

# Lost to the System? The Impact of Fair Access to Care

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Social Care Inspection for the production of  
*The state of social care in England 2006-07*

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# Executive Summary

## Introduction

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- 1 What happens to adults with social care needs who fail to gain access to care-managed services or who lose that support when their situation is reviewed? What about people who are self-funding – how do they navigate their way through the care system and are their needs adequately addressed by the market? These questions are of much more than theoretical interest. The Commission for Social Care Inspection (CSCI) has identified the trend for all councils to raise the threshold for access to social care services, with nearly two thirds setting the FACS (Fair Access to Care) entry point at 'substantial' in 2006-07 and almost three quarters expecting to be operating at such thresholds in 2007-08. What impact this targeting has on people needing support must be a matter of concern. Can it be assumed that people below the threshold are having their needs met elsewhere, or are the consequences altogether more uncertain? It was to address such issues that CSCI commissioned this special study. The core findings will be presented as a chapter of the *State of Social Care* report for 2006-07; however, the depth and breadth of the findings cannot be adequately presented within that limited space, and this is the full report of the study.
- 2 The study was undertaken in six anonymised councils in England; these six provided not only a spread of authority types and of geographical location, but also a range of different approaches to FACS. One of the councils had – until recently – only addressed social care needs in the critical FACS band. At the other extreme, one of the councils operated all four FACS bands of eligibility (Critical, Substantial, Moderate and Low); one council addressed needs within the top three bands, and the three remaining councils all addressed the top two only.
- 3 Fieldwork was undertaken at the levels of policy and operational staff, but also – and most importantly – at the level of people using services or attempting to do so. There was an attempt to match individual cases to the care managers and other staff responsible for assessment decisions in order to explore different perspectives on the same situation. Most – but not all - of the individual cases concerned older people, and it was not possible in the time available for the study to cover all of the other user groups adequately. However, interviews also took place with some younger disabled adults, people with chronic ill health, and people with learning disabilities, and with carers.
- 4 Much of the report presents a critical analysis of policy and practice and highlights many of the shortcomings uncovered. It is important to view this in context; the report is *not* – by and large – looking at the experience of people benefiting from care-managed services. Rather, it is focusing on people unable to gain such support but who believe they have significant needs for help. Alongside the many negative experiences we found it is important to acknowledge the positive stories where the FACS model was able to appropriately target support on people in need and to withdraw it when it was no longer required. It is also necessary to acknowledge that councils are having to implement FACS in a difficult financial climate and will

inevitably be very uncomfortable about some of the decisions they feel they are having to make.

## Policy & Operational Issues

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- 5 Councils develop and implement their FACS policies as a key mechanism for rationing and controlling demands on limited resources. We identified an inter-related trinity of rationing models: rationing by *directive*, by *discretion*, and by *diversion*. Rationing by directive refers to the formal policy on FACS. This top-down model of policy implementation is typically mediated by the operation of professional discretion in interpreting and applying policy. On occasions social workers may deliberately seek to find ways around the policy in order to better meet the needs of people. Rationing by diversion provides a middle path where a decision to decline care-managed support from the council might be off-set by diverting (and signposting) applicants to other sources of help. Such diversionary strategies are *most* likely to develop when eligibility criteria are restrictive and explicitly defined. The approach to diversion can be active or passive, with social services taking a hands-off approach of simply diverting demand elsewhere, or acting as a go-between to facilitate referral and trying to ensure that such diversion meets the reasonable needs and expectations of applicants.
- 6 The reasons why the threshold for FACS eligibility is rising and rationing by directive is more apparent are multiple. In particular, increasing pressures on resources are identifiable in the numbers of younger people with complex needs; rising numbers of elderly (and very elderly) people; substituting home-based care for residential solutions; and trying to address prevention services while also concentrating resources on people with greatest needs.
- 7 Where FACS eligibility bands had been tightened it is apparent that this was not the easy solution to managing demand that might have been predicted. Not only was it recognised that this strategy was inappropriate because it failed to address legitimate (and potentially increasing) needs, but it was also ineffective because it failed to save money. Moreover, while closing an eligibility band is relatively straightforward; re-opening these subsequently was far more problematic.
- 8 None of the councils in this study had addressed the relationship of self-funders to FACS eligibility. Indeed, self-funders; constitute a significant and often highly vulnerable population, but are often effectively invisible to politicians, service managers and practitioners. While one council had a strategy towards self-funders in preparation, this had yet to be implemented. Most councils claimed that they would offer assessment if requested, but the onus was very much on people seeking this out for themselves rather than it being actively promoted. Some felt that self-funders were simply nothing to do with them.
- 9 Getting the balance right between the goals of the organisation and the important contribution of professional judgement was far from easy. There is a widespread view among practitioners that social work is becoming 'de-professionalised', with little opportunity for social workers to apply their skills because of the continuing demands of rapid response and meeting performance targets.

- 10 Service-led rather than needs-based approaches to assessment were more entrenched among non-professionally qualified staff, often with a background in home care services. However, these people often occupied a particularly important role in undertaking intake assessments and referrals through Customer Liaison or Customer Relations Units, and judging which people were passed through for assessment and which were simply turned away or diverted elsewhere.
- 11 Attempts to limit the discretion of professional staff were evident in training programmes, peer review arrangements, supervision and management, and in processes to bring about cultural change.
- 12 Signposting to other sources of support (typically to third sector organisations) was a widespread practice, and the term itself was in general currency. Signposting strategies varied in sophistication, and while in some councils this was confined merely to the provision of information, elsewhere more proactive approaches were followed. In all but one of the councils signposting was typically an exit strategy where no further responsibilities towards applicants were acknowledged and no attempts were made to follow up individual referrals. In the one council which claimed to operate all bands of eligibility, people signposted to other services were still viewed as the responsibility of the council and to some extent could be identified.
- 13 In all six councils the lack of monitoring or reviewing the effectiveness of diversionary techniques represented a significant lacuna in councils' information that might have informed future planning and commissioning.
- 14 People who were self-funding and facing the momentous decision of moving into a care home received little or no help or advice from councils. At most they might be given a booklet with information on choosing a home. The same lack of attention to self-funders was evident once they were established in homes and there was no on-going contact or review. In many cases people who were self-funding appeared to be steered towards residential care with haste and before other options had been explored.
- 15 The only other way in which councils become aware of self-funders is when their resources become depleted and they are referred back to the council for help. None of the councils had a systematic approach for identifying such people in advance.

## Outcomes and People's Experiences

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- 16 The framework adopted for analysing people's experiences of social care services is outcomes-based and grounded in the seven dimensions set out in *Independence, Well-being & Choice* (that is, quality of life; choice and control; making a positive contribution; personal dignity and respect; freedom from discrimination and harassment; improved health and emotional well-being, and economic well-being).
- 17 It was striking that many people experienced a very poor quality of life. While few described their lives in wholly negative terms, most expressed a degree of resignation and acceptance of their lot. However, it was equally clear that the

quality of life for many could be significantly enhanced with relatively minor social care interventions.

- 18 Deciding to seek help from social services is rarely made lightly or frivolously. People typically seek help only as the result of a crisis and when they have exhausted all other possible avenues. For people who fail to meet the eligibility criteria of FACS the experience of assessment is one of frustration and disappointment that they can be offered no help. For people who are just about coping, but with considerable difficulty, the situation is bewildering.
- 19 People are resourceful and many will manage to put together a patchwork of support using a combination of friends, family and privately purchased services. However, what often characterises these situations is the fragility of arrangements which may break down when they are really needed.
- 20 People who fund their own care and support might be thought to have the greatest choice and control of all – they can use their money as they please. In practice, the study found that self-funding people on the contrary were often the most disadvantaged and isolated in the whole system. Rather than making active choices, many appear to end up in their situations as a matter of chance. None of the people we met who were self-funding had experienced a social care assessment prior to entering a care home, and most had not considered alternative solutions.
- 21 The provision of information and advice to self-funding residents is more likely to come from bank managers and solicitors than from people who are experts in social care.
- 22 The needs most frequently excluded by FACS eligibility criteria were those associated with domestic support and practical help. People care about the state of their homes and gardens; when their world is reduced to little more than their four walls these issues become disproportionately important. Denied help from the council, and often unable to access alternative help through signposting, the risk is that these low level needs can escalate as people try to cope unaided and may have accidents in the process.
- 23 Low level needs are often dismissed as trivial by councils and people seeking help with these tasks sometimes seen as trying to dupe the council into giving them help they are not entitled to. This picture did not appear to fit the people seeking help from social services who were interviewed for this study.
- 24 Eligibility for support can be approached in a flexible and personalised way, or in a task-based and mechanistic manner. The difference for people receiving personal care can be profound: a strip-down wash may satisfy requirements for basic hygiene but it fails utterly to meet people's needs for dignity and self-respect.
- 25 The FACS framework is intended to apply equitably to all adults needing social care. In practice it was acknowledged that there are inherent weaknesses and those who are most disadvantaged are young people in transitional groups, and old people who fall victim to cultural and institutional ageism.

