	80	301	217	278	166	353	82	183
<b>Support with participation in community activities</b>	703	1,437	54	150	110	383	242	294	201	385	93	218
<b>Counselling/emotional support</b>	493	1,406	40	147	73	380	167	283	147	376	65	210
<b>Day care</b>	1,261	1,257	95	125	231	334	370	268	374	336	179	184
<b>Residential/nursing care</b>	1,297	1,226	101	118	221	330	389	259	391	337	184	172
<b>Equipment/adaptations</b>	1,347	1,326	123	148	250	372	388	274	383	335	195	185

**Table 9: Help people get and should get: percentage of each group responding**

Type of help	All respondents %		People who could benefit from services		People who are carers		People employed in council social care		People employed in another sector of social care		Other	
	Help people do get	Help people should get	Help people do get	Help people should get	Help people do get	Help people should get	Help people do get	Help people should get	Help people do get	Help people should get	Help people do get	Help people should get
<b>Personal care</b>	54	45	52	50	39	47	65	43	57	39	60	47
<b>Help with housework</b>	25	49	30	57	18	50	24	43	30	45	30	56
<b>Help with shopping</b>	29	49	29	57	18	48	35	46	31	46	33	52
<b>Help with gardening/odd jobs</b>	8	43	11	56	6	42	8	32	8	44	7	49
<b>Support with work/education</b>	23	44	15	50	14	43	35	42	23	42	27	45
<b>Support with parenting</b>	20	44	15	46	10	39	35	44	20	43	22	49
<b>Support with participation in community activities</b>	24	50	19	53	14	49	38	47	25	47	25	58
<b>Counselling/emotional support</b>	17	49	14	52	9	49	27	45	18	46	17	56
<b>Day care</b>	44	40	34	44	30	43	59	43	45	41	48	49
<b>Residential/ nursing care</b>	45	43	36	42	28	42	62	41	48	41	49	46
<b>Equipment/adaptations</b>	47	46	44	52	32	48	62	44	47	41	52	49

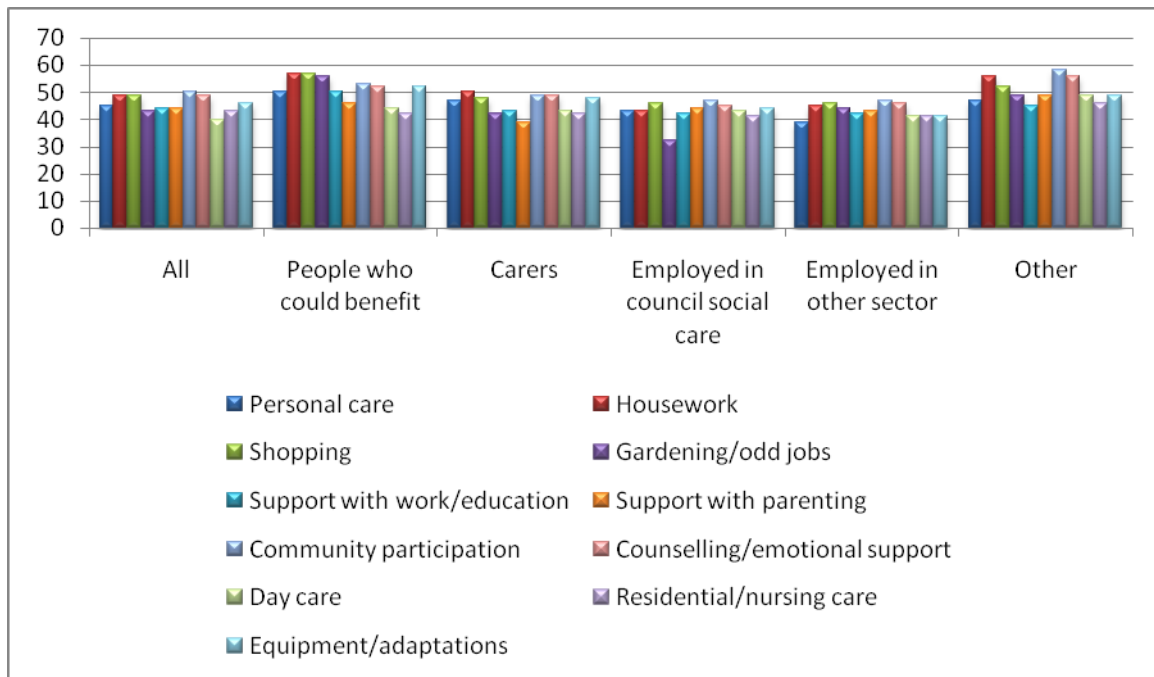
As Figures 2a and 2b also demonstrate that, while there was considerable variation between respondents in their understandings of what support is currently available, when asked about what support *should* be available, there was a clustering of response such that the differences between different types of support were less marked. However, differences *were* still apparent between different types of respondent. People who were using services, or were potential users (ie people who could benefit from services), and people who were carers, were *more* likely to support help with practical tasks and with areas of support often described as 'low level'.

**Figure 2a: Help people do get**





**Figure 2b: Help people should get**



## The need for change

Whether there is a need to fundamentally change the system of eligibility for social care was another issue explored with survey respondents.

As Table 10 describes, a small minority of respondents across all groups strongly agreed that the present system for determining access to social care is generally satisfactory. Overall, 64% of respondents disagreed or strongly disagreed with this statement, and people who were carers were even more likely to disagree (71%).

**Table 10: Is the present system generally satisfactory?**

<b>System is generally satisfactory</b>	<b>Strongly Agree %</b>	<b>Agree %</b>	<b>Neutral %</b>	<b>Disagree %</b>	<b>Strongly disagree %</b>
<b>Someone who could benefit</b>	5	16	16	26	37
<b>Carers</b>	5	8	15	35	36
<b>Person employed in social care</b>	3	25	20	43	9
<b>Person employed in another sector</b>	2	12	22	43	21
<b>Other</b>	3	10	17	43	27
<b>All</b>	4	14	18	39	25

If the system needs to change, on what basis should that happen? Tables 11 to 13 record respondents' views on three further key questions about prioritising access to social care. At least 50% of all groups of respondents *strongly agreed* with the statement that there has to be some way of deciding who can have help from social services. Among people employed in council social services this rose to 67%. Considering those respondents who agreed alongside those in strong agreement with the statement reflects considerable consensus, with the proportion ranging from 89% among people who could benefit from services and among carers to 96% of people employed in council social services.

Despite the strong agreement that there has to be some way of prioritising, or rationing, access to social care, Table 12 reveals that many respondents simultaneously agreed that social care should be provided to everyone needing support. Three quarters of people who could benefit from social care, and almost two thirds of carers, strongly agreed with this statement. People employed in council social services were the least likely to agree, with only 36% strongly supporting the statement. However, when counting both those who agreed or strongly agreed, almost three quarters of people working in council social services supported the principle that everyone needing support from social care should be able to access it, and this was true of at least 90% of all other respondents. The picture painted in Tables 11 and 12 conveys the essential dilemma confronting social care eligibility – how to ensure fairness for people while also exercising some control over demands.

**Table 11: Deciding who has access to social care**

<b>Has to be some way of deciding who can have help from social services</b>	<b>Strongly Agree %</b>	<b>Agree %</b>	<b>Neutral %</b>	<b>Disagree %</b>	<b>Strongly disagree %</b>
<b>Someone who could benefit</b>	50	39	5	2	3
<b>Carers</b>	53	36	6	3	2
<b>Person employed in social care</b>	67	29	2	2	0.5
<b>Person employed in another sector</b>	58	37	4	0.6	0.4
<b>Other</b>	54	38	4	3	1
<b>All</b>	57	35	4	2	1

**Table 12: Social services should be provided for everyone who needs support**

<b>Social services should be available to everyone who needs support</b>	<b>Strongly Agree %</b>	<b>Agree %</b>	<b>Neutral %</b>	<b>Disagree %</b>	<b>Strongly disagree %</b>
<b>Someone who could benefit</b>	75	18	5	1	0
<b>Carers</b>	64	29	4	2	1
<b>Person employed in social care</b>	36	38	11	14	1
<b>Person employed in another sector</b>	62	28	6	3	1
<b>Other</b>	61	31	5	2	1
<b>All</b>	58	30	6	5	1

One way of containing demand on formal services that is often argued is the principle that people should do more for themselves or should get more help from their families. The survey also asked respondents for their views on such a statement, and the responses are summarised in Table 13.

**Table 13: People should do more for themselves and their families**

<b>People should do more for themselves or get more help from their family</b>	<b>Strongly Agree %</b>	<b>Agree %</b>	<b>Neutral %</b>	<b>Disagree %</b>	<b>Strongly disagree %</b>
<b>Someone who could benefit</b>	5	12	26	28	29
<b>Carers</b>	2	9	32	33	24
<b>Person employed in social care</b>	6	25	43	20	6
<b>Person employed in another sector</b>	3	13	35	37	12
<b>Other</b>	5	16	40	25	14
<b>All</b>	4	15	36	29	16

There was little strong support for the view that people do not do enough for themselves or for their family members. However, almost one in five of all respondents agreed with the statement to some extent. Not surprisingly there was less support for this position among both people who could benefit from social care services (17%) and carers (11%). The highest support came once again from people working in council social services, where 31% agreed to some degree with the statement.

## Conclusions

This appendix has presented the key numerical data captured through the online survey. Extensive qualitative data were also recorded in thousands of free-text comments. The overall picture to emerge from the survey confirms the findings in *The state of social care in England 2006-07* which highlighted the problems for many people who fall outside council eligibility criteria for social care, but who nonetheless have needs for support.

Almost one in five people identifying themselves as carers, and around one in eight people who could benefit from social care, reported that they had failed to have an assessment of their needs when they had asked for help from council social services. One third of these people understood this was because they did not meet financial criteria for help. Of those people who *did* have an assessment, more than three quarters went on to receive some help, although this rarely met all their needs for support.

People who still needed support that they were not getting from council social services were most likely to manage with no help at all, or to get help from family

members or through private arrangements. The majority of people (more than 60%) reported that they were not given information about other organisations that might be able to help them. Where such information was provided it was rare for this to lead to any help being provided (true for only 5% of respondents).

The types of support that people needing help from social care and carers were most likely to see as priorities for support were help with practical tasks and what is often termed 'low-level support'. People employed in council social services were considerably less likely to prioritise these types of support although they *did* generally support an increase in these areas compared to current practice.

Most respondents indicated that the present system needs to change, but the direction of such change was not clear. The reality of the need to ration social care resources was widely acknowledged, but at the same time there was strong support for the principle that anyone in need of support should get it. There was relatively little support for the view that people and their families should be more independent and do more for themselves. Given the findings about the centrality of family support for people who lack other help this is hardly surprising.

The central dilemma of how to meet people's needs while also exercising control over the use of limited public funds is at the heart of any discussion about eligibility criteria for social care. The main body of this report addresses this issue in greater depth, drawing on both written evidence and the online survey findings.

# Appendix 2: CSCI Review of Eligibility Criteria Survey

---

Thank you for taking the time to complete our survey into eligibility criteria that councils use to decide whether or not a person receives help from the council with social care services.

The survey is open to anyone with an interest in social care. We are especially interested to hear from people, and their relatives and carers, who have personal experience of using social care services because they need help or support in day to day living.

## Alternative formats

---

The survey is also available in alternative formats.

Please contact our Customer Services Team, [enquiries@csci.gsi.gov.uk](mailto:enquiries@csci.gsi.gov.uk), if you require a copy in an alternative format.

## Complete the survey

The survey should not take you more than 15-20 minutes to complete.

## About You

Before we ask about your experience of social care it would help us to know a bit about you.

### 1. Are you:\*

- A. Someone who could benefit from social care support
- B. a carer or relative of someone who could benefit from social care support
- C. someone employed in council social services
- D. someone employed in another sector of social care
- E. Other, please specify

\* If A or B go to Question 2

\* If C, D or E go to Question 15

## Your needs

---

People need support from social care services for different reasons.

### **2. Please tell us about the main care needs you have (or the person you support has).**

Please tick all that apply.

- Help with personal care (washing, dressing, bathing, etc)
- Help with housework
- Help with shopping
- Help with gardening or 'odd jobs'
- Support with work or education
- Support with parenting roles
- Support with taking part in community activities
- Companionship
- Counselling or emotional support
- Equipment & adaptations to help you remain independent
- Other, please specify

## Getting help

---

### **3. Have you asked for help from social services?\***

Yes

No

\* If yes go to Question 4

\* If no go to Question 6

### **4. When you asked for help from social services, did you have an assessment of your social care needs?\***

Yes

No

\* If yes go to Question 8

\* If no go to Question 5

### **5. Was the reason why you didn't get an assessment of your social care needs because the council advised you that you did not meet its financial criteria?**

Yes

No

Now go to Question 6



## Alternative arrangements

---

**6. If you did not qualify for help from social services (or if you did not apply for help from social services) but you still needed support, what did you do?**

- I managed without help
- I made private arrangements and paid for it myself
- I got help from a local voluntary organisation
- I got help from my family
- I got other help, please specify

**7. Please briefly describe the effect on your life of not having the help that you need?**

Now go to Question 15

## The assessment

---

Please say whether, in your experience of the assessment of your needs, the following three statements were true or false.

**8. During the assessment I felt able to express my views.**

True

False

**9. During the assessment I felt my wishes were listened to.**

True

False

**10. During the assessment I felt my culture and lifestyle were respected.**

True

False

**11. After the assessment did you meet the eligibility criteria for services?\***

Yes

No

\* If yes go to Question 12

\* If no go to Question 13

**12. Having met the eligibility criteria for services, were you given all the help you needed?\***

- A. Yes, I got all the help I needed.
- B. Partly, I got some of the help I needed.
- C. No, the help I got did not meet my needs.
- D. I had help for a time, but lost this when my situation was reviewed.

\* If A, go to Question 15

\* If B, go to Question 13

\* If C, go to Question 13

\* If D, go to Question 13

## Level of support

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**13. Please tell us what was the help you needed that you didn't get:**

## Information and advice

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**14. Were you given information and advice about other organisations to contact who might be able to help you even if social services could not?**

- No, I was not given information and advice about other organisations to contact.
- Yes, I was given information but this did not lead to getting appropriate help.
- Yes, I was given information and it did lead to getting appropriate help.