- 26 Older people are also most likely to have assets and savings and therefore the most likely to contribute significantly towards the costs of their care. This is widely perceived as unfair and a tax on thrift and savings.
- 27 There are instances of the FACS system working effectively to target support on people in need and then to withdraw that support at review when it is no longer required. Intermediate care services and the provision of short term rehabilitation are examples of such interventions. However, these were in contrast with the more widespread experience of people unable to get access to the support they need, or having support withdrawn before they feel able to manage.
- 28 People who are self-funding are particularly anxious about the future and about what will happen when their savings run out. Few were well-informed about the savings threshold where they could apply for help from social services. For their part, councils' identification of such people was largely a hit and miss process.

## Conclusions

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- 29 The decision to restrict eligibility for social care to certain FACS categories is probably not one that any council makes lightly. Resource pressures in social care make it inevitable that councils are obliged to find ways of rationing.
- 30 It is clear that reducing eligibility *does not* eliminate demands for support and people with ostensibly eligible needs are rejected by councils.
- 31 Councils are increasingly focusing on narrowly defined areas of core business of adult social care. In practice there are tensions with the objectives of personalised support which are being encouraged by models of Direct Payments and the adoption of Individual Budgets.
- 32 The experiences and voices of people who use services, and of their carers, were sought out in this study. It is here that the impact of decisions on priority setting and rationing unravels in people's lives. Sometimes those experiences were positive; too often they were dismal, and much poorer than they could have been with minor amounts of service input. Many cases were uncovered where the absence of any help, or the provision of inadequate help, resulted in very poor individual experiences. It is possible for FACS to operate in a sensitive and flexible way to match the changing needs of individuals. In reality the risk is that FACS is used as a crude tool to limit demand, with potentially risky consequences for vulnerable people, and overwhelmingly poor quality life experiences for those who are deemed ineligible for support.
- 33 The precise point at which councils establish the threshold for FACS eligibility is not necessarily a predictor of how criteria operate in practice. On balance, more restrictive criteria are likely to be more restrictive in application, but the major issue is that of *policy implementation* rather than merely formulation. Existing performance measures appear to reveal relatively little about how councils behave towards prospective users of service who are judged to lie outwith their criteria. This underlines the central importance of developing an outcomes-based framework for evaluating councils' performance.

- 34 Fundamental change is required with a greater priority given to social care backed up with sufficient resources; and at local level councils need to develop more sophisticated and sensitive approaches to service rationing. The question to be answered is whether the present situation is both sustainable and – in pursuit of an outcomes focused personalisation agenda – defensible.

# Section 1: Background, Context and Approach

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## Eligibility in a council meeting FACS critical level only

Mrs X was born in 1914 and had been known to local agencies for at least 10 years. First contact occurred in 1996 when she began to have dizzy spells getting in and out of the bath. Following assessment by an OT Mrs X was provided with a stair rail, grab rail and bath board.

In 1998 Mrs X was knocked down by a car and left badly bruised and shocked. She was determined to remain at home, and was greatly assisted in this by support from a neighbour who helped with washing and shopping. This arrangement remained until 2002 when the neighbour became concerned at Mrs X's ability to cope, and about the growing role she was having to perform as a carer. Mrs X was finding it increasingly difficult to hear the doorbell or telephone.

In late 2003 Mrs X suffered several falls and was admitted to hospital. In January 2004 she was referred by the hospital to the local authority. By this time she was suffering from angina, high blood pressure, fainting spells and ongoing hearing problems. Also by this stage her neighbour was finding it more difficult to continue with her caring role. Following assessment Mrs X had her doorbell repaired, and was given advice and information. No further action was taken and the case was closed.

A year later, following representations to social services from the neighbour, Mrs X agreed to have frozen meals to reduce the demands on the neighbour, and the case was put on an annual review basis.

By August 2006 the situation had further deteriorated. Mrs X had fallen again and was found on the floor by friends and admitted to hospital. By this stage her neighbour was no longer able to continue providing the daily support which she had done for the previous nineteen years. No other informal sources of care were available. Assessment revealed that Mrs X was not looking after herself, rarely wore her emergency pendant, was not emptying her commode and was unable to use her walking frame about the house because of clutter. She was assessed as being at risk of major injury or incident and the occupational therapist recommended placement in residential care.

Mrs X was discharged from hospital in December 2006 and received social care help on a daily basis. The house was tidied to make walking easier. Although her independence began to improve Mrs X was not managing her catheter night bag or her medication. It was agreed that a home care package should be considered, but at this point Mrs X fell foul of inter-agency wrangling over budgetary responsibility. The local authority believed that Mrs X should have her needs met under NHS continuing health care criteria, and the PCT disagreed. The district nurse could offer no staff to help with the catheter bag and suggested this be resolved by removing the catheter, which would have left Mrs X incontinent. Ultimately the local GP surgery accepted responsibility for managing the catheter change.

The final entry from the local authority in this file (still in December 2006) records a visit from a social worker which describes Mrs X as unkempt, with her knickers around her knees and evidence of faeces on the floor. She was not taking her medication. Mrs X was assessed as managing her own personal care and meal preparation. Case closed.

### **A story of short term social care intervention**

Miss J is 94 years old and has never been married. She lives alone in a first floor flat and has previously been highly independent and engaged. Following a fall at home in which she broke her hip she was treated in hospital and then moved a few days later to a joint health and social services rehabilitation centre for intensive support. She remained at the centre for just over 8 weeks and was then discharged home.

The experience of rehabilitation was very positive. Miss X spoke highly of the kindness of the staff and the quality of the care she received. She felt ready to return home. A home visit took place to assess her needs and various items of equipment were supplied. Miss X had previously relied on a private cleaner together with help from her god-daughter who does her shopping and laundry, and these arrangements were deemed sufficient. A meals service was arranged to provide a hot lunch each day and Miss X was able to return home and to manage her personal care.

### **The experience of being a self-funder**

Miss Y is 95 years old and unmarried; she has few surviving family members and they live at the other end of the country. Miss Y feels low at times and regrets that she has out-lived all her close friends. Some years ago she was referred to social services by her GP practice; she had broken her wrist and was finding it hard to manage. However, Miss Y declined a visit from social services to carry out an assessment and was sent information in the post.

Miss Y lived previously in a large house which she owned and she used her savings to buy the help she wanted. She had a cleaner, but did not feel the need for personal care. She had got into the habit of taking a taxi to go out for lunch each day to a local restaurant. When she felt unable to cope or in need of a break Miss Y would book herself into a care home for a week or two and then return home. Eventually in 2005 she decided to sell her house and move permanently into a residential care home. Prior to making this decision Miss Y did not explore other options which might have helped her remain at home and did not contact social services for any advice or assistance. Miss Y remains relatively independent; she has diabetes and various digestive problems; she also has osteoarthritis and osteoporosis and her mobility is poor. She gets around the home with the help of a walking frame and regularly goes out and about to take the air on her electric scooter. She regrets that she had to give up driving at 92.

Miss Y has a good relationship with the staff in the home and enjoys joking with the care workers. However, she has become increasingly dissatisfied with the quality of care in her residential home, and particularly feels the standard of catering has deteriorated. Other residents have also become less content and several have moved to other homes. Miss Y saw an advert in a local newspaper for a new care home development under construction nearby and is considering whether or not to move. Her savings are not causing her concern but she doesn't want to get into a situation where she moves somewhere considerably more expensive and then finds herself running out of money at some time in the future. She is trying to make a realistic assessment of how long she is likely to live balanced against how long her savings should last. Her GP visits regularly and comes after surgery in order to be able to spend time with Miss Y. The doctor appears to be a source of advice for Miss Y and she has discussed the possibility of moving to the other home with her. At the time of our interview Miss Y was still weighing up her options and deciding what might be the best course of action.

## Introduction

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- 1.1 The three stories presented above are typical of many which we gathered in undertaking this study. These are stories about people's lives; sometimes about personal tragedies and sadness, sometimes about the failure of services to meet their needs. At other times they are success stories about service interventions which helped people get back on their feet and return to independence. Stories such as these are at the heart of this report. We have begun by introducing these accounts to focus from the outset on the most important voices that need to be heard in social care – those of people who use the services.
- 1.2 What these vignettes also illustrate is something of the diversity of experience: from the person who was arranging their own care and paying for it from savings without any recourse to social services, to a person who on any reasonable grounds might have been expected to be heavily supported by the local council but wasn't, and to another who was offered a time limited response in order to meet specific objectives. These – and many other permutations – were repeated time and again in our fieldwork. All of the experiences reflect on some level the impact of Fair Access to Care (FACS) policies and the operation of eligibility criteria. It is immediately evident that sometimes those criteria can work very successfully in targeting support when and where it is needed. It is equally clear that on other occasions that targeting is questionable. It was the task for this study to explore the variables which determine these different outcomes. What is needed to ensure that FACS operates rationally, coherently and humanely, and what are the consequences when this is not the case?
- 1.3 Before presenting the findings of the study it is important to understand the reasons why the work was undertaken at this time, and the approach that was adopted.

## Background to the Study

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- 1.4 In its State of Social Care Report 2005-6, the Commission for Social Care Inspection (CSCI) drew attention to the "ever-rising eligibility criteria for access to services". Nearly two-thirds of councils had set their threshold for care managed services at 'substantial' in 2005-06, with many more expecting to raise their eligibility thresholds in 2006-07. The consequences for people who do not meet the criteria are limited, "in some cases, people rely on friends and family members. In others, they pay for their own care. Some people have no option but to do without."<sup>1</sup> CSCI made a commitment to examine the impact on people of targeting social care resources so narrowly, and to gather evidence about what happens both to those people who use their own resources to obtain care, and those who are not deemed eligible for council arranged social care.
- 1.5 This study is one part of the response to that commitment. It is important at the outset to emphasise that this is not a study of the experiences of people who receive adult social care. Rather it is a study of people who do *not* receive such care – hence

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<sup>1</sup> CSCI (2006), The State of Social Care in England 2005-06, P. iv.

the term 'lost to the system' used in the title. This means that some of the messages inevitably have a negative ring to them, and they should not be taken as a commentary upon the totality of care that is being arranged and provided by local councils.

- 1.6 The study comprises an exploration of policy, operational and individual levels of activity in six anonymised localities across England. The localities were selected on the basis of the following criteria:
- a geographical spread across England;
  - a mix of urban and rural localities to capture a spread of different sorts of local challenges;
  - a mix of areas with relatively high and relatively low levels of deprivation and with diverse populations around age profiles and ethnicity;
  - a range of localities encompassing relatively high and relatively low CSCI star ratings;
  - a range of different local applications of the Fair Access to Care (FACS) bandings setting thresholds for eligibility at critical, substantial, moderate or low levels.
- 1.7 The localities briefly comprise the following:
- **Authority A** is a large shire county that is very diverse socially, economically and geographically, with some areas offering a high quality of life and others suffering serious urban disadvantage. The population is increasing and getting older – it is projected that by 2010 around 23% of the population will be 65 and over. Around 80% of the population lives in sparsely populated areas which has significant implications for service delivery. Black and ethnic minority (BME) groups make up just over 1% of the total population. For the past five years, Authority A has received a two star rating from CSCI for its adult social care services, but in 2006 its capacity to improve fell from 'promising' to 'uncertain'. In terms of FACS bandings the authority has, until recently, restricted support to the 'critical' band only.
  - **Authority B** is a large city borough that faces significant social and economic problems in the wake of deindustrialisation. In 2005 around 16% of the population was aged 65 or over, about 10% of people in all age groups are classified as permanently sick or disabled, and 2% of the population consists of BME groups. Between the years 2002 and 2006, Authority A received a three star rating for its adult social care services with its capacity to improve ranked as 'excellent'. In the case of FACS bandings, it has kept open all four levels and has no plans to make any changes.
  - **Authority C** is a unitary authority, previously part of a large shire county, which encompasses some highly affluent areas alongside pockets of deprivation. The area enjoys popularity as a retirement area and also continues to have an important tourism role. It has an elderly population that is larger than the national average (just under 20% of people are aged 65 or over), and 5.3% of the population aged 16-74 is permanently sick or disabled. The population is less ethnically diverse than that of England and Wales overall, with 7.5% of the population in BME groups. The Council has been rated as two star for its adult services during 2005 and 2006, improving from a one star in previous years. It

is judged to be serving most adults well; however, its capacity to improve has dropped from 'promising' to 'uncertain'. Eligibility criteria for social care set the threshold at substantial levels of need.

- **Authority D** is also a unitary authority and has enjoyed a two star rating for adult services since 2003, serving most adults well and with a promising capacity for improvement. As in authority C, the threshold for eligibility for social care addresses substantial and critical levels of need. The authority is a growing one which has enjoyed continuing development. It has a relatively young population, with almost a quarter of the population aged 18 or under, and 10.6% aged at least 65. The relatively low proportion of the population that is currently elderly is expected to grow rapidly in the future. The population is also diverse with 9.3% overall (and 23% of the school population) belonging to BME population groups.
- **Authority E** is a diverse and generally affluent area with a population of around 300,000. It has a high density population that increased by around 17% in the decade from 1991 – 40% of the population is BME and there has also been recent migration from Eastern Europe. The council was awarded two stars by CSCI in 2006, following no stars in 2004 and one star in 2005. It's eligibility criteria state that it will address critical and substantial levels of need.
- **Authority F** has been a unitary authority since the 1990s. It has a population of around 160,000 with a mix of urban and rural areas. BME numbers (2.5%) are low compared to the average for England though there has been an increase in people from Iraqi-Kurdish and Polish backgrounds in recent years. Council adult social care services were awarded three stars by CSCI between 2002-4, but this fell to two stars in 2005. The council meets moderate, substantial and critical bands under FACS.

1.8 Fieldwork was undertaken at three levels (policy, operational, individual) and in each locality there was an exploration of the twin dimensions of the experience of people who fall just below the threshold for social care eligibility, alongside those who choose to fund their own care. The methodology comprised:

- a study of all relevant national, local and academic documentation;
- at the policy level, semi-structured interviews with elected members and senior managers;
- at the operational level, semi-structured interviews with operational managers and care managers;
- at the individual level a combination of focus groups with representative groups of people who use services (or have attempted to access services) and their carers, and individual interviews with a sample of people who are self-funding, and people (and their carers) deemed ineligible for council support at the substantial and moderate thresholds.

1.9 In total, interviews were undertaken with approximately 110 people, while a further 15-20 people were involved in Focus Group discussions. Interviews were normally digitally recorded and fully transcribed, and these have been drawn upon liberally throughout the report. Most of the adults using services (or trying to access services) whom we interviewed were older people, and it was this group that emerged as the

one most likely to be disadvantaged by eligibility criteria. However, we also carried out some interviews with younger adults with physical disabilities, chronic ill health and learning disabilities. It is not the intention in this report to produce case studies for each of the six localities; rather the aim is to identify and understand some general issues on the formulation and implementation of FACS insofar as this affects self-funders and those denied council support.

## Context and Focus of the Study

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- 1.10 It is important to put the study into context – to understand the reasons why it has been undertaken, the policy context within which it sits, and the relevant evidence that is already available from other sources. All governments are concerned about levels of public spending and all societies limit access to social care in some way. As Allen et al<sup>2</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;
  - 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.
- 1.11 Resource allocation has become much more open to public scrutiny and debate, and for the most part this debate has been framed within a discourse on rationing. Although the concept of rationing is often used pejoratively, there is nothing inherently wrong with allocating resources according to need; the issue is how this is translated into practice. In setting up such arrangements eligibility criteria are a key mechanism in the definition and management of need by agencies, serving to regulate service provision in line with available resources. Where resources become tighter, these criteria can be adjusted in order to narrow access to support, and issues then arise over the extent to which such criteria are equitable in principle and consistently applied in practice. The issue of eligibility has become increasingly important in social care, and has moved from being localised and sometimes relatively informal, towards a formalised national framework that is locally interpreted and implemented – Fair Access to Care (FACS).

### **Rationing in Social Care: Fair Access to Care (FACS)**

- 1.12 The key national eligibility framework for social care in England is that set by FACS, which originated in the 1998 White Paper, *Modernising Social Services*.<sup>3</sup> This recommended that councils "*should have clear rules about who can get help*" so that "*everyone in the area gets treated fairly*" and in turn led to the publication of

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<sup>2</sup> Allen, D, Griffiths, L and Lyne, P. (2004) Accommodating health and social care needs: routine resource allocation in stroke rehabilitation, *Sociology of Health and Illness*, 26 (4), 411-432.

<sup>3</sup> Department of Health (1998), *Modernising Social Services*. London.

guidance on FACS<sup>4</sup> alongside implementation Questions and Answers<sup>5</sup>. This guidance provided councils with a national framework for setting their eligibility criteria based upon individuals' needs and associated risks to independence, and identified four eligibility bands – critical, substantial, moderate and low. The nature of each of these bands is shown below.

**Critical** when:

- Life is/or will be threatened and/or
- Significant health problems have developed or will develop; and/ or
- There is, or will be, little or no choice and control over vital aspects of the immediate environment; and/or
- Serious abuse or neglect has occurred or will occur; and/or
- There is, or will be, an inability to carry out vital personal care or domestic routines; and or vital involvement in work, education, or learning cannot or will not be sustained; and/or vital family and other social roles and responsibilities cannot or will not be undertaken.