Now go to Question 15

## Help from social services

---

**15. In your experience what help do people get, and what help should people get, from social services? Please tick all that apply.**

	What help people do get	What help people should get
Help with personal care (washing, dressing, bathing etc)	<input type="checkbox"/>	<input type="checkbox"/>
Help with housework	<input type="checkbox"/>	<input type="checkbox"/>
Help with shopping	<input type="checkbox"/>	<input type="checkbox"/>
Help with gardening and odd jobs	<input type="checkbox"/>	<input type="checkbox"/>
Support with work or education	<input type="checkbox"/>	<input type="checkbox"/>
Support with parenting roles	<input type="checkbox"/>	<input type="checkbox"/>
Support with taking part in community activities	<input type="checkbox"/>	<input type="checkbox"/>
Counselling or emotional support	<input type="checkbox"/>	<input type="checkbox"/>
Access to day care	<input type="checkbox"/>	<input type="checkbox"/>
Access to residential/nursing home care	<input type="checkbox"/>	<input type="checkbox"/>
Equipment and adaptations to help people stay independent	<input type="checkbox"/>	<input type="checkbox"/>

## Does the system need to change?

---

### 16. From your own experience please indicate the extent to which you agree or disagree with the following statements:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
There has to be some way of deciding who can have help from social services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The present system is generally satisfactory.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social services should be available to everyone who needs support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People should do more for themselves or get more help from their family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Alternatives

---

**17. Do you have any suggestions for how the current eligibility criteria for social care should be changed?**

**18. Please let us know of any other comments you wish to make:**

## More about you

---

Please could you tell us more about yourself. We will keep this information confidential and only use it for this survey.

### 19. Are you:

Male

Female

### 20. How old are you?

16-24

25-24

45-64

65-79

80+

### 21. What best describes your household arrangements?

Live alone

Live with spouse or partner

Live with other relatives

Live in a social care setting

Other, please specify

**22. What is your sexual orientation?**

- Lesbian/gay woman
- Gay man
- Bisexual
- Heterosexual

**23. What is your ethnic origin?**

- White British
- Irish
- Any other white background
- Mixed: White and Black Caribbean
- Mixed: White and Black African
- Mixed: White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian background
- Black Caribbean
- Black African
- Any other Black background
- Chinese
- Other, please specify



## Survey completed

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Thank you for taking the time to complete our survey.

Your views will be helpful to us in reviewing the impact of eligibility criteria for social care and the approaches that local councils take in determining who is able to get access to social care support.

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This paper was published in People who pay for care: quantitative and qualitative analysis of self-funders in the social care market. The full report is available online at:

<http://www.thinklocalactpersonal/Latest/Resource/?cid=8665>



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# Journeys without maps:

The decisions and destinations of  
people who self fund – a  
qualitative study from  
Melanie Henwood Associates

December 2010

## Acknowledgements

Thanks are due to many people for their help with this study. I am grateful to the Putting People First Consortium for commissioning the work, and particularly to Jeff Jerome and David Walden for their support and helpful comments.

I am indebted to the organisations that agreed to participate in the research, and even if I don't identify them here because of the promise of confidentiality, they know who they are, and I am very appreciative of the time and assistance they provided. I am especially grateful to all the people who had embarked on journeys as self-funders, and their family members, who agreed to share their stories with me and helped me to understand their lives. I hope that this report will inform developments around information, advice and advocacy for people who self-fund and will contribute to improvements.

Finally, I am extremely grateful to Linda Christie who transcribed many hours of interviews with great efficiency and unfailing good humour.

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# Journeys Without Maps:

## The decisions and destinations of people who self-fund

### **Executive Summary**

- 1 A qualitative investigation commissioned by the Putting People First Consortium has been undertaken by Melanie Henwood to retrospectively track the journeys undertaken by people who self-fund care and support, and to explore the decisions they made and the consequences of those decisions in terms of destinations. A central part of the study was to understand the nature and sources of advice and information that people had access to in making their decisions.
- 2 The study had two stages, the first involving face to face interviews with key providers of social care services and support to explore perceptions and understanding of the self-funder market, and also to facilitate access to people who are self-funding for the retrospective tracking. The second stage involved interviews with 30 people who were either using services they were paying for themselves, or were the carers (family members) of people in this situation. Most of the interviews were face to face, but some of those with carers were conducted by telephone.
- 3 The three stages of interviewing provided an opportunity to triangulate information, and to explore recurrent themes and perceptions. A number of key messages can be highlighted:

### **The Provider perspective**

- 4 Providers are of various degrees of sophistication in their understanding of and engagement with the self-funder market; for some this is core business, while for others it is still marginal. Some are deliberately developing a business model to reduce reliance on local authority work and develop new relationships with individual purchasers. Others start from a different place of having little in the way of private business.
- 5 While self-funders often subsidise the residential care market, the opposite can be the case in domiciliary support and can mean that private requests are turned down because of the absence of sufficient business volume, or conversely can mean that private payers benefit from a large volume of work being conducted in an area which allows accommodation of individual requests.
- 6 Providers are disadvantaged by a lack of good intelligence on the self-funder population, compared to publicly funded clients. However, this picture is changing and improving with new quantitative data becoming available both about people privately purchasing services, and the workforce providing these.
- 7 The self-funder population is diverse and there are points on a continuum between the 'pure' self-funder who choose to purchase services; those who become self-funding by default (through the impact of means-testing and social care eligibility criteria); and people who are self-funders through using personal budgets/Direct Payments. Some providers distinguish between these different types of self-funder and may be primarily interested in the pure self-funder because of their greater average purchasing power.
- 8 There is a spectrum of spending by self-funders from people who are just buying domestic or cleaning services, to high net worth individuals who effectively buy live-in staff. For some providers it is a good market strategy to accept people seeking more modest help because this can build over time to more intensive support and personal care.

- 9 Providers recognise that the 'typical' self-funder is someone who has experienced a crisis necessitating action, rather than someone who has made planned and positive choices. In such situations people are rarely well-informed about either what they need or what is available to support them.
- 10 Initial approaches to providers are often made by adult children or other relatives, and they often don't know what it is they are looking for, beyond a general idea that they need some help.
- 11 People find their way by various routes. Some are sign-posted to providers by local councils but the approved provider list is a matter of contention among providers because it excludes some providers, and people seeking help may wrongly believe that the list may offer some guarantee of quality, or that only those businesses on the list should be trusted.
- 12 People need not only information about how to find the right support and services, but also access to independent advice, advocacy and brokerage. This is something that is typically absent for self-funders, even if they manage to secure assessment of their needs. Many people have a good understanding of their own needs or the difficulties they are confronting, but much less idea of what solutions are available and how they might gain access to them. There are some independent care advisors emerging, but this is a fledgling market and there is currently no accreditation for advisors, and some who present themselves as 'independent' are also acting as providers of direct services and may therefore have vested interests.
- 13 While recognising the importance of self-funders to their business, providers are also concerned that the journeys of self-funders are too often guided by happenstance rather than by clear information and advice.

### **Decisions and Destinations: the self-funder experience**

- 14 Interviews with self-funders invited people to tell their personal stories about their journey – how had they reached their particular destination and what were the critical points along the way? In almost every situation it was clear that people had not made their choices in a planned and deliberate way. People generally do not think about their encroaching old age or believe they will need care or support until something happens.
- 15 Being widowed or experiencing a sudden change in health were the key factors that were likely to lead to a change in living arrangements or the need for support. This was particularly the case when people were geographically distant from close family members and concerned that they were becoming too much trouble.
- 16 Having decided that something needed to change, some people are able to be systematic in looking for the right solution for their needs (putting their name on the waiting list of sheltered housing or care homes for example), and were wary of making the wrong decision in haste. In such situations people often chose a level of support that was greater than their current needs (such as in choosing residential care), but did so either because they were not aware of alternatives or because they wanted residential provision to provide them with companionship and security.
- 17 Many people described a range of coping strategies whereby they 'managed' before it became apparent that something more was needed. Typically this coping involved a combination of family, friends and other informal support – these arrangements could be very successful, but were also very fragile and could break down.
- 18 For the majority of people, the transition to using support or moving into a care environment is not something that happens gradually or as the result of considered planning. Most of those interviewed described a sudden and at times catastrophic change that had largely taken decision making out of their hands.



- 19 Major life changing decisions were often made on the basis of little information; people had little idea about where to seek such information or advice.
- 20 Approaching social services for help was something that was not considered by most, or it was seen as something negative to be avoided or treated as a 'last resort'. Those who *did* contact their council typically described being given 'a list' of care homes and nothing more. A minority of people had found their way to other sources of information (such as through Counsel and Care) and reported a more positive experience of advice and information that addressed their particular circumstances. In meeting their responsibilities to provide universal information and advice councils should recognise that people need to be able to access information and advice through a variety of accessible and non-stigmatising routes which offer different models and styles to match people's preferences (such as electronic information; telephone support, or face to face). On the basis of people's reported experiences it is doubtful that the local authority is the organisation best placed to provide such flexible and independent advice when they are simultaneously acting as gatekeepers to limit publicly funded support.
- 21 People with close family were often able to ask family members to help in identifying a suitable care home or to undertake visits on their behalf. For those without family members the process was more difficult and worrying.
- 22 People typically described a 'check list' of features they wanted from support, and anywhere that ticked most of the boxes would be acceptable. Once the decision to move into a care home had been made people generally described it positively or with a degree of resignation – there was no alternative and they had to make the best of it.
- 23 People were in a variety of financial situations and for many there were significant worries about the sustainability of care arrangements and the depletion of savings. None of the people who were self-funding had received independent financial advice on paying for care; some had a vague knowledge about the rules around financial contributions for residential care, but typically this was something that was left to others to handle (with many having Power of Attorney arrangements in place with relatives). For some people there was a profound sense of 'powerlessness' and lack of control over their own financial resources, coupled with some real fear over what would become of them if their savings ran dry.

### Carers' Journeys

- 24 Interviews took place with a number of carers and family members – primarily these were adult children of older people needing care and support, but some were spouse carers. They were generally approached to provide insight in situations where a person who was self-funding was unable to participate in interviews, but carers also had their own stories to tell and their own journeys in trying to navigate the self-funding world.
- 25 Carers largely reinforced the themes already identified, but they also revealed a level of concern and anxiety that was rarely articulated by people who were self-funding, perhaps because the implications of situations were more evident to family members than to the person themselves.
- 26 There was a strong reluctance to approach social services – typically a relative was averse to doing so or did not see the relevance to their own situation. Carers often identified the considerable stigma that still attaches to the idea of social services involvement for many older people and were keen to avoid such a situation if at all possible. Those that *did* approach social services reported largely negative experiences in which the *first* and often *only* question they were asked was about their relative's financial status.
- 27 The experience of sign-posting was rarely positive; with people describing being 'passed from pillar to post' and endlessly encountering people whose sole job appeared to be to pass them onto someone else. Only one person had a positive experience of being signposted to a care navigator who had helped them to find appropriate support.

- 28 The attempt to identify suitable care and support on behalf of a relative was often difficult with carers having little idea of how to go about getting appropriate advice or information. 'Getting a list' of care homes from social services was viewed with derision for its lack of value in indicating which care homes were better or most appropriate to the needs of a loved one.
- 29 Some younger carers who were computer literate had accessed the regulator's reports on care homes and tried to interpret the meaning of ratings in practice and to use this in informing their choice of home. The changes to the quality rating system have created some uncertainty while a new model is developed, and it will be vital that what emerges as the alternative is easily accessible and meaningful. Those carers who did not have access to electronic material relied frequently on visits to potential care homes and making judgements based on impressions and appearance.
- 30 Crisis situations were often exacerbated by NHS pressures to empty hospital beds, putting excessive demands on relatives to find a care home within a matter of days (and with no opportunity to explore other options).
- 31 Financial matters were a dominant concern for relatives and carers who were generally better informed about how financial assessment operated and when and how the local council might contribute to the costs of care. People's information on such matters was typically gathered from the national press and from consumer programmes on television and radio. Independent financial advice on care matters was rarely mentioned and was not something people were generally aware of.
- 32 Fear of what might happen when money runs out was also a major concern for carers, particularly for people whose relative was living in a care home which was more costly than would normally be acceptable within local authority contracts. Trying to calculate how long savings might last was a recurrent concern, with some carers thinking they may need to persuade relatives to 'trade down' to smaller rooms to keep things going, and others who had access to their own resources being prepared to make up any necessary shortfall.
- 33 Some carers were continuing to support very dependent relatives at home and wished to continue to do so as long as possible, while recognising that the arrangement was precarious and very demanding, and while the situation was just about manageable in the short term, it was not clear how long this could be sustained. Indeed, it was apparent that a crisis or sudden deterioration in health would seriously compromise carers' capacity and could lead to the collapse of arrangements.
- 34 The experience of supporting relatives and trying to help them find their way as self-funders had opened the eyes of many carers to the reality they faced and made them think more about their own future as they grew older. Many reflected on the unfairness of the current system which was seen to provide little or no help to people with modest savings.

## Conclusions

- 35 The experiences of people who are self-funding, and of their family members, are complex and varied. For some people, having adequate financial resources had enabled them to make considered and deliberate choices about the type of support they needed and wanted. For others, decisions had been accelerated or necessitated by changing circumstances and they had little control over subsequent developments. In making vital (and often life changing) decisions, people are most likely to consult family and friends. Almost nobody identified social services as a source of information or advice, and people who *did* have contact with their council often had a negative experience that focused solely on their financial status rather than their needs for care and support. Informal information, word of mouth, and reputation were the most significant factors influencing people's decision making and destinations. This picture is depressingly similar to the findings in earlier research and indicates the considerable challenges that have still to be met by many local authorities in developing their universal offer of information and advice for everyone in need of care and support.