**Substantial** when:

- There is, or will be, only partial choice and control over the immediate environment; and/or
- abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out the majority of personal care or domestic routines; and/or
- involvement in many aspects of work, education and learning or will not be sustained; and/or
- the majority of family and other social roles and responsibilities cannot or will not be undertaken

**Moderate** when:

- There is, or will be, an inability to carry out several personal care or domestic routines; and/or
- Involvement in several aspects of work, education or learning or will be sustained, and/or
- Several social support systems and relationships cannot or will not be sustained; and/or
- Several family and other social roles and responsibilities cannot or will not be undertaken

**Low** when:

- There is, or will be, an inability to carry out one or two personal care domestic routines; and/or

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<sup>4</sup> Department of Health (2003), *Fair Access to Care: Guidance on Eligibility Criteria for Adult Social Care*.

<sup>5</sup> Department of Health (2003), *Fair Access to Care Services: Implementation Questions and Answers*

- Involvement in one or two aspects of work, education or learning cannot or will not be sustained; and/or
  - One or two social support systems and relationships cannot or will not be sustained; and or
  - One or two family and other social roles or responsibilities cannot or will not be undertaken
- 1.13 The framework is not simply a guide, and councils should not vary the wording. Once a council decides where to draw the line in the light of the resources it has allocated to adult social care, then it should use the exact wording of the bands to describe the risks from which eligible needs will be identified and met. However, councils may add additional risk factors as extra bullet points within a band, and they may create 'sub-bands' such as 'moderate-greater' and 'moderate-lesser'. The guidance confirms that when setting their eligibility criteria, councils should take account of the resources locally allocated to adult social care. Because of the different resource positions of councils, the guidance does not require them to reach similar decisions on eligibility, or to provide similar services to people in similar needs. However, *within* a council area, individuals in similar circumstances should receive services capable of achieving broadly similar outcomes, and people should be treated equitably.
- 1.14 The remainder of Section 1 reviews some of the issues and existing evidence on FACS and self-funding at the three levels that constitute the framework for this study – policy, operational and individual. This review has informed the course of the investigation and the judgements that will be made later in the report.

## FACS: Policy Issues

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- 1.15 The introduction of FACS has raised several policy issues, some of which have been explored further in this study, notably:
- Local determination of FACS banding
  - Audit and performance monitoring
  - Intersections with continuing health care
  - Developing the preventive agenda

### Local Determination of FACS Banding

- 1.16 The targeting of support upon people with the greatest need did not begin with the introduction of FACS – indeed the Victorian Poor Law was based upon the premise of 'less eligibility'. However, the issue has received more attention in recent years. An Audit Commission report in 1997,<sup>6</sup> for example, drew attention to the 'vicious circle' in which the provision of 'crisis' services was consuming the vast majority of resources, thereby precluding possibilities for more preventive and rehabilitative work. Academic research undertaken prior to the introduction of FACS similarly suggests that councils were concerned to tighten both their initial screening

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<sup>6</sup> Audit Commission (1997), *The Coming of Age: Improving Care Services for Older People*. London.

processes and their own local eligibility thresholds.<sup>7 8</sup> What the introduction of FACS has done is expose this trend to greater scrutiny and debate.

- 1.17 As noted at the beginning of this section, it is now widely recognised that councils are increasingly withdrawing support from people with low, moderate and even substantial levels of risk. Latest evidence from CSCI indicates that the proportion of councils who have set their social care eligibility threshold at 'substantial' has increased from 53% in 2005-06 to 62% in 2006-07. This upward trend is expected to continue with 73% of all councils anticipating that they will be operating at substantial or critical eligibility thresholds in 2007-08.<sup>9</sup> Other evidence also suggests the tightening of criteria is intensifying. Annual surveys are now being conducted by Counsel and Care, the second of which was published in July 2007<sup>10</sup> suggesting that the 'care gap' is widening and low level services are being further squeezed out in favour of critical and substantial care services. In 2007-8, it is estimated that 15% of councils surveyed raised their service thresholds, and none had extended their eligibility criteria from the previous year in order to become more flexible. The study found just over 70% of councils provided services for people with high needs (critical or substantial), and 12% confined their help to the critical band only. A survey of half of all relevant councils by *Community Care* magazine revealed broadly similar findings.<sup>11</sup> The councils that comprise the sites for our study cover the full spectrum of possibilities – from a council that was (until very recently) critical only, to one that has kept all four bands open.

### **Audit and Performance Monitoring**

- 1.18 FACS makes a distinction between 'presenting needs' (the needs described by adults seeking social care support or made by others on their behalf) and 'eligible needs' (those needs that are assessed as falling within a council's eligibility criteria, and which should be met). FACS guidance is clear about the importance of monitoring both those whose needs are deemed as eligible and those whose 'presenting' needs are not considered to be eligible. In particular it is said that councils should be able to:
- monitor the extent to which different groups are referred, which groups receive an assessment and, following assessment, which groups go on to receive services;
  - monitor the quality of the assessment and the eligibility decisions of their staff;
  - monitor which presenting needs are evaluated as eligible needs and which are not.

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<sup>7</sup> Davis, A, Ellis, K and Rummery, K (1993), *Access to Assessment: Perspectives of Practitioners, Disabled People and their Carers*. Bristol. Policy Press.

<sup>8</sup> Janzon, K. (1998), Eligibility Criteria: A case of muddling through? *Managing Community Care*, 6 (5), 209-16.

<sup>9</sup> Commission for Social Care Inspection (2008), *The State of Social Care in England 2006-07*

<sup>10</sup> Counsel and Care (2007), *Care Contradictions: higher charges and fewer services*.

<sup>11</sup> Where the Poor Law Lives On. *Community Care*, July 19<sup>th</sup> 2007, p18-20.

1.19 Although councils are urged to audit and monitor performance in these and other ways in order to inform service delivery, planning and commissioning, it is unclear how far this actually takes place. Without such activity, councils will lose data which could be valuable in informing the development of preventive services (another requirement of the guidance) and will accordingly have no idea what befalls those who have failed to access support. There is evidence that little information on unmet need is gathered from individual assessments, and that such data as exists is rarely aggregated for planning and commissioning purposes.<sup>12</sup> Indeed the concept of 'unmet need' is one which is often interpreted solely to refer to needs that meet eligibility criteria and takes no account of unmet presenting needs. One of the purposes of this study is to help fill this gap in our understanding and awareness of those people who do not fall within the remit of council eligibility.

### **Intersection with Continuing Health Care**

1.20 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 the councils, the 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.

1.21 The CHC-social care boundary has long been troublesome. The Royal Commission on Long-Term Care<sup>13</sup> recommended that all nursing care and personal care should be provided free of charge (and funded through taxation), while people should be means-tested for the living and housing cost components of their residential accommodation. The Government did not accept this central recommendation, but did address anomalies which meant that people accommodated in nursing homes were effectively paying for nursing care that would have been free of charge in any other setting. The Registered Nursing Care Contribution (RNCC) was introduced from October 2001 and established three bands for nursing care (low, medium and high) that would be paid for by the NHS.

1.22 This settlement has not proved to be durable and anomalies have persisted. Each of the Strategic Health Authorities (SHAs) has 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>14</sup> The NHS Ombudsman

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<sup>12</sup> Clough, R. And Manthorpe, J. (2006), *The Support Older People Want and the Services they Need*. Joseph Rowntree Foundation.

<sup>13</sup> Sir Stewart Sutherland (1999), *With Respect to Old Age: A Report by the Royal Commission on Long-Term Care*. Cm 4192-1. London: The Stationery Office.

<sup>14</sup> *Official care figures reveal true state of postcode lottery*. Age Concern Media Centre, 13.07.07.

has repeatedly highlighted the continuing inconsistencies, a series of high profile judicial reviews (notably the Coughlan<sup>15</sup> and Grogan judgements<sup>16</sup>) have challenged the legality of local interpretations, and the House of Commons Health Committee has also criticised the anomalies which beset CHC.<sup>17</sup> In 2003/04 the Department of Health required all SHAs to review their processes and to make restitution in cases where criteria had been wrongly interpreted or applied and people had been wrongly denied continuing care.<sup>18</sup> Finally, in response to on-going difficulties and the need to improve consistency of approach and ease of understanding the Government has (from October 1<sup>st</sup> 2007) introduced a new national framework for CHC designed to end the postcode lottery, replace regional criteria with a national system of eligibility, and to simplify the RNCC 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 7000 per annum, up to a total of 31,000. The fieldwork for this study preceded the introduction of the new arrangements.

## Developing the Preventive Agenda

- 1.23 There is a considerable body of evidence testifying to the importance of 'low level' preventive support. A three year study by Bowling et al<sup>19</sup> of people aged 85 and over found that the activities experienced as most difficult were odd jobs around the house, shopping, using public transport and dealing with finances – all tasks that, in isolation, are unlikely to be considered as priorities for council funding. The high value placed by older people on 'low level' work has been repeatedly established<sup>20 21</sup> and appears to be significant in terms of their perceptions of day-to-day coping and independence and the maintenance of a positive identity.
- 1.24 All of this does, on the surface, 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 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.

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<sup>15</sup> R v. North and East Devon Health Authority ex parte Pamela Coughlan.

<sup>16</sup> R v. Bexley NHS Care Trust ex parte Grogan.

<sup>17</sup> House of Commons Health Committee (2005), *NHS Continuing Care*, Sixth Report of Session 2004-05, Volume 1, HC 399-1, London: The Stationery Office.

<sup>18</sup> Henwood M (2004), *Continuing Care: Review, revision and restitution*, London: Department of Health.

<sup>19</sup> Bowling, A., Grundy, E. And Farquhar, M. (1997), *Living Well into Old Age*. London: Age Concern

<sup>20</sup> Clark, H., Dyer, S. And Horwood, J. (1998), *'That Bit of Help': The high value of low level preventative services for older people*. Bristol: Policy Press.

<sup>21</sup> Raynes, N., Clark, H. and Beecham, J. (Eds), (2006), *The Report of the Older People's Inquiry into 'That Bit of Help'*. Joseph Rowntree Foundation: York.

- 1.25 While the guidance sees FACS as a way of remedying such a narrow approach, others identify tension between preventive aspirations and the targeting of resources on those with the highest needs. Counsel and Care,<sup>22</sup> for example, argue that:
- "If the Government's direction of travel is towards more older people remaining at home for as long as possible, then there is a clear contradiction in the rhetoric and what services are actually available."* (p5)
- 1.26 One answer to this dilemma is the creation of 'sub-FACS teams' which are targeted at working with individuals likely to fall below FACS thresholds.. Although some such teams may operate under the auspices of the POPP (Partnership for Older People Projects) programme, little is yet known about their incidence or impact.

## FACS: Operational Issues

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### The Influence of Professional Discretion

- 1.27 While the FACS process establishes a framework and apparent 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. It is well established that there is an inevitable element of professional judgement made in interpreting eligibility for service, and it is therefore vital to understand professional behaviour as well as the organisational and financial frameworks within which this takes place.
- 1.28 Assessment is a dynamic activity that is, to some extent, negotiated between the potential service user and the frontline practitioner, and this will shape the implementation of eligibility frameworks such as FACS. The guidance is clear that assessments should be 'person-centred' not financially driven, and recognises the contribution of sound professional judgement rather than a tick-box approach to the determination of eligibility. The Question and Answer guidance, for example, states that:
- "...councils should always bear in mind that needs assessment and risk evaluation rely for their quality on person-centred conversations with individuals seeking help, carried out by competent professionals prepared to exercise their judgement. Frameworks, case examples and the like can only ever support the exercise of person-centred, competent judgement."* (p6)
- 1.29 Professional judgement is also 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 best these can be met. Two recent studies reveal the influence of professional staff and

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<sup>22</sup> Counsel and Care (2007), *op cit*

the judgements they make. First a study by Foster et al<sup>23</sup> into the assessment dynamics of practitioners working with adults with disabilities, which reveals the power of front-line practitioners to either restrict or extend the nature of the assessment exercise. The authors note that:

*"By exercising their power over the assessment process, practitioners can limit the assessment process and therefore access to services, or conversely they can look beyond the referral priority and engage users in considering other priorities and responses."* (p130)

1.30 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.

1.31 A study that focuses more specifically upon the impact of the FACS framework upon professional behaviour is that by Charles and Manthorpe<sup>24</sup> in their analysis of the social care assessments of older visually impaired people. They found unanimity amongst the professional practitioners that the introduction of FACS had not made much, if any, difference to their assessment practice. Amongst the professionals there was a determination to ensure that those being assessed met local eligibility criteria wherever the eligibility level was set. Whilst this may have some benefits for users in terms of service access, the authors do pose an important question that is central to this study also:

*"Is it appropriate that in a modernised social care system, local solutions are developed by design or accident, which in part are based on inevitable differences in professional interest, wisdom or experience?"* (p74)

### **The importance of Access to Information**

1.32 One of the implications of the denial or withdrawal of services from people in some of the FACS bands is the growing importance of 'signposting' to potential forms of support other than council services. Whilst this may involve active support (such as the 'sub-FACS' teams mentioned earlier) it will tend to depend primarily upon the provision of good information, and it is far from clear that this is routinely available. The Counsel and Care study,<sup>25</sup> for example, claims that the pressure on social services staff means that signposting is often overlooked, and this is particularly important for those whose needs have been assessed as below the criteria for eligibility.

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<sup>23</sup> Foster, M., Harris, J., Jackson, K., Morgan, H. and Glendinning, C. (2006), Personalised social care for adults with disabilities: a problematic concept for front-line practice. *Health and Social Care in the Community*, 14(2), p125-135.

<sup>24</sup> Charles, N. and Manthorpe, J. (2006), *Understanding Social Care Assessments*. Social Care Workforce Research Unit, King's College London.

<sup>25</sup> Counsel and Care (2007), *op cit*

- 1.33 The whole issue of information provision has been explored more deeply in a recent report from the Picker Institute<sup>26</sup> which looks at how patients, service users and carers currently find out about health and social care services. The findings give rise for concern:
- that 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.
- 1.34 The report accordingly recommends 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. It forms an important part of this study since many councils will justify the loss of a FACS band by pointing to an enhanced 'signposting' service.

## FACS: The Individual Level

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- 1.35 This study is primarily concerned with two types of cases – those assessed as ineligible for council funded social care, and those who (for whatever reason) become self-funders. In both cases relatively little is known about the fate of people in these situations. FACS guidance is strong on procedural propriety where councils do not offer direct help following an assessment or review, but has little or nothing to say about tracking the fate of those who are turned away. It is said that councils should:
- put decisions and reasons in writing and make a written record available to the individual;
  - be prepared to provide individuals with useful information and advice about other sources of support;
  - make individuals aware that they may use the complaints procedures to challenge decisions;
  - tell individuals that if their circumstances change they should renew contact for a re-assessment.
- 1.36 Filling the information gap on what happens to such people is one of the main reasons for this special study. Much the same could be said of the case of self-funders whether in care homes or in their own homes. The Wanless Report<sup>27</sup> points

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<sup>26</sup> Swain, D. et al (2007), *Accessing Information about Health and Social Care Services*. Picker Institute Europe

<sup>27</sup> Wanless Social Care Review (2006), *Securing Good Care for Older People*. London: King's Fund.

out that the data on self-funded care is much less complete than that on state-funded care, especially in the case of home care support where it is difficult to distinguish between private care and private domestic help. In the case of residential care, the evidence suggests that self-funding residents tend to be relatively physically independent on admission, and that it is common council practice to encourage self-funders to admit themselves directly to care homes without a needs assessment<sup>28</sup> or any help or guidance in choosing a home.<sup>29</sup> Many of these individuals will be funding their care through the sale of their homes - a minimum of around 40,000 such people per year<sup>30 31</sup> - and they constitute around 30% of all care home residents. People who are potentially ineligible for services but who would have to fund themselves *are* still entitled to an assessment of their needs, but it is unclear to what extent this is offered to them, or indeed taken up. The most recent estimate based upon a CSCI study<sup>32</sup> suggests that half of all people self-funding their own care do not have a care assessment.

- 1.37 The distinction between people who are council supported and those who are self-funding is arguably becoming increasingly blurred. The promotion of the personalisation agenda in social care – through the development of Direct Payments and Individual Budgets – will be increasingly significant in further blurring of this boundary. When people have their own budget to purchase the social care they need they will operate in a way that is comparable to self-funders. That is, they will identify their needs (through self-assessment), agree on the support they need to help them live their lives, and make the arrangements necessary either independently or with help from the local authority or another party acting as broker. The expansion of personalisation will simultaneously drive the development of brokerage and self-directed support services which may also prove to be of value to self-funders who currently get little or no support and advice in making their own arrangements. However, for those needing council funding it will still be necessary to demonstrate eligible needs under local FACS arrangements.

## Conclusion

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- 1.38 Section 1 has been a prelude to the main body of the study which reports upon the fieldwork findings. It has covered some of the key issues that emerge from existing literature and research, and has helped to form our own lines of enquiry. The three levels of analysis – policy, operational and individual – are obviously not discrete, but they do provide a conceptual framework that allows a better understanding of how a

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<sup>28</sup> Wright, F. (2003), Discrimination against self-funding residents in long-term residential care in England. *Ageing and Society*, 23, p603-24.

<sup>29</sup> Personal Social Services Research Unit (2002), *Self-Funded Admissions to Care Homes*. University of Kent.

<sup>30</sup> Hamnett, C. (1997), Housing wealth, inheritance and residential care in Britain. *Housing Finance* 34, p35-38.

<sup>31</sup> Henwood M (2006), *Self-funding of long-term care and potential for injustice*: Background paper for BBC Panorama.

<sup>32</sup> Commission for Social Care Inspection (2007), *A Fair Contract with Older People?* London: CSCI.

policy is formulated and implemented, and with what consequences for affected individuals.

- 1.39 Section 2 of the report examines the policy and operational dimensions of FACS arrangements in our six localities. It identifies three main forms of rationing for social care services:
- rationing by directive
  - rationing by discretion
  - rationing by diversion
- 1.40 Section 3 then goes on to explore the impact of these modes of rationing upon the lives of individuals, both people using services and their carers, with a specific focus on those who self-fund their care and those judged to be ineligible for council-funded support.