- 36 Almost nobody thinks very much in advance about what they might do if they need care and support. People typically cope until a tipping point is reached, and at that stage decisions often have to be made quickly and with little information to inform major decision making.
- 37 It is clear that having sufficient resources to be a self-funder does not automatically give people greater control over their situation, and meaningful choices are often lacking. While people have few expectations of their local council to provide them with any help, they also have little idea of where else to go for guidance in navigating the complex world of care and support. There was a profound sense throughout the project of people undertaking major life journeys without the benefit of maps to guide them, and with no clear sense of their destination. In many ways people who were self-funding were considerably disadvantaged, relative to people qualifying for publicly funded support, by not having access to independent assessment of their needs (as opposed to their means), or to clear information about their options, and care advocacy to help them in achieving their preferences. For people who were without a close family member to help them on their journey, the options were fewer still and the path a lonely and bewildering place to navigate.

# Supporting People Who Fund their Own Care

## 1 Introduction

- 1.1 In 2009 a two part study was commissioned by ADASS, SCIE and JRF examining information, advice and advocacy for people who fund their own care. The study led to two reports: a literature review across a range of policy, research and development<sup>i</sup>, and a preliminary exploration of national organisations involved in providing information and advice around social care support.<sup>ii</sup> The two complementary pieces of work produced consistent conclusions, and highlighted four key themes:
- The issue is complex and multi-faceted and even definitions are unclear.
  - Performance and provision are highly variable across the country.
  - The position of self-funders is of increasing significance, but exhortation alone is likely to be insufficient to ensure the needs of this group are addressed.
  - The evidence base on self-funders is weak.
- 1.2 Following discussion of the findings with key stakeholders it was agreed that further investigation was required. A retrospective qualitative study was developed to explore the experiences and stories of people who are self-funding. The core purpose of the study was to examine:
- How and why did people make the choices they did?
  - What information and advice was available to help them to do so?
  - Would they have made different choices with different information or advice?
- 1.3 The study had two stages. The first part involved interviews with key providers of social care services and support in order to explore perceptions and understandings of the self-funder market, and also to provide access to a sample of people who are self-funding for the retrospective tracking stage of the study. The second stage identified around 30 people who were self-funding and living in a variety of situations, from those still managing largely independently, to people receiving home care or other support, people living in assisted living and sheltered housing, and people living in residential and nursing homes. Most interviews were undertaken face to face, but a number were conducted on the telephone (particularly with family members) where the practicalities of visiting people in a number of different parts of the country were not feasible. Visits were undertaken to a number of locations including London; Surrey; Hampshire; Northamptonshire; Nottinghamshire and Oxfordshire. Interviews were digitally recorded and subsequently transcribed. All interviews were conducted on the basis of confidentiality and we do not identify any of the individual respondents in this report. All fieldwork took place between July and October 2010.

### Policy Context

- 1.4 The significance of support for people who fund their own care needs to be understood within the wider context of the transformation agenda in social care as set out in *Putting People First* in 2007<sup>iii</sup>. The first phase of transformation covers the period from April 2009 (when the Adult Social Care Reform Grant was first allocated to councils) to April 2011. In 2009 ADASS, LGA and the Department Of Health worked in partnership to develop a set of milestones against which progress with delivery might be judged. Five key priorities were agreed for phase one:
- Transformation developed in partnership with existing service users (public and private), their carers and other citizens.

- A process is in place to ensure that all those eligible for council funded adult social care receive a personal budget via a suitable assessment process.
  - Partners are investing in cost-effective preventative interventions which reduce the demand for social care and health services.
  - Citizens have access to information and advice regarding how to identify and access options available in their communities to meet their care and support needs.
  - Service users experience a broadening of choice and improvement in quality of care and support service supply that can meet the aspirations of all local people (whether council or self-funded) wanting to procure social care services.
- 1.5 Against each of these priorities milestones were identified for April 2010, October 2010 and April 2011. By April 2010 all councils should have had “a strategy in place to create universal information and advice services”, and by October 2010 this should have been translated into having “put in place arrangements for universal access to information and advice.” This ‘universal access’ should be available to *all* citizens whether they are using publicly-funded services or organising their own support through personal budgets or self-funding. A working paper for the Transforming Adult Social Care Programme Board has identified ‘a core spine’ in terms of the content of national information in relation to adult social care (across the dimensions of information, advice and advocacy).<sup>iv</sup>
- 1.6 How are councils progressing with this agenda? A review carried out by Opportunity Links in June 2010 focused specifically on progress with implementing information and advice services. It identified “considerable variation” across the country:
- 12% of local authorities stated they are fully delivering information and advice services.
  - 40% do not have an information strategy in place (the milestone for April 2010), and 16% were not yet at the planning stage.
  - Two thirds of local authorities have identified a delivery model.
  - More than half (56%) had not yet started delivering their services or related activities such as training, marketing and evaluation.<sup>v</sup>
- 1.7 These findings paint a similar picture to that previously revealed by self-assessment reporting.<sup>vi</sup> Both rounds of self-reporting (October-December 2009, and January-March 2010) indicated that fewer than 60% of councils reported they had a strategy for universal access to information, support and guidance for adult social care. Between the two rounds of self-reporting the proportion of councils indicating that they *were* including all citizens (i.e. including self-funders) in their strategy rose from 55% to 74% , but over the same period there was a fall in the numbers helping voluntary organisations and other partners to provide universal information (a drop from 89% to 86%). Clearly, there is still considerable work to be completed in developing strategies and putting arrangements in place if subsequent milestones are to be attained.
- 1.8 It is possible, perhaps even likely, that during the early months of 2010 some councils adopted a ‘wait and see’ approach in the lead-up to the general election. The uncertainty about the outcome of the election and whether that might signal a change of policy direction could have caused some degree of planning blight around the further implementation of the transformation agenda. It is helpful, therefore, that the coalition Conservative-Lib-Dem Government moved relatively quickly to emphasise their continued commitment. In July 2010 it was announced in a written parliamentary statement that a Commission was to be established on the funding of care and support, with a white paper to follow in 2011. Moreover, it was stated that the recommendations of the Commission “must also be compatible with the Government’s vision for care and support – supporting personalisation, prevention and partnership, and offering protection for people.”<sup>vii</sup> This re-statement of core policy around adult social care underlined the continued importance of councils achieving the milestones for the transformation agenda.

- 1.9 In November 2010 the Department of Health published ‘a vision’ document for consultation, setting out “A new agenda for adult social care in England.”<sup>viii</sup> In many ways this document restated the importance of taking forward the reforms that have already begun, emphasising the rollout of personal budgets, and devolved decision-making within a framework of seven principles (prevention; personalisation; partnership; plurality; protection; productivity, and people). The vision also reiterated the importance of information and advice as “a universal service” for everyone – whether using a personal budget or their own funds, and recognised “that people funding their own care have a particular need for information and guidance to help plan how their care needs are met.”<sup>ix</sup>
- 1.10 Alongside the vision paper, the Department of Health also issued a further consultation on proposals for an outcomes framework in adult social care,<sup>x</sup> and “a new approach in which councils are in the lead, the role of the regulator is refocused, and Government Departments are enablers.” The new ‘permissive collective’ approach to outcomes that is proposed is concerned with “describing the ends, not quantifying the means”, and is to be achieved by the removal of national performance management, targets and annual assessment of councils by the regulator (the Care Quality Commission). The proposed approach centres around a single set of agreed data requirements (the Quality and Outcomes Data Set), and outcome-focused measures to allow local interpretation of data and achievements. The focus of the consultation is on four domains for social care outcomes:
- Promoting personalisation and enhancing quality of life for people with care and support needs.
  - Preventing deterioration, delaying dependency and supporting recovery.
  - Ensuring a positive experience of care and support.
  - Protecting from avoidable harm and caring in a safe environment.
- 1.11 It is not yet clear how the wider roles and responsibilities of councils might fit within this new framework. It is possible that universal services and support for people who are self-funding *could* be accommodated within this model, but there is a risk that it will focus too narrowly on ‘service users’ – i.e. people who meet council eligibility criteria, rather than *all* people who use care and support.
- 1.12 Around the same time that the Department of Health papers were issued, a new sector-wide partnership agreement was also published (*Think Local, Act Personal*) which also addressed the next steps in transforming adult social care. The agreement built on learning from implementing *Putting People First* over the past three years and focused on areas where further action is required. In particular, the agreement underlined the connections between preventative, community-based approaches and personalised care and support. The local leadership roles of councils was emphasised in supporting the development of local resources and opportunities “regardless of how they are paid for or who provides them.” Ensuring that all people have the information and advice they need is part of this role and should include help for people “to make the best use of their own resources to support their independence and reduce their need for long term care.”<sup>xi</sup>
- 1.13 It is against this emerging policy background that the current study was undertaken. We begin by exploring the perceptions and understanding of the self-funding market among some of the key providers of services and support.

## 2 The provider perspective

### Understanding the market

- 2.1 The self-funding market in social care and support is of growing importance. This is driven by two inter-related trends. First, more people are finding themselves as actual or potential self-funders both because they may hold assets above the means-testing threshold, but also because of rising eligibility levels which exclude people from help organised by social services. Second, many providers are actively seeking to develop the self-funding market as an alternative to reliance on council contracts at a time of increasing economic austerity, as these respondents commented:

*“(...) a number of our members now, given the difficulties with local authorities and the tightness of money, would actually prefer to work with and for individuals rather than going through the local authorities.”*

*“...their self-funder market is the thing that makes their business sustainable, because they're under-funded by the local authority commissioned work.”*

- 2.2 At present providers who can be seen as 'more able' in their level of sophistication are deliberately developing a new business model that reduces their reliance on local authority work (or indeed reliance on block contracts with a single local council). Some providers do not yet fully understand or welcome the way the market is developing and the importance of establishing new relationships with individual purchasers (whether these are people who are self-funding, or those using personal budgets). Even if most providers were to recognise the wisdom of such a model, not all are able to develop it with equal success. In particular, the need to address marketing and promotion is something to which many have had to give little consideration when their business has been virtually guaranteed by a monopsony commissioner. As this provider described, working with local authority contracts can carry particular frustrations, but it also has obvious benefits:

*“The majority of our work is still local authority contract driven (...) in some ways it is easier to deal with a local authority where you've got blocks of work or frameworks of hours, because you have density of volume coming through.”*

Whereas, when dealing with private payers, none of this is true and a private client may have particular requirements that do not necessarily fit with other provision:

*“and the challenge (...) is that you get the single enquiry private self-funded market.”*

- 2.3 From a provider perspective the situation can be very different between residential services and domiciliary. It is widely recognised that self-funders effectively subsidise publicly funded clients, although this has often been far from transparent (particularly for the people who are self-funding). However, in the domiciliary setting subsidies can work in the opposite direction; the financial viability of a contract will be influenced by volume, as this major provider described :

*“I guess the cross-subsidy element is if you get one contact here for a private client (...) because you've got carers in the vicinity and they're being paid a rate to do all this work, you can quite easily accommodate that need (...). So there's a lot of private pay work that we can't take on because you haven't got the coverage or volume of work because private pay work doesn't come in a kind of block combination.”*

- 2.4 For providers who have a relatively small private client business segment these issues may not be a consideration, but others are likely to see both the opportunities that a private market offers and the costs of *not* pricing this segment differentially, as this person remarked:

*“I think that they will eventually start wising up to the fact that they are being asked to deliver services that are different and, in some instances, more expensive than what the council procures*

to. But, of course, we are starting from the base where many agencies don't have much in the way of private patient business."

- 2.5 However, as yet there is little evidence that providers are pricing their domiciliary services differently for the private and public markets. There is some expectation that this may change in the future, but much depends on the size of the private market and providers' level of understanding of it. It is clear that the self-funder market is very diverse:

*"And how you reach them and how you approach them can be quite different as well, how you market yourself to them (...) Some just have a private need and they come to you from word of mouth or reference, and (...) there's a whole range of different services: it can be companionship; it can be someone who is recovering from a hip operation; it can be somebody who needs shopping, someone to take them to the theatre. So we have a whole spectrum in our business from the high net worth individuals – you know Lord and Lady whatever – who we're caring for down to someone who previously had a package of care from the local authority but is now funding it themselves, and you have a multitude of different services needs."*

- 2.6 In addition to questions around the pricing of services, there are wider issues about general provider awareness and understanding of the self-funder population. Some providers are only too aware that "there is very little hard and fast intelligence", and contrasted this with the data available on publicly-supported clients. However, it was also recognised that this is work that is developing and that information *is* gradually improving (and the minimum data set developed by Skills for Care was identified as one such area). Further work has been undertaken by the Institute of Public Care to estimate the numbers and distribution of self-funders in England (also published in this volume),<sup>xii</sup> and a major quantitative study has been commissioned from the National Centre for Social Research by Skills for Care. The latter piece of work will report in 2011 and will quantify both the size of the privately purchased home care market (whether funded through Direct Payments or self-funded), and the size and nature of the workforce providing it.<sup>xiii</sup> Even if quantitative information about self-funders improves, some respondents emphasised that what is needed is 'the richness of information' to understand the motivations behind the decisions of people who are self-funding. One of the objectives of this piece of work is to provide some illumination of these issues, and these are explored in greater depth in Sections 3 and 4.

## Defining 'self-funders'

- 2.7 As we highlighted in our earlier review of the literature, the definition of self-funders is not entirely straightforward, is in many ways subjective and includes a continuum of arrangements.<sup>xiv</sup> This conclusion was further reinforced by the current research. A respondent described an apparent 'softening of our self-pay market', whereby more people are becoming self-funders as a result of means-testing rather than "by virtue of personal choice." In addition to the 'pure' private payer who is buying care and support services with their own money, there is an increasingly grey area, or points on a continuum, which also encompasses people who are emerging as private payers by means of personal budgets, as this respondent observed:

*"I find it very difficult to distinguish between those two, to be honest (...) I will often say, if I talk about self-funders, I mean people who are either paying for it with their own money or because they have been given money (...) I'm really talking about people who haven't got an intermediary purchasing care on their behalf."*

- 2.8 Another respondent commented that because of the roll-out of personalisation:

*"sooner or later everybody will be in the self-funder market (...)and I think also it starts to get everybody orientated in businesses to understand that their customer is the person who they work for, not the commissioning manager in the local authority."*



- 2.9 Another provider similarly remarked that the experience of working with ‘stand alone self-funders’ provided a model of care that could inform the approach to personalisation:
- “..people are asking for what they want and we’re providing the service to make a difference (...) so we’ve used quite a lot of that thinking to sort of shape our thinking of what personalisation could be for an individual.”*
- 2.10 Such an approach will be increasingly important as personal budgets continue to develop (while recognising as the Audit Commission has cautioned that some councils will need to make significant efforts to achieve the milestones on local targets).<sup>xv</sup> The role of councils as commissioners is also changing, and new contracting methods for people using personal budgets are emerging in place of existing block contracts (including collaborative commissioning between people using personal budgets, and outcomes-based contracts for example).
- 2.11 While there may increasingly be a blurring of boundaries between people who are self-funding and those who are not, and the benefits of having direct purchasing power may be spread more widely, it was also recognised by providers that there remain some significant differences between self-funders and people using personal budgets. A small independent sector provider was particularly forthright in his views and believed that personal budgets would drive increasing fragmentation of the market and that some providers would only want to work with clients who were genuinely self-funding. However, this would not be a realistic position for most providers, and such a perspective was not widespread.
- “So we are going to start to look at personalisation and say well we can only take so many people on because we can’t afford it (...) I can see some businesses saying well, we won’t do personalisation; it’s not a viable business model (...) you will have companies that will say we do not deal with personalisation because you haven’t got the money.”*
- 2.12 Another respondent observed that “self-funders are the original personal budget holders, aren’t they?” Certainly, personal budgets and Direct Payments *should* equip more people with purchasing power, and the emphasis of the transformation agenda is to ensure that there are components of the system that are universal and everyone uses, nonetheless, it is hard not to conclude that there will be an emerging hierarchy of purchasers in social care which could lead to self-funders being paradoxically both the most sought-after clients, but also in many ways the least well-served.

### **The self-funding journey and experience**

- 2.13 Independent care providers, and bodies representing such providers, have relatively little hard market intelligence about people who are self-funding. This is an area in which evidence is often replaced by anecdote. Nonetheless, the anecdotes reveal a considerable degree of consistency. Typically, providers first encounter the self-funder as someone who has experienced a crisis which necessitates decisions being made about what to do next, rather than someone who has actively planned and made positive choices about their care and support, as this respondent observed:
- “So it may have been a critical incident like the loss of a partner but it might not be a need – totally physical need – it might be for company, it might be a fear of being in the house by yourself and those sorts of things. So I think there’s a real need for richer type data around motivations and also whether motivations help you in terms of your decision making.”*
- 2.14 The fact that people often seek help for themselves or a family member at a time of crisis (“*they’re largely making a fairly urgent or emergency purchase*”) also means that they may not know what it is they are looking for, or what might be available. This reflects the generally low awareness and understanding of the nature of social care across the population, and as this respondent described, “*people tend not to come with a shopping list*”, rather “*I need somebody to come and tell me what’s possible, because I have no idea.*”
- 2.15 This was a picture that was widely recognised and sketched out time and time again by

interviewees, as these comments highlight:

*"I think often people are working in a crisis situation, so a critical incident, a fall, a stroke, something that's produced 'I can't live in this house any more'. And then, of course, what people do is they then make decisions about care but they're not necessarily informed decisions, and they certainly aren't decisions that are taken with a view to things like re-ablement."*

*"It's a wide range of crises, like somebody coming out of hospital or somebody having a fall at home and now wants to go into residential care, or a family member moving away who was providing care."*

- 2.16 A provider of private residential care described how 60-70 per cent of all their admissions come via acute hospitals. In such circumstances there is little or no consideration of options; rather, a 'tipping point' is reached by an event that leads to hospitalisation and from there to permanent residential care.

*"The single thing that we know above all else is that they come to us primarily as a consequence of a health crisis rather than a plan."*

- 2.17 In such circumstances people may make decisions in haste and without good knowledge or understanding of the options. As this person remarked, the issue is not just about what services are available, but also about properly understanding the needs of the person for support:

*"I think often people are working in a crisis situation (...) and then, of course, what people do is they then make decisions about care but they're not necessarily informed decisions, and they certainly aren't decisions that are taken with a view to things like reablement (...) so there's a whole raft of information needs."*

- 2.18 The crisis admission picture contrasts with the position of a minority of self-funders who *have* made an active decision and have planned their care decisions, as this provider described:

*"At the very, very top, there will be a tiny percentage – and I'm not sure I can actually identify it in percentage terms – but let's say probably under 5% of our beds, and probably nearer to 2 or 3 - where you've got people who have made a choice to spend their money and bypass all sort of local authority and other advisers, and approach us directly."*

- 2.19 It may be that this is also indicative of a changed role for care homes, particularly for people who are self-funding. A decade or so ago it was less unusual for people to make their own arrangements to enter a residential home with low or minimal care needs, and to see this primarily as a housing choice if it offered them a lifestyle of their choosing. There are plenty of anecdotes of people moving into residential homes (and even nursing homes) in previous years who would have still been driving their own cars, and for whom the care home was more akin to living in a hotel where they had company if they chose it, their meals and laundry taken care of, and the security of not being alone if anything should go wrong.

- 2.20 The overall dependency levels of people living in residential or nursing homes have been rising. In part this reflects later admissions of publicly-funded residents, and the consequences of raising the threshold of eligibility criteria. Several respondents remarked that this trend creates a barrier to self-funders choosing to enter care homes because it is apparent that these no longer offer 'a balanced community' of people at different levels of dependency, and many residents will be in an end of life care situation or will have advanced dementia (we return to this theme later in the report).

- 2.21 The consequence is that people's duration of using services is now shorter than in the past; the intensity of activity has increased with more admissions. People are less likely to spend a lengthy period as residents, as one director of services described, *"the average length of stay of our frail elderly non-dementia is under a year."* The emphasis on supporting people to live in the community is one which commands widespread support; however, it also means that residential care is rarely seen as a positive choice. An independent care home director observed:

*“I think we would see that publicly funded people are being rationed access to care. I could argue that some of that must be good for maintaining independence but I also think that we’re now getting people coming in too late in the life course to get a reasonable benefit (...) I mean they’re basically coming in to die.”*

And another remarked:

*“Care homes are perceived as the worst possible thing that could happen, to be avoided at all costs.”*

2.22 Such developments raise important questions about the role of residential care and quality of life.

## Navigation

2.23 As indicated previously, very often it is the adult children of an older person who make the initial inquiry about support. Sometimes this is for personal care, but it is also often for lower levels of support such as help with housework, gardening etc. Indeed, some providers of social care and domiciliary support acknowledge that accepting customers seeking domestic support is a good business strategy because a relationship can be established which provides a platform over time to develop a more intensive or personal service.

*“And sometimes we start with just domestic care because that’s all they come to us for, but in that way we can establish that we’re reliable, and they like our people and we turn up and so on, and then they get sort of progressively...”*

And as another commented:

*“There’s a spectrum of budget spend - so you move from the high net worth individuals to actually you’ve got people who are looking to pay for a far more modest cleaning service, and it gets you in. And as they get older, there’s a requirement then for personal care and other things to creep in.”*

2.24 With the raising of eligibility thresholds such ‘low level’ help has virtually disappeared from publicly funded support. This is also evident where people who approach home care agencies or umbrella bodies for such agencies report:

*“that they have been directed to us by the local authority (...) where the message has been ‘well you don’t qualify for help from us’.”*

And:

*“..you probably end up with your local authority and then get turned away (...) and I think that constitutes a fair bit of the referrals and that problem that people don’t actually know where to start.”*

2.25 For some people there is also something of a stigma attached to approaching social services (as we explore further in sections 3 and 4), and many self-funders will totally by-pass this route if they believe that they are unlikely to qualify for any help because of the level of their assets. As this independent adviser described, for example:

*“There are a lot of people that won’t touch Social Services (...) I had one potential customer and I said something about Social Services and she just turned around and said ‘with all due respect, we won’t be using Social Services’, and put the phone down. So that was it.”*

And another observed:

*“Because [self-funders] haven’t engaged with statutory providers in the past, they are quite reluctant to get information or advice on things like this (...) because a lot of that goes to society’s view about care and how you’re in a way giving up, or you can’t manage things, and people don’t want to draw attention to that.”*

*“I think we are still very much in the shadow of the workhouse in some ways, and yet, you know,*

*nothing could be further from the truth in terms of what happens now.”*

People’s needs for information are not just around how to find their way into the system, but also with what is available for their particular situation. As some respondents highlighted, people who are self-funding risk not having a proper assessment of their needs, as this person remarked:

*“there’s also proper assessment required, because I do think assessment is an area where self-funders are very badly served.”*

- 2.26 Without such knowledge and support people end up making decisions which may not meet their particular needs, but offer a solution to their immediate situation. In so doing, other options are closed down and people’s opportunities to maintain their independence for example may be compromised and prematurely closed off, as this person observed:

*“...some people might, for example, want a very intensive reablement package or they might want to buy in some convalescence, or they might want to buy in some support services to stay where they are, but they’re never given those sort of option appraisals at the time of assessment (...) People don’t know what’s out there (...) when people are making decisions about care (...) they’re people in a crisis and they know what everybody else knows – which is very little. And that’s the basis on which care is commissioned.”*

## **Information and Advice**

- 2.27 People who don’t qualify for support from social services are often left to find their own way in a bewildering environment where they have little idea of where to begin. For some people this can lead inappropriately or prematurely to residential care because of lack of awareness of alternatives:

*“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.”*

- 2.28 People seek different levels of information and advice, and while some will want detailed help for a specific situation, others will be seeking broad reassurance. This may especially be the case when children or other relatives are contacting an information or advice service about the well-being of a parent, particularly if they are concerned about the risks that are being taken in enabling that person to continue living independently, and especially if they live at some distance from the parent.

- 2.29 Some broad signposting of self-funders by councils is clearly taking place, with people being referred to agencies or given a list of approved providers they might want to consider. However, such lists may be very limited, out of date and fail to reflect the range of services that people may wish to buy, as these comments highlight:

*“At the moment approved provider lists are generally shut; they only represent providers willing to trade with the council, that the council is willing to trade with and has done some checking (...) and they become more and more out of date, and the innovative provider who wants to do something different – I mean, the last place to go for innovation is a local authority contracting department!”*

And

*“The approved provider list – it’s a bit naughty, because you may have perfectly good providers who are not approved providers and they will just refer people to someone off the list (...) there is this mindset that says approved provider, there is some sort of accreditation process, but that’s rubbish – you have to tick hundreds of boxes (...) but it’s not about quality at all.”*

- 2.30 People who are involved in providing information and advice to people using social care recognised the frustrations for self-funders trying to get information, and the difficulties of negotiating access with some local authorities. As this advisor described:

*“(…) at the time I didn’t know how to apply for Attendance Allowance, so I’ve been to see the Money Advice Unit at Social Services who must be the most protected group of people I’ve ever come across! Social Services wouldn’t give me the number; they said ‘Oh we can’t refer you directly’. It’s like a secret mafia, you know, it’s unbelievable. And in the end I pushed and pushed and someone did give me the number but said ‘Don’t tell them I’ve given you the number.’ I mean, this is a public service!”*

- 2.31 For people who are under pressure or struggling to make sense of their situation, having to grapple with bureaucracy is extremely challenging and it isn’t surprising that people give up if they can’t easily find their way into the system. Several respondents described how despite being knowledgeable about social care because they worked in the sector, they *still* found it difficult to find their way:

*“When I phoned yesterday for something, and I got put through to completely the wrong department (…) but they just wanted to get rid of me, you know, they didn’t want to answer the question.”*

- 2.32 Another respondent who was involved in providing information recognised that anyone who reaches them has probably already been passed from ‘pillar to post’ and exhausted all other options such that a place which might ideally be the first port of call is actually “almost the last resort.”

- 2.33 The role of the local authority in providing information and advice can take different forms with councils either providing information and support directly or commissioning others to provide it. While many councils have websites that provide information and signposting, some are also taking on a wider advice role which can be problematic. Several respondents expressed their unease, for example:

*“The first thing to say is it should be independent, and there is a real grab going on within local authorities to take over the information/advice functions (…) I don’t think they should have a role in advocacy and advice.”*

And another observed:

*“The question is how do you ensure that people get the advice, so you have to really push it from a number of different directions. Whether the local authority is the best place for an organisation to do it is questionable actually.”*

- 2.34 A model such as that offered by FirstStop and Counsel and Care was viewed by some as the way forward:

*“[they] are particularly well placed, because they are one of the few organisations that did advice and casework rather than just information. And hopefully, through that they’ve established a really clear understanding about what some of the issues are and can develop a bespoke response.”*

- 2.35 It is not only broad information and advice about what support is available that people need, but also assessment of their own situation and consideration of all the available options. In practice, people are rarely experts in social care and have poor information and knowledge on which to base their decisions. The idea of ‘care advocacy’ and ensuring that people are supported in accessing the care that best meets their needs is generally something “that the self-funder doesn’t get.” As this person observed:

*“I think the word ‘abandonment’ is strong, but I think in my experience (…) there is a relative abandonment of self-payers. Once you’ve had that means test that says you’re over the threshold and you’re on your own.”*

- 2.36 Several respondents highlighted the apparent lack of independent advisors who can help people to navigate their route (in a way similar to independent financial advisors). This is an area where services are beginning to emerge, but this is on a small scale and there is currently no accreditation for advisors. Some respondents emphasised the need for a wide range of responses:

*“..this is potentially a huge market (...) and what I think we need to do is to create a pluralist market in the information/advice services, as long as it is quality-assured and as long as people can have absolute assurance that it is independent (...) you do need more than information (...) what you need is somebody who can go through and give you option appraisals.”*

And

*“I think there always will be room for lots of providers of advice (...) but you need the sort of high volume people to direct to the specialist people.”*

- 2.37 As we have already explored, many people who may need information and advice are in a life-changing situation. The decisions they make will have far-reaching implications and may result in a change of residence or permanent admission to a care home. Clearly, in addition to providing information about the financial implications of any decisions, many people will also need support with the practical and emotional consequences. One such independent care advisor described how they had developed the concept for a service, which they had originally assumed would simply be about assisting people to relocate:

*“I realised that nobody was doing it just for older people. And even though some would profess to do it for older people, it was still with an estate agent’s hat on, and it became clear that there was nobody doing it with a social care hat on.”*

*“People had problems with the whole kind of relocating bit, but actually they didn’t want to relocate, they wanted to stay in their own homes, and had they known what support was available in their homes they wouldn’t have wanted to move.”*

- 2.38 Several respondents emphasised the importance of trying to get people to think about the future, and their potential care needs, at a much earlier stage of life. For most people, the likelihood of needing some level of care as they age is something they simply do not consider until it becomes a pressing reality:

*“...pretty much everybody, even as they get into quite advanced age, doesn’t take seriously the fact that they are old (...) Nobody plans (...) they’re simply not going to confront those demons until they have to.”*

- 2.39 The need for people to have financial information and advice has been identified as a critical gap, and this is of particular concern “because of the evidence that significant numbers of people make both poor care and financial decisions without access to this information and advice.”<sup>xvi</sup> The Putting People First Social Care Consortium has issued a document providing core information about personal finances and care costs for the public for the use of local authorities and third sector organisations in raising public awareness and signposting to further information (such as to the Society of Later Life Advisers – SOLLA).<sup>xvii</sup> The importance of such information and advice was underlined once again by the findings from the current study which highlighted the absence of such financial knowledge or understanding for many people who are self-funding.