## Section 2: Policy And Operational Issues

### Introduction: the 3D Framework

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- 2.1 In this part of the report the ways in which councils have formulated and operationalised their FACS policies are described and analysed. Conceptually there are two distinct issues at stake – *priority setting* which denotes the allocation of resources to particular services or programmes, and *rationing* which refers to the distribution of resources to individuals at the point of service delivery. Both are important, but the thrust of this report is upon rationing rather than priority setting. Rationing can take place in many different ways and at different points in the process of policy formulation and implementation. Klein et al,<sup>33</sup> for example, identify nine service rationing strategies:- denial; selection; deterrence; dilution; delay; deflection; substitution; termination; and charging.
- 2.2 For the purposes of this report a simpler '3D' framework will be adopted – rationing by *directive*, rationing by *discretion* and rationing by *diversion*:
- **Rationing by directive** refers to 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 national policy on eligibility criteria (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'.
  - **Rationing by discretion** refers to the exercise of professional judgement in the operationalisation of 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 important issue here is the extent to which the exercise of professional discretion can, in practice, reformulate policy and thereby make or break the paradigm of rationing by directive. 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.
  - **Rationing by diversion** refers to the attempt to limit demand upon one part of the system by either diverting it to other parts, 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. Rationing by

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<sup>33</sup> Klein, R, Day, P and Redmayne, S. (1996), *Managing Scarcity: Priority setting and rationing in the National Health Service*. Buckingham. Open University Press.

diversion may encompass characteristics of both of the other modes of rationing – it may be explicit and rule-based, but it may also be heavily contingent upon discretionary judgement.

- 2.3 These categories will be used to structure the analysis, but it is important to note that they are only conceptual tools designed to help our understanding of how policy is put into practice. In reality the likelihood is that all three will be operating simultaneously, and any one locality will exhibit a complex mix of each of them, with different outcomes in the lives of people who use (or are denied) services.

## Rationing By Directive

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### Budgetary Pressure and Demand Management

- 2.4 The distinction has already been made between priority setting and rationing, with the former setting the parameters within which the latter takes place. 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, and – in some instances – revising the threshold for eligibility. The increasing pressure upon adult social care resources came from several sources, as highlighted below.

- 2.5 **Younger people with complex needs:** The high cost of meeting the needs of younger people with very complex needs, with a knock-on effect to resource availability for other groups, was a recurring theme across the sites.

*"We have issues with funding high cost packages or residential placements for people with Asperger's syndrome or learning disability. The carers rightly want a say in the placement but they pick a £2-3000 placement."*

*"The big area that we are concerned about is the upward trend in demand for services from people with learning disabilities. It is costing us about a million pounds for six clients."*

- 2.6 The pressures caused by high cost packages for people with a learning disability alone were often cited as the main explanation for budgetary deficits, and in terms of the FACS bandings such cases were normally squarely within the critical band and guaranteed priority funding (with knock-on consequences for people judged to have less complex needs). Although a return to less expensive local arrangements was a frequently cited goal there was little evidence that much progress was being achieved in revoking out of area placements.

- 2.7 **Rising numbers of older people:** It is well known that the population of England is ageing – in the next ten years the number of people aged 85 and over is set to increase by two-thirds, compared with a 10% growth in the overall population. In terms of the demand for social care, the Wanless Review<sup>34</sup> projects a rise in the number of older people with a high level of need of 54% by 2025, and these trends are already in evidence. One of the sites in this study has a relatively young

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<sup>34</sup> Wanless, D (2006), *Securing Good Care for Older People*. London. King's Fund.

population (though even here the numbers of 'young elderly' are rising rapidly), but all of the rest were experiencing a pronounced increase in demand from the rising numbers of older people, sometimes at well above the average rate for England.

- 2.8 **High cost home care support:** In accordance with Government policy, councils were generally seeking to reduce the use of care home placements and to increase home care for people who in the past may have entered a residential setting. Although this trend may well have resulted in better outcomes for the people using the service (and also resulted in better CSCI star ratings), it did little to resolve budgetary problems (indeed, quite the reverse). Some respondents seemed surprised that this was the case:

*"Putting a brake on care home spending hasn't worked at all because you end up spending more on them remaining at home with domiciliary support. In fact funding has gone up!"*

*"What we have saved in residential funding is more than offset by a huge overspend on domiciliary support. The hardest challenge is how we unlock that resource to fund the prevention agenda. There may be some difficult decisions to make in the next year or so."*

- 2.9 **Addressing the prevention agenda:** Attempting to concentrate resources on those people with the greatest needs whilst simultaneously developing preventive services was a common dilemma facing councils – as one respondent noted, *"one of the notable features of that is that there is no additional funding"*. Indeed, for some, the mixed policy messages were felt to be contradictory:

*"Prevention is pretty big in the White Paper, but having FACS and also having to meet the wider wellbeing agenda is completely contrary."*

- 2.10 The partial exceptions to this situation could be found in the two councils in the sample that had successfully bid for funding under the Partnerships for Older People Projects (POPP), both of which were able to offer support for people who would otherwise have fallen outside of their eligible FACS bandings. However, POPP is not a source of long-term funding and it remains to be seen whether such support will endure beyond the period of funding.

- 2.11 **Frontline culture:** An exploration of frontline culture will form the basis of the second form of rationing in the 3D framework – rationing by discretion – but even at this early stage in the report it is important to highlight the role of professional culture in contributing to budgetary pressures. Again this seemed to be a factor that had taken policy makers somewhat by surprise:

*"Our social workers had been doing their own thing. Everybody was helping everybody and we suddenly woke up to a £3 million overspend."*

*"There was a feeling that the budget came out as a result of your activity, not that your activity controlled the budget. There is now a far greater understanding that if you do not manage your budget then it will get worse in every possible way."*

*"Their attitude was 'you have turned up on my doorstep so you must need a service and I'm going to be damned if I can't find you one."*

- 2.12 In these circumstances it seemed that local management had effectively abandoned responsibility for budget management to practitioners, with perhaps predictable results. Indeed, one of the key threads running through this report is the ways in which agencies have subsequently attempted to retrieve this situation by much closer surveillance and control of professional behaviour.

### **Responding to Financial Pressure: FACS as a Budgetary Tool**

- 2.13 The culmination of these pressures resulted in all of the localities facing considerable financial difficulties, with much criticism of the amounts of funding made available from Government, as well as of the ongoing central requirement to produce annual 'efficiency savings'. It is at this point that priority setting becomes the crucial parameter for rationing, as local politicians then have to determine the local budget for adult social care. This is inevitably a complex area within which local politicians have to weigh up a range of factors such as the needs of the local population, the cost of meeting those needs, and the likely responses of key stakeholders such as central government, the electorate, fellow politicians and officers and staff.

- 2.14 Overall in the sites covered in this study, there was a perception that adult social care was not a particularly high political priority, and it is in such circumstances that raising the threshold of eligibility for social care can appear to be an attractive option. Although adult social care portfolio holders tended to be supporters of their own domains (though even this could not be taken for granted), the attitude of fellow politicians was not always similar:

*"In the Cabinet, people were quite joyful that my budget had more or less broken even. When I mention FACS in Council or Cabinet they just look blank."*

*"Social services always seemed to be one of those services that consumed copious amounts of money and had an overspend every year. We had to ensure that it didn't keep consuming more and more council tax."*

- 2.15 Politicians can never be certain which decisions may turn out to be politically volatile with their electorates, but there was a strong view in some places that cutting FACS bands was a strategy with surprisingly limited political consequences:

*"When members are setting their priorities they will speak to people on the streets and ask them what is important to them. Social care won't feature in that."*

*"There isn't a lot of grey power out there really. It's not as if you are withdrawing something like a special needs school – that would cause a massive outcry."*

- 2.16 This was not a universal view. In one council (which met only critical and substantial needs) any reduction of bands was viewed as an act of political suicide by the portfolio holder:

*"Many authorities are now going for critical only and that would be over my dead body. It was mentioned on one occasion in Group and there was almost a revolution."*

*It is absolutely sacrosanct. Do that and we are in the press who will say it's the elderly paying the bill."*

- 2.17 Other factors could also sway a council against such an approach. In one locality it was felt that a move to restrict the range of bands would run counter to the prevailing political culture:

*"We did go through a period of thinking whether we should take away bands but we knew politically that wasn't going to be a winner. Rightly or wrongly we have elected members who like to be paternalistic and like to look after people, and we have a very culturally dependent population, not just social care but benefits and everything."*

- 2.18 National figures indicate a lot of movement in the availability of the lower ranges of the FACS banding, and this suggests that many councils nationwide have indeed seen FACS as the answer to their budgetary problems. The localities in this special study varied - most of them had maintained the same range of bands for several years, though the range of bands on offer varied from critical and substantial only, to all bands open. One of our sites had moved from critical and substantial towards critical only, but at the time of the fieldwork was in the process of re-opening the substantial band.