- 2.40 Just as there is widespread ignorance about how the social care system operates, there is often considerable surprise and alarm when people *do* need care and support and then discover that they will have to pay for it (or make a significance contribution to costs). Respondents commented on the need to *“incentivise people to think about these decisions sooner rather than later,”* and underlined the importance of the Commission on the Funding of Care and Support addressing such issues for the whole population, and to consider the need for appropriate products and advice for people who will not qualify for publicly funded support. Some financial products already exist that enable people to limit their liability and make arrangements for their care while still protecting the majority of their capital (such as through an Immediate Needs Annuity), but awareness of these arrangements is low and people have been reluctant to buy financial products when future arrangements and responsibility for long term care have continued to be contested and uncertain, as this person observed:

*“If the Commission does what we hope and expect it will do, it will say very clearly, for the foreseeable future – and it’s a long future – Government will only be able to do this bit. In which case you need (and hopefully they’ll also be saying we’ll help you to do this) to provide for that in some way.”*

- 2.41 Ensuring that self-funders receive appropriate financial advice is also of potential importance to councils who may otherwise have to deal with the consequences of people in residential care who run out of money (often the first time that councils become aware of their existence). Running out of money can clearly be a worry for people who are paying for their residential care, as respondents recognised:

*“Most of the people who are approaching the situation are aware that there is a limit and might not know exactly what it is but they know the money is running out. And their main concern is if they suddenly have to be funded by a local authority, are they going to move them?”*

*“I would imagine that the two years before you actually run out are fraught with horrendous psychological concerns, thinking (...) what’s going to happen?”*

As the interviews with people who are self-funding, and with their carers indicate in the following sections, this latter comment proved to be particularly prescient.

## Conclusions

- 2.42 This brief overview of the reflections of providers on the self-funding market has highlighted a number of themes. A prime purpose in contacting key service providers was in order to find a way of identifying and approaching people who were self-funding. At the same time, it was also an opportunity to explore providers’ understanding of self-funders. It is clear that providers vary in their sophistication and understanding of the private pay market – for some it is core business, for others it is more marginal. Moreover, it is evident that this is a market that is changing and evolving as more people are defined as part of the ‘self-funding’ population. This includes people who have their own resources and have never approached the local authority for help; those who *have* sought help but been told that their needs don’t meet eligibility criteria and/or that their assets place them above the level where they can receive public support, and finally, there is a newly emerging ‘quasi self-funder’ in the form of people who are receiving Direct Payments/personal budgets and are effectively commissioning their own care and support. The prime focus of this study is with the two former groups and not with people using personal budgets; however, it is recognised that many of the issues will be common across these groups and it is important that there is shared learning.
- 2.43 Providers are disadvantaged in their capacity to understand and work with the self-funder population by the lack of good market intelligence. However, both quantitative and qualitative information is accumulating and within the next year there will be considerable improvements in understanding both the self-paying population and the workforce that is employed by some sections of this population.
- 2.44 The appeal of the self-funding market to providers is affected by many variables. It has long been the case that private business in the residential sector allows providers to cross-subsidise publicly funded clients; however, in domiciliary services the economics are rather different depending on both volume and location of clients. For individual self-funders this can create significant impediments to accessing services or finding them at an affordable rate (particularly in rural and remote areas).
- 2.45 Self-funders cover a broad spectrum both in terms of their needs and the nature of support they wish to purchase. Some who start by buying domestic support may go on to access personal care, and the potential of a market strategy that starts from people needing modest levels of help is recognised by some providers who wish to be able to offer the full spectrum of support and ensure continuity of service.

- 2.46 The 'typical' self-funding person that providers encounter is someone who needs care and support as the result of a crisis, rather than someone who has planned their care or is gradually extending the type of support they receive. In a crisis or emergency situation there is rarely the opportunity for people to carefully consider their options or be fully informed about what these might include. This is especially true when people do not have access to expert and independent assessment of their needs. There is an emerging market in independent care advocacy aimed at the self-funding market, but this is unregulated and the independence of some service providers is doubtful.
- 2.47 It is also clear that many providers express considerable concern that the journeys of self-funders are too often guided by happenstance. In such circumstances the experience can be one where despite having personal assets, people experience little control over their situation and rarely approach care and support in a planned manner or as a positive choice. It is to explore these personal journeys, the decisions made and the destinations reached, that we now turn.

## 3 The decision making and destinations of people who self-fund

### Background and Introduction

- 3.1 The focus of this stage of the study was to explore the journeys undertaken by people who were funding their own care and support – how they had gone about accessing services; what advice and information had been available to them and what destinations they had reached. As we discussed in an earlier report, councils have some obligations towards people who fund their own care.<sup>xviii</sup> Guidance issued by the Department of Health on the Community Care Act 1998 was explicit that the duties of local authorities include the following:

*“Local authorities are under a legal duty under the NHS and Community Care Act 1990 to assess the care needs of anyone who, in the authority’s view, may be in need of community care services. It is the Department’s view that the law does not allow authorities to refuse to undertake an assessment of care needs for anyone on the grounds of the person’s financial resources, e.g. because they have capital in excess of the capital limit for residential accommodation. Even if someone may be able to pay the full cost of any services, or make their own arrangements independently, they should be advised about what type of care they require and informed about what services are available.”<sup>xix</sup>*

- 3.2 More recently, guidance on Fair Access to Care issued in 2002 reiterated that:

*“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>xx</sup>*

- 3.3 The latest guidance on eligibility criteria (2010) was issued in the light of the recommendations from the CSCI review *Cutting the Cake Fairly*, and was 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. A person’s ability to pay should only be used as a reason for not providing services in circumstances where a person has been assessed as needing residential accommodation, the person has the means to pay for it and if the person, or someone close to them, is capable of making the arrangements themselves.”<sup>xxi</sup>*

- 3.4 The guidance also underlined that eligibility should be placed ‘within a much broader context’ of



place-shaping and promotion of well-being that offered some level of support to all:

*“For example, people who do not meet the eligibility threshold should still be able to expect adequate signposting to alternative sources of support.”<sup>xxii</sup>*

3.5 Moreover:

*“All individuals, whether or not they are funding their own care, can benefit from effective information, signposting and support planning (...) councils should consider how they can work to support high quality outcomes for all their citizens, including those funding their own care and support.”<sup>xxiii</sup>*

3.6 The importance of ensuring that people who fund their own care are not excluded from access to assessment, information and support planning was underlined by the findings of CSCI.<sup>xxiv xxv</sup> Where people are screened out prematurely, or not given adequate signposting to other sources of help there are significant risks that prevention and reablement opportunities are not addressed, with increased likelihood of people needing higher levels of support further down the road.

3.7 It is clear from the content and tone of guidance and other commentary that it is not the intention of policy that people who fund their own care and support should be left to find their own way. However, there is evidence that councils have historically adopted a range of positions towards this group of people, ranging from denial of any support, to minimalist support and – in a minority of cases – a structured strategy to ensure that self-funders are given appropriate information and support.<sup>xxvi</sup> The indifference towards self-funders that has characterised the response of many councils needs to change in fulfilling the requirements of the transformation agenda for social care. Whether the experiences of people who are self-funding indicate that this *is* happening is the focus of this section of the report.

3.8 As described previously, interviews with service providers were used in part to provide access to people who self-fund their care and support. This was not a straightforward process; some of the providers operate on a national basis and it was necessary to identify some specific areas or services to focus on. In doing so we were also concerned to cover a range of locations and parts of the country. We were reliant on the service provider being able to identify potential participants for the study. We wanted to speak to people using a range of services, from domiciliary support to sheltered housing, assisted living, and residential care. This also meant that some of the people concerned would be too frail or would have levels of cognitive impairment that would prevent them participating directly. Where this was the case interviews were undertaken with family members (see Section 4). There were also some instances where people who had been identified as ‘self-funding’ turned out to be using Direct Payments, which were not the prime focus of this study.

3.9 A consent form was developed which explained the purpose of the research and gave assurances about confidentiality. Some people, but very few, were reluctant to become involved and declined to participate. This was to be expected given that these are private matters and it may have seemed intrusive and personal to be asked questions about how and why people have made their decisions. However, sufficient numbers of people *did* agree to take part, and we are extremely grateful to them for their time and for allowing us to gain a glimpse of their world. Most of the people interviewed were female, and all were elderly; the youngest was 71 and the oldest was 93, with most aged over 80.

### Thinking ahead?

3.10 In all interviews people were invited to tell their stories and to explain how they had made the decisions about care and support that they had. In almost every situation it was evident that people had *not* made their choices in a deliberate and planned way. Most people just get on with living their lives on a day to day basis rather than thinking about the longer term, as the following comments illustrate:

*"It was something I never thought about (...) that there would come a time when I wouldn't be able to look after myself."*

*"My plan was to stay at home (...) I've got a beautiful house, but I was getting to the point where I couldn't get up and down stairs safely by myself."*

*"I couldn't see myself getting old and decrepit."*

*"I'd never thought about it, you see."*

- 3.11 Some people acknowledged that they thought ahead in terms of practical arrangements such as making their wills or "arranging for my burial with my solicitor," but did not think about whether they might need care or support in the future, at least not while they were able to manage without anything ("I was doing everything."). This was especially the case where people had been married and living as a couple where they were able to provide mutual support:

*"No, it happened to other people (...) I mean, you carry on as if you're going to live together forever."*

*"Well not before, certainly not before my husband died (...) no, we hadn't talked about 'the future'."*

- 3.12 A minority of people *had* planned ahead. One person described how the lease on her flat had been due to end when she was 83 and she had thought that by the time she reached that stage she would move to a care home. At the time, this had been many years in the future:

*"When you're young 83 sounds like ancient (...) and then when you are there, you're alright, and so I thought well, I don't really think I need to go into a home really do I? (...) I wasn't ready to go into one."*

- 3.13 In this particular situation, this had been the beginning of a period of ongoing uncertainty about what to do for the best which remained unresolved and was a matter of some worry and distress.

## **Making a Change**

- 3.14 Being widowed, or experiencing a deterioration in health were identified as significant factors that can precipitate a change in living arrangements or need for support. Where people were living at some distance from other family members this often compounded the situation and brought a realisation that something needed to change. Many people commented on how they had become concerned that they were putting their adult children "to a lot of trouble", and taking up a great deal of their time if they needed to visit more frequently. For some, the obvious solution was to move nearer their children, either to supported housing or into residential care, as this person described:

*"So I was 80, just nearly 80 when I came, yes (...) I just sort of said to my daughter, look, have you got any small flats or something [near you]?"*

- 3.15 In such circumstances where people had decided they needed to move but there was no actual crisis necessitating that they did so immediately, several described putting their 'name on the waiting list' until the right vacancy became available. At the same time, however, it was also recognised that a decision had to be made, and it was better for some if they were able to make it for themselves sooner rather than later:

*"You know when you're getting on – you've got to make a decision and that's it, or else somebody else can make it for you!"*

- 3.16 Where people had time to make their decision they described being able to approach it methodically – researching various options before committing themselves, and being aware of the need to 'get it right'. For example, as this person recalled:

*"But what I decided was that if I was going – I had already moved twice in 5 years – and I thought when I move now I want to try to find somewhere where I can be settled and not have to move*

*umpteenth times.”*

This was viewed as a particularly positive feature of schemes where sheltered housing, assisted living and nursing home provision were all located on the same or linked sites, which gave people the security that if their needs increased over time they could still be cared for without another major change. There was also a strong sense of needing to move ‘at the right time’ rather than leaving it until it was too late, as this person described when recounting her move into a warden controlled flat:

*“And I don’t think you should be too old before you move. Because now some people are coming in at 85, which I think is a bit old (...) I would say 80 is the limit; you can do it a bit before, but not too early (...) but luckily I did it at the right time I think.”*

And as another in a similar situation observed:

*“I did feel quite strongly that if I left it much longer I would not be fit and able to do it myself, because I was getting a bit tired. Well, no – I truly was very tired (...) But I had also witnessed other people leaving it too late and not being able to cope with their moves.”*

And

*“My experience had taught me that if you’re going into a home, you shouldn’t leave it too long. There are a lot of adjustments to be made when you go into homes.”*

- 3.17 Some of those interviewed who had decided to move into care homes had clearly done so at a stage when they needed little actual ‘care’, but felt the need for additional security, companionship or to be ‘looked after’. The latter was a particular consideration for people who had often had extremely hard lives and had looked after elderly and other relatives and had reached the point of needing some rest and support for themselves.

### **Crisis management**

- 3.18 In Section 2 we highlighted how interviews with service providers identified that it is often a crisis that triggers people into using services or moving to a care home. This picture was reinforced by the interviews with people who are self-funding. For the majority of people the transition to using support or moving into a care environment is *not* one that happens gradually or as a result of considered planning. Most people who were interviewed described a sudden, and at times catastrophic, change that had largely taken decision making out of their hands. One woman described how she had been coping at home following a hip replacement and her son had been in the process of installing a walk-in shower to make her life easier, when she had experienced a break-in and burglary while she was asleep,

*“And it just seemed to knock everything on the head you know (...) and the next thing I knew I was installed in here.”*

- 3.19 Another person also recounted how she had been in hospital and was getting ready to return home:

*“They were just getting me fitted up for living at home when I had a fall and I split my head open (...) and then I sort of transgressed down to this state. It made a difference; if I hadn’t have split my head open, I don’t quite know what would have happened to me.”*

- 3.20 One of the oldest interviewees described how she had been living independently in her own home - well past her 90<sup>th</sup> birthday - when she lost the use of an arm and found herself discharged from hospital to a care home where she didn’t want to be and which was unsuited to her needs:

*“I just suddenly deteriorated and had to come into a home (...) but I wasn’t too happy there; it was a nice home, there was nothing wrong with the home but most of the occupiers had dementia (...) and I’ve got most of me marbles I think! (...) I had a relative and I think she didn’t want any responsibility so she whipped me in there without any thought for me.”*

- 3.21 Fortunately this person was able to move to another home when a vacancy became available. Several other people also described moving to a care home directly from hospital “because something had to be arranged” and they were under pressure to move:

*“In the end I was in hospital for about ten days and then they said ‘well, you’ve got to go.’ (...) so I came here.”*

*“They let me stay in the respite centre for a little while (...) well, you knew your options really. You either stayed at home or you came into a home; there aren’t any other options if you can’t cope by yourself.”*

*“I think perhaps it was one of those cases where I’d got to be got somewhere and that was the only one available at the time.”*

- 3.22 The youngest interviewee (aged 71) had been living in a nursing home for six years following a stroke, and described the events that had led to his admission and which still caused great distress:

*“I was in hospital a few months; they told me I’d had a stroke (...). The hospital said I couldn’t stay; I had to come out and they wouldn’t let me go home because I wasn’t capable of looking after myself; I said I wanted to go home and they said we can’t discharge you for that, we can only discharge you to a nursing home.”*

- 3.23 This person was unable to care for himself and hadn’t been able to walk since the stroke. However, he clearly felt that he had no control over his situation and what had happened to him subsequently; he had not been able to exercise any choice, didn’t want to be in the care home and was clearly unhappy, harbouring hopes that somehow there would be a change in his circumstances and he could return to some independence:

*“I’m still sort of living in cloud cuckoo-land, and think maybe I might start walking again despite what they’ve said.”*

## The journey

- 3.24 How people made the choices they did and what help they had in doing so were important issues to explore. Most people described various coping strategies whereby they had managed for a period of time before it was apparent that other help was needed. Typically this involved a combination of family, friends and other informal support. People described how these arrangements worked for them, for example:

*“I’ve also got a ‘treasure’, if you know what a treasure is! And she’s worked for me for 28 years – all my life I’ve had cleaners.”*

Over time such arrangements can evolve and develop from simply housework, and into practical and even personal help:

*“A couple of years ago I had pneumonia and I wasn’t well and so forth, and she came in at weekends you know (...) if I wanted extra I think that she would come.”*

- 3.25 Other people described how the person who they employed to do their ‘shopping and cleaning’ also started to do other things for them:

*“She was good; she gave me a shower twice a week, and washed my hair for me. And when she first started to help me she said, ‘you tell me what you want me to do; I will do anything’, and she would.”*

- 3.26 People explained how they got to know people who could help them through their social networks and communities (particularly the church). In one instance it was this cleaner/carer who helped the person decide to move into a care home (“she said she felt that I couldn’t do any better than this.”). A person living in a sheltered flat described how she had found her cleaner through other people

living in the development:

*"I've got X, she comes and does a bit of cleaning (...) she's only got two of us left now, I think she would give it up but she says she doesn't really like to because she looks on us more as friends."*

- 3.27 Such arrangements can be very successful, but they are also extremely fragile. For people who are largely or solely reliant on the help, advice and kindness of someone who is partly a 'friend' but is paid for their service, there is a high degree of uncertainty and vulnerability. The arrangement has no contractual basis and can break down; there is scope for exploitation, and there is considerable potential influence over the decisions people might make, even though they may have no expertise or real knowledge in this area. Family members were the major source of help people identified, but it was often to avoid such help becoming too much that people decided to change their living arrangements. For people who are elderly, many of their friends and family are similarly aged which restricts how much support they can be expected to offer, as this person recognised:

*"The thing is that most people who would be willing to help are people who've got so much to do anyway, and most of them are elderly (...) which is the problem with my brother and his wife. They would do it; they would do anything for me, but sometimes I say 'no, that's enough', because they're getting to the stage now where it's a bit of a struggle for them to get upstairs in their own house."*

- 3.28 While people described how they appreciated the help from their family, they were also very concerned not to become a burden, as these comments highlight:

*"What I wanted to do was to be within easier reach of the two boys (...) but I don't want to be so near to either of them that I have to be invited to Sunday lunch every week."*

*"You see I sold my house so that I could come into care because I've got two sons (...) and I didn't think it was fair on them."*

*"I don't expect any of the kids to come into me because they've got their own lives to lead."*

*"So I came here [from hospital], not with the idea of staying forever, but I decided (...) that for the sake of both my sons (...) for their peace of mind, they know I'm safe here."*

- 3.29 For people who have no children or partner to offer support it was recognised that relying on neighbours and friends was unsustainable, as this person described:

*"I wasn't prepared to be in that place by myself (...) I've got a brother in Scotland and that's it, so I really had no option."*

## Information & Directions

- 3.30 Having made a decision that a change in living arrangements was needed, how did people go about finding out what was involved and what they might need to do? In talking to people about their experiences it was apparent that major life changing decisions were often made on the basis of little information, and people had little idea about where to seek such information or advice, as the following comments illustrate:

*"Well, to tell you the truth, I began to dither, to know what to do."*

*"I were not sure, you know, I thought – I don't want to do the wrong thing, it's a big decision."*

*"Well, I'd always sort of thought it was a nice home, but I didn't know much about it, not had much experience of homes."*

- 3.31 The idea of approaching an organisation such as Social Services for advice or help in this situation was something that was simply not considered by most, as this person remarked:

*"No, I'm afraid, you know having spent my life making my own decisions, I tend not to seek advice."*

And as another person also remarked about what they might have done differently:

*“Oh I’ve got no idea; I don’t know (...) I’m afraid I’m very independent. I don’t know what I would have done.”*

3.32 Some people took a different approach:

*“I rang up [the Council] and asked them to send me a complete list of all the care homes in [this area]. I hadn’t realised how many there were (...) and on paper evidence we boiled them down to about half a dozen.”*

And as another person described:

*“So I decided to start looking and in fact I got a few telephone numbers and saw some adverts and things (...) then I was sitting in the doctor’s waiting room one day and looking at Saga magazine, and I had a pencil and paper in my bag and I wrote a few things down, and I thought, well, we’ll start here.”*

3.33 Another described how moving into a home was primarily a practical decision because the alternative was less appealing:

*“It was going to cost me more in many ways to have permanent help [at home], and also a consideration was that you can’t rely on one person. I mean if someone lets you down then where am I? (...) and also, I wouldn’t want somebody messing about in my kitchen!”*

3.34 The first port of call in exploring options was usually family members and people described undertaking visits to care homes or sheltered accommodation either with family members, or with them doing so on their behalf in order to find somewhere suitable, for example:

*“We boiled it down to those [homes] that were handy for my son and daughter in law’s house (...) and one Sunday we came up and I joined my son and his wife and we went around all these nursing homes.”*

*“Well, I’d got [my son] to go and look at places, and he phoned me one Sunday morning and he said ‘at last I’ve found the place’, because he had looked at so many and he thought they were terrible. And I said ‘okay then, I’ll come and see it’, and he brought me here, and I liked the look of it.”*

And

*“Well, I got a list of all the care homes and I had one friend that was very good to me and she took me round, and we went round to visit some of them.”*

3.35 Others referred to undertaking research about homes via the internet:

*“Well the reputation [of this home] was so good, and a friend of mine, her husband is a computer expert and he went on the [internet] to read about this place and he said it was three star.”*

3.36 While several people described approaching social services and being given a list of homes, no one recalled being given any further information or advice, or being signposted towards other sources of help. For some people having to find their own path came as a shock:

*“When you’ve got the money to pay, you’ve got to pay yourself and (...) they knew I could afford to pay (...) I thought they would take me round to see some of the places, but they wouldn’t.”*

3.37 In fact, on this occasion a person described having had some help from social services “but it was accidental”. A social worker who had been involved in conducting an assessment had taken the initiative to call in to a local home that he thought might suit the person and had picked up a brochure, “so when he was passing he said ‘I thought this might interest you’, so inadvertently he helped me.” Such support from a social care professional was exceptional, and no other person interviewed had a similar experience.

3.38 Once somewhere suitable was identified people generally made an immediate decision and decided against looking at other options. For such a major life decision this is in some ways surprising, but this needs to be viewed in context. People who are making such decisions are doing so when they have already accepted that a change is inevitable; having done so the issue is then about finding somewhere that will be 'acceptable', rather than somewhere they actively wish to live.

3.39 For people who do not have immediate family to help them in making decisions about the future, the situation can be very difficult. Trying to find out about what options might be available and to investigate them is demanding and worrying. One person described the various things that she had considered:

*"So I thought, well what do I need? And also, if I'm going into a home, what sort of home should I go into? Should I go into a home in London where my friend is nearby, or should I go down to Brighton because it's by the sea?"*

3.40 In this situation the person thought her best option was to move into sheltered housing but she had been unable to find anywhere suitable. Some of the places that she liked were run by charities that had policies about eligibility based on religious grounds that excluded her, while others could only offer studio accommodation rather than the one bedroom unit that was wanted. The result was that she remained in limbo on a waiting list for suitable accommodation but was becoming more and more pessimistic that anything would ever become available (particularly as the providers of sheltered schemes had advised her that that people moved into studios to await the availability of a larger unit, so one bedroom sheltered flats rarely became available to people who were not already resident). The result for this person was an impasse where she felt sure she should be moving to different accommodation with some support, but she simply did not know what to do for the best "so, I've come back and dithered ever since." At the same time, the person recognised that she might have only a limited window within which to make a decision and thought that sooner or later needing help would be inevitable:

*"I think eventually what will happen is that, if I live as long, and you can't blind yourself to it, you're going to have to have help because you revert back to being a child you know, I realise that."*

3.41 Almost all the interviewees recognised that moving into sheltered housing or residential care was a major decision and one that they needed to get right. Some people had checklists of things that they wanted in any new situation, for example:

*"I didn't want to be upstairs. I wanted a door where I could walk out to the garden, you know, sort of thing. And there were quite a few things I wanted (...) and unless you're going to do something like this, what was the point of moving?"*

3.42 Almost none of the people who had moved into a care home or sheltered housing said that they were unhappy about the choices they had made, and most described their decisions positively, or at worst with a degree of resignation. Almost everyone who was interviewed was remarkably sanguine about their situation, and even those who had needed to make major adjustments in their living arrangements and to move from their own homes to residential care viewed it as just something they had needed to do, rather than it being a major trauma or source of distress. At one extreme were comments such as the person who remarked:

*"Well I frequently say that it's one of the best things I've ever done coming in here (...) nothing to worry about now."*

And

*"I felt when I'd made the decision, I felt that it was the right one because in a place like this there's always somebody around."*

3.43 Others were clearly bearing an unhappy situation with some stoicism. For example, this person observed that while he was content with his choice of care home, his days were very long:

*“My day consists of ‘killing time’ essentially; you know, whatever I say about it. Killing time, yes.”*

Similarly, another person remarked:

*“I consider I’m very lucky for my age (...) oh, I don’t get melancholy; I just wish things weren’t as they are, but they are (...) so no good moaning is there?”*

*“I mean, if I hated it I wouldn’t be here, I would have moved on (...) but you don’t know what – out of the frying pan into the fire.”*

*“And I do look at life like that, you know, you’ve got to get on with things, not expect somebody else to do it for you. So there you go.”*

- 3.44 The most negative comments were made by someone who would have much preferred to be living in a flat or supported accommodation and whose frustration was evident. In having to rely on other people for help he described a situation that was made worse by the attitude of some staff members:

*“Everything they do here is not for your benefit, it’s for theirs – what makes it easier for the carers; I think they are probably all the same these homes.”*

### **Paying for Care & Financial Advice**

- 3.45 As we have already discussed, the term ‘self-funder’ covers a wide range of scenarios. Not surprisingly, therefore, the people who were included in the research sample also represented a range of circumstances and a variety of financial situations. There are national rules on charging for residential care and as of April 2010 this means that people with capital over £23,250 must meet the full cost of their care. People with capital between £14,250 and the upper limit must make a contribution from both capital and income to the costs of their care, while no contribution is made from capital below £14,250 (although income is still contributed).

- 3.46 For many people – particularly those living in care homes - awareness of their finances and concern about what might happen in the future, were significant worries. The following comments were typical of many:

*“What terrified me more than anything else, was the cost of these things (...) I was horrified! I suppose I hadn’t stopped to think.”*

- 3.47 Others also remarked that they were paying more than £200 a day for their care and were concerned that this would rapidly deplete their savings:

*“I’ve got to be very careful [that] I’ve got enough money to get through.”*

- 3.48 Most of the people who were paying for residential care had sold their homes in order to do so (although one still owned the property and was paying for her care from her savings, with her house still available to be sold “if the worst comes to the worst”). Many of these did not know the detail of their financial situation and simply left this to other people to manage on their behalf, and several mentioned Power of Attorney arrangements either with family members or solicitors (“my son deals with most of my financial things”). For some people, the management of money had become an issue of contention.

*“I’ve got a relative who got to be my Power of Attorney, even though I said I didn’t want one (...) that’s caused me an awful lot of problems (...) I’ve had my head screwed on ok all my life, it’s horrible to feel that somebody else is messing around with your bank accounts (...) I don’t think she would rob me of a penny, but it’s just the inconvenience.”*

- 3.49 This person – living in a care home - also thought that their savings had already dropped below £14,000 but did not know who he should contact about the situation or whether he would get any



help. While people often did not know in detail the state of their remaining assets, there was a concern about what might happen when their money ran out. One person was particularly concerned because of the discussion about the national financial deficit and the impact that the public expenditure review might have on councils' ability or willingness to meet costs:

*"What concerns me is (...) I pay [for the care home] until my savings have disappeared almost, and then I was interviewed by Social Services to make a record of what I'd got and how long it was likely to last, and then it would be topped up by the council tax. But now with the problems that we've got with budget cuts and so on, what do I do if they don't want it any more?"*

3.50 What was striking about these situations was the level of worry that it was causing the elderly person, and the apparent absence of anyone who might be able to allay their fears or give them reliable advice.