- 2.19 The limited shifts in banding across the sites did not mean that people living in these localities had no change in levels of support – demand management can be secured through a multiplicity of routes other than by a change in directive about the formal rules on eligibility. Perhaps the most common was to clarify and tighten up procedural guides in order to eliminate, or at least minimise, variable, expensive and, arguably, inappropriate interventions. Although often being utilised explicitly as a way of reducing expenditure, these techniques were claimed to be an improvement on previous bases for decision-making. One respondent with over forty years service with the same authority, for example, was able to recall that previous eras did not constitute a golden age of service availability:

*"Resources were never plentiful – we held waiting lists of nearly a hundred people waiting for residential care, and people who went in walked through the door carrying their own bags."*

- 2.20 This is a useful reminder of the widespread use in the past of rationing by delay. Others were willing to acknowledge that without clearer procedural guidelines for implementing FACS there could be little confidence that needs were being met equitably and appropriately – one manager described needs banding decisions by operational staff as having been tantamount to playing 'pin the donkey'. This can be especially true where all bands are open because practitioners may see little consequence in selecting one band over another except in the most extreme of circumstances:

*"Basically you just did the job and then afterwards you thought 'Oh God what band is it?' The actual banding wasn't a point of concern. We wouldn't go out and assess, and then go back to the banding – as long as I wasn't recommending somebody to go into a nursing home and putting them down as low! If I was challenged on an*

*assessment by a team manager I would have found it quite difficult to, say, differentiate between a critical and a substantial.”*

- 2.21 All of the sites in this study had recently developed or refined a range of procedural guides for use by practitioners in determining eligibility for services – typically some form of eligibility guide or grid, sometimes with a scoring system attached. This report is not the place to reproduce this material in full, but it is appropriate to briefly outline some of the different approaches. Typically, councils confine themselves to producing a local ‘matrix’ that essentially reproduces the definitions of the FACS bands contained in the national guidance. Practitioners are required to record risks to independence which are then compared with the risks set out in the council’s eligibility criteria. Sometimes they are supported in making their decisions by the use of illustrative ‘practice examples’ alongside each potential area of risk.
- 2.22 A more elaborate procedure has been recently developed in one locality that felt practitioner decisions had become a prime cause of budgetary difficulties. Here the sort of eligibility matrix described above is complemented in two ways. First, a scoring system is attached to the matrix. Of the 24 groups of eligible need, substantial need is said to arise where 11 or more of these groups have been identified in relation to the user; moderate needs where between three and 11 have been identified; and low needs where only one or two have been identified. If one or more factors are assessed as *vital* to the individual’s independence or health and safety, then the risk can be classified as critical.
- 2.23 Although more demanding than other approaches, managers here were adamant that the purpose was not so much to curb professional behaviour as to gain a better understanding of how decisions had been arrived at:
- “We weren’t challenging their ability to make a professional decision. What we were looking for was the evidence – why are you making this decision? We had to start somewhere”*
- 2.24 Secondly, and in addition to the score-based matrix, this council has produced what is known as a ‘Statement of Purpose’. This consists of a large (127 pages) manual that identifies 39 ‘Areas of Independence and Associated Need’ based upon the FACS domains – personal and domestic; work, education, learning and leisure; social support systems and relationships; and family and social roles. The manual in effect identifies the ‘core business’ of the council, describing the activities and needs that it regards as eligible and which it is prepared to provide or arrange in some other way. The key aims are said to be to:
- describe the eligible needs for which support will be provided – the ‘core business’ of the council;
  - guide assessors sequentially through a range of potential solutions for eligible needs;
  - identify the rules in relation to these potential solutions – in effect a template for practitioner decision-making that aims to cover every eventuality faced by a practitioner.

## Implementing FACS Directives: Implementation Issues

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- 2.25 These widespread attempts to strengthen the role of 'rationing by directive' constitute a new phase in the FACS policy journey, one in which much greater attention is focused upon policy formulation and the ways in which it should be operationalised. Few people expected this to be a straightforward process, and several problems with the directive model were duly identified: - unbundling bands and services; problems of de-banding and re-banding; the position of self-funders; and tensions with the personalisation agenda.

### Unbundling Bands and Services

- 2.26 At the conceptual level there are some tensions between FACS directives, and the need for individualisation and (increasingly) personalisation; the former thrives on standardisation and consistency, the latter on dealing with individuals on a unique case by case basis. Some respondents felt this tension more keenly than others:
- "It was said that FACS would not be a way of managing budgets, but it was always going to be. It should be about individual care for individual people, and standardisation is anathema to that."*
- 2.27 Others could see theoretical advantages to FACS, particularly in tackling previous inequities between different client groups, but felt these had not been fulfilled:
- "I loved the theory of FACS, that it would wipe out discrimination. We wouldn't be paying £700 per week for the residential care of people under 65 and only agreeing £350 for somebody older. It's been a great disappointment to me."*
- 2.28 It often seems to be the case that FACS is seen as the appropriate resource allocation mechanism for older people, but is perceived as less suitable for other groups, especially people with a learning disability.
- "It's really difficult because of the way it is worded; it doesn't talk about learning disability. An influential part of the service is delivered by clinical psychologists and psychiatrists, and they want to talk about an IQ of 70."*
- 2.29 Underlying some of these difficulties is the potential difference in assessment approach towards the two groups of users, with learning disability more likely to be person-centred, and older people more likely to be service-centred. One learning disability manager who had also sat on a panel for deciding the funding of care for older people described the differences:
- "I saw a marked difference between the information that is gathered for older people's services and my services. I appreciate that turnover makes it more difficult, but there is much less information and it is more difficult to form a full picture."*
- 2.30 This difference in approach can become crucial where operational staff conflate FACS bands with the allocation of 'band-specific' services, with the accompanying danger that support can be highly standardised but potentially inappropriate. In more than one of the localities in this study the FACS directive had linked bands to services, with front-line staff making decisions in a very inflexible manner – the fact that this

is not the intention expressed in FACS national guidance is yet another illustration of the weakness of top-down directives. However, the idea that operational staff would necessarily balk at the inflexibility of this band-service link appeared to be unfounded.

*"Staff are very busy and dealing with complex human issues. What they want is a nice framework that is very black and white, very clear and easy to understand. They quickly latched on to the idea that if a person is in a particular band they can get this, this and this."*

*"It was as if where someone was critical we would throw open the doors to them and do everything we could to them."*

- 2.31 Additionally such an approach can lead to the assumption that social care equates with service delivery by the council – a model that has ceased to be dominant for at least the past two decades – and may lead to problems when services are stretched.

*"A carer was told not long ago 'Oh there's no point in me doing your carer assessment because I have got no services to give you'. Well, how can you know? It might not be about their service."*

- 2.32 In all of this, the central pillar of FACS – an assessment of risk – can get completely lost.

*"My perception is that practitioners have got a bit lost in terms of how they think about eligibility criteria. They tend to translate people's needs into low, moderate and so forth rather than the risk to that person's independence of the needs not being met. The impact of the service not being provided could put that person into substantial or even critical."*

- 2.33 The implication of all of this is that a FACS strategy that seeks to combine standardisation with individualisation will need to withdraw from the common mantra of *'we don't do house work and shopping'* – a shift that could be tantamount to reinstating the low and moderate bands where these have been eliminated. A policy advisor in one locality felt there may be a case for such an approach but only in tightly circumscribed cases:

*"In terms of service there was a view that 'we don't do housework' and we struggle with this. We have to be very clear that actually sometimes we might do some laundering even though it's housework, say if it contributes to a skin care problem or an incontinence problem."*

- 2.34 Some respondents took a broader interpretation and highlighted the contrast between council policy and a common sense view of life:

*"Unfortunately we do put ourselves in boxes. We have this 'no housework' rule but if you think about your own quality of life we would not let housework go, yet we are expecting people out there who can't do it themselves to do that very thing."*

- 2.35 The key concept here is *'contextualisation'* – the acknowledgement that a relatively 'low' level of service can be critical to the individual, depending upon circumstances.

This was seen as especially relevant to the situation in which carers may find themselves.

*"The things that might help a carer might be the kind of stuff that wouldn't be offered if you closed down some bands. It might be better to pay for housework to free up the carer to do higher band eligible need, it would be much better value for money."*

- 2.36 This need for contextualised flexibility seemed to be appreciated across most of the localities in this study. One practitioner described her liberation from the tyranny of the bands-services equation:

*"The difference now is that you can have a critical need but you wouldn't necessarily be requiring a high level of care, whereas before the understanding would be that you would hit a lot of triggers in order to get to the critical band. The only eligible need could now be short-break care but it could be judged as critical, whereas before, the majority of critical services would have been 24 hour care."*

- 2.37 However, the commonly professed conversion to a contextually sensitive approach to FACS banding is accompanied by some difficulties. One problem is the perceived lack of equity by rejected applicants who may know of people whom they consider to be in similar circumstances to themselves and who do receive support. A second difficulty is that all of the budgetary pressures outlined earlier are still there, and managers will be reluctant to let contextualisation be used as a pretext for higher expenditure. The impact of the various FACS directives can, ultimately, only be known by looking closely at the lives of people and their carers who apply for or use services, and this will be explored in Section 3.