3.51 Another person similarly remarked on fears about what would happen in the future, but was in the happier position of being reassured by her family:

*"Well I talked it over with [my son] and I said 'my money is not going to last very long in a place like this.' And he said 'well we are going to pay for it between us, and we will ask Social Services to pay for some of it, why shouldn't they?'"*

## Conclusions

3.52 This section has explored the experiences of people who are self-funding and using a variety of forms of social care and support. The picture that emerges is a complex and varied one; for some people having adequate financial resources had enabled them to make considered and deliberate choices about what sort of support they might need. For others (the majority), decisions had been accelerated or necessitated by changing circumstances such that things happened *to them* over which they had limited control. In making their decisions people are most likely to consult with family and friends, and to get help from these sources with finding out additional information. Almost nobody identified social services or any other organisation as a source of information. Informal information, word of mouth and reputation were far more significant in influencing people's destinations and decision making. It was striking that the experiences of people who are self-funding seemed to have changed little since previous research undertaken in 2007 which found people who were self-funding being "steered towards residential care with haste and before other options had been explored."<sup>xxvii</sup>

3.53 It is clear that almost nobody thinks very much in advance about what they might do if and when they need care or support. Most of the people who were interviewed were in their 80s and had only needed help in relatively recent times. Because they had been coping until there was a sudden change in social support or a tipping point was caused by a change of health status, they had convinced themselves that they were – if not immortal – then certainly not needing to make plans for their 'old age'. As many observed ruefully, this was something that happened to other people, not to them. If older people are unlikely to think about their future care needs, it is even less likely that younger people give the matter much consideration; although some of the family members and carers who had seen the difficulties their parents experienced may have been forced to confront the realities for themselves.

3.54 It was difficult for some people to recall the chain of events leading up to their current situation, or to be clear about when things had happened and what they had thought about it at the time. Where people were too frail or confused to be consulted about events and their self-funding journey, interviews were instead undertaken with family members. While many of these confirmed the themes that have already been highlighted in this section, they also introduced some further dimensions. It is to the experiences and insights of family members that we now turn.

## 4 Carers' Journeys

### Introduction

- 4.1 Interviews also took place with a number of family members and carers. These were mainly adult children of older people needing care and support, but some were spouse carers. Carers were approached partly to provide insight to situations where a person who was self-funding was unable to participate in interviews, but carers also had their own stories to tell and their own journeys in trying to navigate the world of self-funding. In many ways the themes that emerged from these interviews reinforced those already identified. However, they also revealed a level of concern and anxiety that was rarely articulated by people who were self-funding, perhaps because the implications of situations were more evident to family members than they were to the person themselves.
- 4.2 In all the interviews undertaken carers indicated real concern for the wellbeing and security of their family member, and compassion for the difficult situations and poor quality of life which many of those relatives faced.

### The stigma of social services

- 4.3 Most of the carers were very clear that they and – more importantly – their relatives, were either reluctant to approach social services or did not, for a variety of reasons, see the relevance of that service to their own situation. The following comment was typical of many:

*"I don't particularly want Social Services – or rather, Mum and Dad don't particularly want, it's about them not about me – Mum and Dad don't particularly want Social Services coming in and saying what they already know."*

- 4.4 For this person, both he and his parents were only too aware that they had significant and increasing needs for support and could see not value in Social Services coming in simply to provide confirmation:

*"...and then saying, 'well actually we can arrange it for you but you're going to have to pay for it'. And I think Mum and Dad's view is that actually they are compos mentis and Mum particularly knows what help she needs."*

- 4.5 In such situations family members were reluctant to force relatives into accepting something that they were uncomfortable with, and were concerned that as far as possible they should support their relatives "to be in control of their own destiny" and make their own decisions. The issue for most people was not a reluctance to pay for the support they might need, but to have any involvement with social services:

*"I think their perception of social services is that it is almost a point of last resort."*

Another person similarly remarked:

*"But I suppose a lot of people associate social services with when you're really down and out."*

And indeed some very elderly people had good reason to have this perception:

*"Well I suppose my mother's generation, there's still some knowledge of the workhouse."*

- 4.6 The reluctance of some other people to involve social services was less to do with the perceived stigma than it was with previous experience as self-funders, for example:

*"I wasn't desperate to have social services in here (...) I've been through this process, a very similar process with my father-in-law, and it seemed to me (...) when he called them in, I mean they*

*seemed to be more preoccupied with how much he'd got than what the problem was, and I wasn't happy to have all those people crawling all over the house."*

- 4.7 People who had made contact with social services were generally disparaging about the experience, and similarly recounted how an assessment of their means seemed to be the dominant consideration:

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

And as another person also recalled:

*"So I rang social services and said could they help me with this, and the first thing that they said to me was 'does your father own more than £23,000?' That was the very first question before they said anything else or if they could help."*

Another person who had tried to find a suitable care home for her mother:

*"They just said 'oh, she's self-funding' that was it, you know (...) somebody did come out from social services. She came out to see Mother and to make an assessment. We never heard anything more."*

- 4.8 Some other people were offered assessments by social services, but these were often viewed negatively or rejected out of frustration. The benefits that an assessment might offer in terms of identifying someone's particular needs and matching these to available services did not appear to be explained. Rather, people perceived 'assessment' as something bureaucratic and unhelpful, as this comment underlines:

*"At one point I got someone offering to do a carer's assessment on me. And I was jumping up and down in fury by then, so what I didn't need was a carer's assessment! I don't need another assessment; I need some help."*

- 4.9 Not surprisingly, when people had negative experiences of this nature they then recounted how they were very unlikely to approach social services on future occasions, and ended up often feeling "very jaundiced about the organisations because nothing seemed to apply in our case." Frequently this left people with nowhere else to turn for help or advice and information, a point we return to later in this section.

## Navigation

- 4.10 Just as the previous sections have described crises triggering people becoming self-funding for care and support, carers described a similar trajectory. Typically there was a realisation that things could not continue the way they were either because carers were unable to cope with increasing needs, or because of an event that led to a hospital admission and the need for subsequent ongoing support. In such circumstances carers described how they set about trying to find a suitable care home, for example, but did not know how to go about getting appropriate advice or information that would inform their decisions, as this person described:

*"And we had a chat to a lady from social services who wouldn't give us any specific advice about a care home, but we played a game called 'go through the list', and if she shook her head it wasn't a good one, and if she nodded it was a good one, but she 'couldn't possibly comment'."*

Another carer described a similar experience of being given a list and left to find their own way:

*"They say they can't tell you which ones are the best. You get a list and they refer you to looking up online at, you know, what the reports say."*

- 4.11 When decisions had to be made in a hurry, trying to make the right judgement was more difficult and often upsetting. This carer recalled the experience when her father had been admitted to hospital

following a stroke:

*"...and then they said 'there's nothing more we can do for him; you must get a nursing home' (...) this was extremely difficult (...) I was fairly distressed about the fact that they gave us ten days to get him out of there."*

- 4.12 Some carers were able to undertake their own research on behalf of elderly parents, and explored the ratings of services by CSCI (as it then was) or CQC. One carer described how he had become attuned to interpreting the reports:

*"We went through that and I got to the stage where I could tell by how many pages it had whether it was good or bad. The more pages, the worse it was!"*

Others were less convinced that the reports told them anything meaningful on which to base a decision:

*"I think a lot of those, well it's very difficult to assess from them because a lot of the assessment is a box-ticking exercise. It doesn't really tell you how they treat people, or [if there are fewer] facilities but there are, you know a couple of really dedicated staff which may be better than somewhere that's got more."*

- 4.13 For carers who were less technologically able, or wanted to look behind the reports, the task of finding out about care homes was an arduous one that involved visits to as many places as possible, with little knowledge of what to look for beyond the obvious signs, as this person described:

*"And I had gone round them all and been totally disappointed with all of them (...) places that were nearby. And I went to view them all and the majority of them were just, you know – it's awful, you go through the door and you are nearly knocked back. And I couldn't put my mother in somewhere like that."*

- 4.14 The typical carer journey was a lonely one where people were unsure of how to go about finding appropriate and good quality care, and where the difficulties were compounded by the need to do so quickly. A carer described how as soon as she realised that her parents would be self-funding for any help they received, she believed there was no point in trying to organise it through social services:

*"I thought, well you know, social services – by the time they've done their assessments and everything else, it would take forever, so I was trying to go direct to the agency. But a lot of them, because we're in a rural area, a lot of them really aren't interested in coming to somewhere a bit out in the sticks."*

- 4.15 Some interviewees described a real sense of embattlement in their dealings with social services, and an apparent tension between social workers and social services management, where social workers tried to 'stick their neck out' to get the best result for someone (such as when their money was running out), rather than being driven solely by financial pressures.

- 4.16 It is evident that navigation is about far more than simply finding out what services are available – are they able to meet the particular needs of a person, and – as in the situation above – are they prepared to meet those needs wherever that person is located? Simply having the resources available to purchase care is no guarantee either that the most appropriate care can be found, or that the purchaser is in control of what help they can get and when.

- 4.17 Many of the people who were self-funding would be described as middle class, articulate and educated. Some had run successful businesses and been used to organising their lives and had demonstrated considerable personal resources and confidence. Even so, the social care world was one that was unfamiliar and confusing, and decision making was therefore far from easy. As these carers described the dilemma:

*“Here I was in a completely unknown and new situation as far as I was concerned, so I had got no idea what steps I should be taking with local authorities or social services or anybody. I hadn’t got a clue.”*

And

*“If we decide to go down the residential care route, you do feel a bit kind of on your own. It’s not that I want somebody to tell me what to do, but, yes – you are in a mass of statistics and names and numbers and trying to find the right place isn’t easy.”*

- 4.18 All of the carers who were interviewed had views about how things could be better organised and navigation made easier. Some people identified ‘a single point of contact’ as something that would be particularly beneficial. This was seen as something that probably should not reside either with the NHS or with social care given the potential for cost-shunting and territorial disputes, and the inappropriateness of ‘gatekeepers’ giving out information, but there were also concerns about locating such a role within the third sector, for example:

*“There are an awful lot of charities and organisations who are only too keen to help. Unfortunately what they do and how they do it isn’t particularly clear (...) there are all sorts of people (...) but there is no clear path as to this is what you need to do.”*

And

*“And so I was going round and round in circles. I’d got lots of people very kindly on the phone referring me to someone else, and them referring me to someone else.”*

*“And there seem to be an awful lot of people whose entire role is pushing you to someone else. Sort of passing the buck on, and not so many people actually doing anything.”*

*“One of the things that really, really annoyed me when I was looking, trying to find someone to come in to help because we had reached a little bit of a sort of hiccup and a crisis point, was that I kept getting referred to everyone else.”*

- 4.19 Another carer similarly made a plea for the personal touch with information and knowing where to go to access it:

*“Somebody to physically come and discuss the situation or information to be sent that we could (...) and a contact that we can speak to and discuss problems (...) somebody who can actually talk you through the various things that are available, so that you can decide which course you want to take.”*

- 4.20 The sense of isolation and having to seek out information rather than being able to easily access it was uppermost for many, and was “very wearying” as this person remarked:

*“I just think there is something dramatically wrong with the system. And if you want to find out anything, you’ve got to find everything out yourself.”*

And as this person observed:

*“It would have been nice if they [social services] had come, and they’d explained to her the options and, you know, we really feel that you might benefit from this path or that path.”*

- 4.21 In retrospect people wished they had known how the care and support system worked before they had to find out in the middle of trying to manage a traumatic or urgent situation. One person thought that “some sort of information could be sent to all households”, but in reality it is unlikely that people take much notice of generic information *until* it is relevant to their lives.

- 4.22 Concerns about what to do and how best to make decisions were particularly uppermost in people’s minds when they were thinking about the future and the uncertainty of what might lie ahead:

*“And what we haven’t got at the moment is the answer to ‘what’s the next step that we take?’ (...) You know, ‘this is how you do it, this is how you access this; these are the services that can help*

*you, these are the ones that can't.' That would be great."*

And

*"It is quite clear to me (...) I know it's a situation that will undoubtedly get worse (...) I've no doubt that some time in the coming months I'm probably going to have to make the decision about whether my wife should remain here or not."*

- 4.23 But such decisions would be far from easy, and many carers (themselves elderly) were struggling to cope with the pressures, as this person acknowledged:

*"To be frank with you, I mean I'm not sure where I am. I mean, it's taken me all the time, energy and effort to get in place the things I have got in place."*

- 4.24 One carer described being given another contact number by social services, without any information about who the number was for or what they might be able to offer ("we can give you a number to ring"). However, this turned out to be a service commissioned by the council to provide advice and brokerage, which was able to identify information exactly tailored to her needs, and provided in a helpful and sensitive manner. The carer's positive experience of this service was in stark contrast to everything else she had encountered:

*"And she was very compassionate, very kind. She knew exactly what I required and, true to her word, by the Wednesday morning a dossier arrived on the doorstep with three care homes that I could visit immediately [she had arranged] I could go to, and about another three that had a little waiting list but she suggested I might also like to go and see."*

- 4.25 This service and personalised support was greatly appreciated by the carer but this help had not been easy to find, and the impression was that social services had passed on the phone number with reluctance rather than seeing it as a key element of their signposting responsibilities.

## **Financial and Legal Matters**

- 4.26 Financial matters and concerns about money were a dominant theme for relatives and carers. Unlike most of the people who were self-funding and who had a vague knowledge of how financial assessment was undertaken or how the local authority might be able to help and in what circumstances, their carers and families were generally well informed (or had acquired expertise through the experience). As this person observed, such knowledge was picked up along the way and could be very useful:

*"Things like 'Working Lunch' and things like that on the TV, and 'Money Box', and all those sort of things; you pick these things up and you know that there's some limit at which somebody else has to pick up the bill."*

- 4.27 The impression that some people acquired about how and when the local council might 'pick up the bill' was not always accurate, and the reality could be more of a challenge, as this person discovered:

*"So you think, oh that's going to be great – Mum's only got that much money now so no trouble at all. But then the council are involved and they then started referring to this third party who was going to pay the difference. And I thought 'oh that's nice, who's that?' and they said, 'you!' (...) and it was something like £180 a week!"*

- 4.28 By trying to find the most suitable care homes for their relatives to move to, carers were usually making arrangements where charges were significantly in excess of the fees that their local council would normally meet. In the case above where a shortfall was identified it was reported that the council had told the family that another option would be to move the resident to a cheaper home, and indeed the way this was communicated appeared to be a 'threat' to do just that. Having already seen some of the other homes on offer and been unimpressed by their quality, the relatives refused

this option. In this situation there was considerable correspondence about what would happen next, and the carer was an articulate and determined person who was able to challenge the system and not give up easily:

*“They did say it was above the price band, but we had another review and, good on the lady that did it, she said it would be detrimental to my mother to move. And with me and my letters and all the rest of it, and I eventually found someone higher [in the organisation] who I suppose didn’t really want to be bothered, and they said ‘Okay, we’ll pay’.”*

- 4.29 However, even in this situation the family were left in a position of uncertainty where they were afraid to ask questions and unsure if the council was ‘picking up the tab forever or just until the end of the month’. The process from the time the family had advised the council that their relative was approaching the financial limit and an offer being made was a long one, and in part it appeared to them as a process of attrition where they had to keep to their position in order to get any response. It was recognised by this family that other people would find such challenge a considerable struggle, as they remarked:

*“I can just imagine for other people, it’s difficult to get the information. And you do have to be quite resolute. I would imagine – say a couple living together and one of them is in very ill health, or not good health and needs to go in, it would be a nightmare (...) the eyes are on the budget and not on the person.”*

- 4.30 Another carer whose mother had entered a nursing home was similarly worried about how long the money would last and how to slow the rate at which it was being spent:

*“My brother worked out she had four and a half years (...) that’s a big worry. That’s something I need to do. I mean we were hoping that, for a start, she might move into a single room rather than the suite [she has at the moment] (...) it’s awful to think we’ve just got a time limit, you know.”*

- 4.31 Another carer was supporting both of her very elderly parents in her own home and had resisted looking at residential care because she was so concerned about the consequences of money running out:

*“Well no, because to be honest with you there wasn’t enough for them [both] to go into a private home. They would have gone through it by now at the price they all are (...) initially anyway (...) they had more than £23,000. Not a huge amount. They wouldn’t have gone without each other, so you’re talking about a double whammy here. And although I know one can get help it’s fairly minimal I think. So it just simply wasn’t an option.”*

- 4.32 And yet another carer whose mother had moved into a care home was in the position of knowing that there was a significant amount of money available:

*“My father was very prudent and, you know, they had a property. Well, when she came to us because she couldn’t manage on her own, she sold her property and that’s...I just put that into a pot for her care.”*

This person recognised however, that the funds were finite but hoped that they would outlast her mother:

*“I’m lucky that she has the means to be cared for. It won’t go on forever; it can’t go on forever, but I think as she is very elderly and has been very poorly (...) we shall probably get through. But, you know, if this had happened in her 70s – no way.”*

- 4.33 Carers and family members were in the invidious position of hoping their loved ones died before their money ran out. Indeed, carers often expressed the wish that they would prefer for it ‘all to be over’ for the sake of the quality of life of their relative.

- 4.34 None of the people interviewed had sought or received independent financial advice specifically relating to their care situation. Some had been given general information through their council at the

time of the financial assessment, although this wasn't always accurate or helpful:

*"We decided what a load of rubbish! You know, we wanted to believe him because what he was saying was to our advantage, but when we tried to follow through it was a load of rubbish (...) he said 'can I see the bank statements?' and 'she's entitled to this and she's entitled to that, and entitled to something else.' And she was entitled to nothing!"*

- 4.35 All the carers had Power of Attorney arrangements to facilitate them supporting their relative and managing finances on their behalf. One person had made arrangements following the discovery of 'Solicitors for the Elderly' which he had found particularly helpful. Other financial help, such as Attendance Allowance was often discovered by chance rather than as the result of accurate information or advice.

## Conclusions

- 4.36 The experiences of carers were remarkably similar. To a lesser or greater extent all had found themselves struggling to find their way in a system of which they had little or no prior knowledge, and where the pathway was by no means clear. Experiences of contact with social services were primarily negative – focused principally on assessing the financial means of the person needing care, or were frustrating in failing to offer any clear information or advice and referring them elsewhere to other organisations which often in turn passed them on again. On many occasions people felt that they had to learn to play a 'game' in their dealings with the council – either to get information that was of value, or to persuade the council to accept financial responsibility when assets had been spent down. Moreover this was a game where the rules were hidden and apparently fluid. For people who were unskilled in such negotiations, or lacking in the time or other resources to engage in them, the process was bewildering and frustrating.
- 4.37 Being issued with a list of possible care homes was often the sole information that people were given, and of itself such a list was of limited value. People had little knowledge or expertise with which to judge the respective merits of one home over another or to interpret inspection reports, and although some people acquired knowledge rapidly (not least by undertaking personal visits), this was an uncertain science and one that was only viable for carers living in some proximity to the person needing support. Finding out how to navigate the system was all the more difficult when people were responding to the immediate demands of a crisis and having to make decisions in a hurry.
- 4.38 People acquired knowledge and information from various sources but typically these were informal and relied on word of mouth and reputation, rather than the result of clear sign posting. A minority of people had found their way to specialised advice (such as through Counsel and Care or local advocacy and brokerage services) and these were highly valued. However, for the most part these services were more apparent by their absence in people's lives than by their presence. While it was common for people to make Power of Attorney arrangements to better support a relative and handle financial matters, no one had taken independent financial advice or was aware of specific financial products that might be of benefit to their situation.
- 4.39 Not surprisingly, most carers viewed the future with some trepidation and concern. Where people were endeavouring to support someone at home they were doing so in situations that were often precarious and where increasing dependency would – sooner or later – be a tipping point, with the likelihood of residential care becoming necessary. In such situations some people were desperate and had no clear idea of what to do for the best. For carers already supporting someone in a residential situation the predominant concern was around whether people would outlive their savings and what might then happen.
- 4.40 As with the experiences of people who were self-funding, carers and family members were often isolated and poorly equipped to make important decisions about care and support. Having financial resources was no guarantee of itself that people were able to secure the best or most appropriate care and support or know how to access it.



## 5 Conclusions

- 5.1 This qualitative study of people's experiences of self-funding has revealed a picture in which there are many features that give cause for concern. Many of the emerging conclusions have been highlighted in the course of the report, and this final section does not repeat all of these, but does underline the major issues arising. In implementing the transformation agenda of Putting People First councils have been required to meet a number of key delivery milestones. All councils should already have a strategy and arrangements in place for universal access to information and advice services; by April 2011, the public should be informed about where they can go to get the best information and advice about their care and support needs. On the basis of the evidence of the current research, meeting this target will be challenging for many councils. Moreover, it is not enough that information and advice should be 'available', but it needs also to be relevant, accessible and timely – and satisfying those requirements will be considerably more demanding.
- 5.2 Few people – whether self-funders themselves or members of their families – have good awareness or understanding of how to go about getting information or advice on care and support. Most people consult with family and friends for advice, and gather information from informal sources, by word of mouth and reputation. For people who do not have close family members who can help them, or worse have relatives who have no wish to be involved, the process is even more challenging and stressful. In such circumstances it is not surprising that many people ignore the reality of their position and their increasing need for support until such time as a crisis in their health or a sudden change in their ability to remain independent forces a change of tack. Decisions were typically made as a matter of urgency and in practice people had little control over their situation and meaningful choices were often lacking.
- 5.3 Some people made use of the internet and the quality ratings of the regulator (CQC) to inform their decisions. However, under new arrangements the Care Quality Commission stopped awarding quality ratings on 30 June 2010 and ceased the process of key inspections that would result in awarding a quality rating from that date. A new information system is being developed to address the quality of adult social care and to "provide information about the quality of registered services for people who use and commission them, to help them make choices and decisions." Work is also taking place with the Social Care Institute for Excellence to develop the concept of 'excellence' in quality ratings (which a provider would have to apply for).
- 5.4 A consultation on the CQC proposals for quality information is expected in 'winter 2010/11' but had not appeared at the time of writing (December 2010), and the cessation of the quality ratings system in advance of the development of a new model has been the focus of criticism.<sup>xxviii</sup> The reduction in the amount of information being collected by CQC, and the emphasis in the new outcomes framework on 'essential standards' and 'risk-based inspection' could prove to be a retrograde step. It is essential that any new system of regulator judgements is readily accessible and understandable if it is to be of value to self-funders, carers and other people using care and support in making informed choices.
- 5.5 For most people in this study, contacting social services or the council for help or information would be anathema. The image of social services is such that for many people – particularly for those who are elderly – there is considerable stigma in approaching them for help. Furthermore, while people have little knowledge of how the social care system operates, most *do* have a general awareness that if they have any savings and own their own home they will have to pay for care and support. Armed with this information people may see little added value in approaching social services only for this to be confirmed. The experiences of people who took part in this study provided recurrent evidence that their low expectations were repeatedly reinforced.

- 5.6 The most frequent experience of people who *did* approach the council for help was to be provided with a list of care homes and other social care services. It would be very generous indeed to interpret such a list as an offer of information and advice. Councils should also play a part in signposting people towards other organisations that *can* provide such help, but again the overwhelming experience of most people was merely of being ‘passed from pillar to post’. In the single instance where someone was referred to an organisation that could provide tailored advice and information, the process of referral was handled poorly and a contact number passed on with apparent reluctance. Some people had found their way to other sources of specialised information (such as through Counsel and Care) and these were highly valued for their relevance and courteousness, particularly when contrasted with less favourable experiences of trying to access help or information. There is a pressing need for a range of independent and high quality information and advice services, together with individual advocacy and brokerage support, that can be easily accessed and does not require people to navigate multiple portals before arriving at the right place.
- 5.7 Despite all the emphasis of policy guidance on assessing people’s needs *prior* to looking at their financial means, many people had negative experiences of the opposite situation. It appeared to be commonplace that people would be asked about their financial situation at the outset and effectively told that no help was available if their assets were above the means testing threshold. Perhaps as a result of this experience the idea of ‘assessment’ was one that many people regarded with negative connotations; none of the people who were self-funding, nor their family members, had an experience of assessment that focused on identifying their needs for care and support, how best these might be met and what options were available.
- 5.8 It is possible that the term ‘assessment’ is inadequate to convey to people anything positive or to encourage them to go through the process in the hope of getting some help or useful advice. Similarly, those involved in providing assessment rarely seem to offer this as anything helpful concerned with identifying people’s needs rather than with identifying them as ineligible for help. In the absence of needs assessment people have inadequate knowledge about what support might be available to them and how to access it. People who could benefit from reablement and prevention services are at risk of missing such opportunities and being directed instead towards permanent residential care which might otherwise be avoided or deferred.
- 5.9 Councils that take on the responsibility for providing information and advice themselves, rather than ensuring that it is provided as part of a wider strategy, are likely to struggle to reach key audiences who are unlikely to access information from this source. Furthermore, the independence of information and advice provided in this way is also dubious, and there are dangers in trying to accommodate this function with one that is essentially providing a gatekeeper to limit access to publicly funded support.
- 5.10 It is also clear that people who are self-funding make major decisions, with consequences for large amounts of personal expenditure, on the basis of little or no independent financial advice. Few people were aware that specialised financial advice even exists in this field, and there is clearly a major task in raising the population’s awareness and knowledge. A similar issue arises in respect of people’s awareness of care and support in general. It was striking that while many older people had made wills and arrangements for their final wishes to be known, and many had made sure that their funerals were already paid for; none had thought about whether they might need care and support and if so what they would want to happen.
- 5.11 The responsibilities of councils to ensure that everyone can access the information and advice they need require a range of approaches if this is to truly be a ‘universal service’, and one that delivers high quality outcomes. Information alone is not sufficient; people also need guidance and support in planning how their care needs might be met, and in making some of the most important decisions of their life. The milestones for delivery of the transformation agenda remain important targets, but it is also vital that these are not seen as something that can be ticked as ‘done’. Rather, these will remain important objectives that need to be refreshed and revisited to ensure approaches are dynamic and delivering the intended outcomes.

- 5.12 Similarly the proposed outcomes framework for social care provides both risks and opportunities. In focusing on localism and a more permissive approach, rather than a top-down and centrally driven model, councils have opportunities to address outcomes that are meaningful to their communities. It will be essential that these, and the parallel Quality and Outcomes Date Set that is envisaged, are sufficiently broadly based that they do not focus only on people currently using social care services under the ambit of eligibility criteria, but that they include *all* people using care and support services, however these are funded.
- 5.13 The experiences of people who are funding their own care and support are complex and varied. In this study, a minority of people had sufficient financial resources and the support of family members to enable them to make considered and deliberate choices about the type of support they needed and wanted. For others, perhaps most, being a self-funder did not automatically mean that they had control over their situation and in practice their choices were few. With little idea of how to go about seeking help to navigate the complex world of care and support, most people were undertaking major life journeys and making significant decisions without the benefit of maps to guide them, and with little clear view of their destination. For people who did not have close family members to help them on the journey, the options were fewer still and the path a lonely and bewildering place to travel.
- 5.14 With the continued roll-out of personal budgets and wider social care transformation, all councils need to address the provision of information, advice and advocacy. There is much in the experience of people who are self-funding that could and should inform this development. Councils should recognise that people need to be able to access information and advice through a variety of accessible routes which offer different models and styles to match people's preferences (such as electronic information; telephone support, or face to face). On the basis of people's reported experiences in this study it is doubtful that the local authority is the organisation best placed to provide such flexible and independent advice when they are simultaneously acting as gatekeepers to limit publicly funded support, and when the involvement of social services is still widely perceived as stigmatising.
- 5.15 Too often the experience of self-funders is still poor, and the impact this has on their lives and decisions has been explored in this report. However, what people need from information and advice services is clear, and where good services exist, people's experiences are altogether more positive and lead to better outcomes. The vision for adult social care emphasises that personalisation should mean "people, not service providers or systems, should hold the choice and control about their care." This report has highlighted the considerable challenges that remain in ensuring that people *are* enabled to exercise autonomy, and that the journey through care and support becomes one that is well charted and clearly marked. Such dimensions must become integral to the key outcome domains being sought in adult social care.

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