### **De-banding and Re-banding**

- 2.38 Although only one of the localities in this study had 'de-banded' (from substantial and critical up to critical only) most of the others had at least considered the possibility of doing so. The general view across all of the councils was that the tightening of FACS bands was neither an appropriate nor an effective strategy – inappropriate because it failed to meet legitimate needs, and ineffective because it failed to save money.
- 2.39 Different councils had different perspectives on this matter. In the council that had kept all FACS bands open there were some real issues of intelligence gathering that had made it difficult to reach an informed decision on the consequences of removing one or more bands. This problem had, at least in part, arisen as a result of keeping all bands open, since care managers had felt there was no real significance in putting people in one band or another – the case of '*pinning the tail on the donkey*' alluded to earlier in this section. Although it was accordingly possible to produce a figure for the number of people in the low band, there was no confidence in the accuracy of the figure. Indeed, determining such accuracy in this locality would have involved reviewing the individual cases, but it was felt that this could turn out to be a complex exercise that could backfire:

*"When social workers go back to reassess they may not necessarily put them in the same band. They will always be cautious and say 'actually this is the next band up'. Social workers don't want to take things away and they don't like saying no."*

- 2.40 Lack of accurate data was not the only problem; there was also the concern that a tighter banding policy would create a lot of political pain for little budgetary gain:

*"We looked at other authorities who had raised their entry, and whilst there was an initial saving, within a year or two they were not saving much more. People were coming back into the system at a higher level and at a more costly stage."*

- 2.41 For the council already using the critical band only, there were problems of a different order. Having reached that point, there was nowhere else to go in terms of any further tightening, and 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."*

- 2.42 However, 're-banding' – in this case to also accommodate substantial – is not straightforward. Although it may be politically easy to decide to re-open certain bands, the implementation task on the ground is complex and potentially costly, especially where information systems are poor. In the case of this council there was still considerable reliance upon paper records, with only a minimalist electronic system that recorded little more than basic details. This left the council with the problem of determining which cases to target for 're-banding', which meant trawling through paper records or relying upon practitioner memory. In order to address the issue this council appointed a special team of reviewers (12 staff plus a project manager) who examined 600 cases, of whom only around 250 received a visit – an outcome that caused some disappointment. The key message from this experience is that whilst closing a band is relatively simple, re-opening it is very difficult.

### **The Position of 'Self-Funders'**

- 2.43 Self-funders (people paying privately for the costs of their care) constitute a large and often very vulnerable part of the care sector, but seem to be invisible to politicians, managers and practitioners alike. Three broad responses to self-funders could be identified across the sites – service denial, minimalist support and structured strategy.

### **Service Denial**

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

*"I can't think of any offhand, no."*

*"I'm not quite sure how to become proactive."*

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

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

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

- 2.45 These sorts of observations (of which there were many) have been quoted at some length because they raise issues of problem *conceptualisation* rather than issues of implementation – many people in key positions had simply not addressed the matter of self-funders. Ignorance can breed its own solution as summed up in the observation by a social worker that *"unless we know them, we don't know them"*.

### **Minimalist Support**

- 2.46 Where service was not totally denied, councils generally conceded that self-funders, along with others, were entitled to an assessment of their needs.
- "I've always been clear that when someone comes to us and they may require an assessment, then they should get that assessment irrespective of their financial status."*
- "Our responsibility is that anyone who knocks on our door is entitled to an assessment."*
- 2.47 The drawback to this position is that it normally relies upon self-funders taking a proactive stance and approaching the council for advice and assessment – an unlikely occurrence. There is very little evidence that councils are taking a proactive stance towards inviting people to take advantage of an assessment, and indeed one care manager felt that any such action would be discouraged:
- "We have a duty to assess but it is not encouraged. If you go to your manager and say this person has asked for an assessment you would be discouraged. The general consensus is that they don't need us."*

### **Structured Strategy**

- 2.48 Only one of the councils in this study – one with a high proportion of self-funders – had a strategy for supporting people who self-fund, though even here the strategy had yet to be implemented at the time of the fieldwork. In this council some respondents took a somewhat different view of the situation:
- "Self-funders are our business. I don't really think there should be a distinction."*
- 2.49 The plan in this council consisted of eight action points for improving information and support for self-funders, each of these having accompanying targets and deadlines:

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

2.50 Overall, the situation of people funding their own care, and of their carers, could be described as one of policy neglect or even indifference, and this has resulted in some very poor outcomes in the lives of some people who self fund. These outcomes will be traced in more detail in Section 3 of this report.

### **Tensions with the Personalisation Agenda**

2.51 The tension between FACS and individualisation has already been noted, but there is a further difficulty that can be expected to intensify over the coming years – the fit between FACS and the quest for ‘personalised’ care in the sense of individual budgets and the principles represented by the *In Control* model. Again at the conceptual level the tensions are evident: 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 arms-length accountability for expenditure decisions.

2.52 On one reading the two approaches could be seen as complementary, with FACS constituting the decision on eligibility for support, and individual 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. In the localities that form this study there was very little evidence that the tensions between the two paradigms had been understood, let alone addressed.

2.53 The notion of personalised budgets normally attracts support in principle, and this was largely true of respondents in this study. One portfolio holder commented:

*"The answer for me is direct payments; that would be the way that you would allow people to make choices for themselves. It's what happens in normal life, you choose how you are going to spend your money. Your luxury is my necessity, and the other way round."*

2.54 Similarly, a service manager saw individual budgets as solving the problem of accessing what some councils see as marginal, ‘low level’ services:

*"The whole thing shifts to outcomes. I wouldn't rule out housework because it's ultimately about the outcome. If somebody has needs that are substantial or critical*

*and we say we are going to meet those needs, I wouldn't automatically say that housework couldn't be provided within that framework. We would have to understand how it fitted in."*

- 2.55 Such sentiments were fairly common across all of the sites, but there had been little exploration of the ways in which a shift towards individual budgets could be consistent with the parallel drive towards the identification of 'core business'. This drive has been fuelled by different forces at both ends of the FACS bands. At the 'high' end the imperative has come from disputes with the NHS over what constitutes a social care responsibility and what should fall within the remit of NHS-funded 'continuing health care'.

*"Cost shunting has made us think about services that should be provided by someone else. You can't leave the gap – it can lead to a lot of tension between agencies."*

- 2.56 One senior respondent was able to reflect back upon over four decades of change in the determination of budgetary responsibility:

*"I can remember the days when all elderly people were looked after on wards in hospitals, even if they were just incontinent. The battle now is over continuing care. We have people with three or four serious ailments, people who have lost the ability to walk and suffering from dementia, and we are keeping them in the community. It's a massive change that just amazes me."*

- 2.57 It is important to emphasise that none of the respondents in this study wished to see a return to accommodation in long stay wards for any of their clients; the dispute was over funding responsibility. A much tighter definition of what a council sees as a social care need is part of the response to this situation, and in the case of continuing health care it has resulted in the development of national guidelines as outlined in Section 1. Much less attention, however, has been given to the parallel development at the 'lower' end of social care activity, especially around domestic support, shopping and socialising. Here the imperative has been different – a concern about 'over assessment' and hence 'overprovision'. One senior manager summed up the dilemma:

*"The service does something that actually they could be motivated to do for themselves, and that is one of the great risks of service provision – getting used to someone coming in and doing whatever, even though you are able to get up and do it for yourself."*

- 2.58 Just as the disputes over continuing health care have resulted in increasingly tighter descriptions of which agency holds responsibility for what type of circumstance, so there have been moves at council level to distinguish what forms of social care it is legitimate for the council to fund, and what should be the responsibility of individuals, families and other agencies. All of the councils in this study were feeling the need to address this issue, and in doing so they echo recurrent calls at national political level for a debate over funding and responsibility for social care support.

*"It's that thing about what is the role and purpose of social care. We need a clear framework for saying as a local authority that we are responsible for some of that,*

*but actually yourself, your family, your community, your private resources, are also responsible for some of it. The tricky thing is working out where the line is."*

- 2.59 For the one council in this study that was keeping all four FACS bands open, this concern had resulted in the compilation of a 'Statement of Purpose' briefly described above. This is an attempt to comprehensively delineate what adult social care support the council would be prepared to fund in every type of professional scenario, and – by inference – what would be expected to be the responsibility of others. Managers could see little other than benefits to flow from the Statement of Purpose.
- "We needed a clear statement of our core business...a statement to the public and to our staff about what our business actually is, to say these are the jobs we do. We now have something that says 'yes we can do that' and 'no we can't do that'"*
- 2.60 The Statement of Purpose was variously described as a 'social work toolbox' and a 'social workers bible' that covered every eventuality that operational staff might be likely to encounter. It was seen by some respondents as both a controlling and a liberating mechanism.
- "It is a controlling mechanism, but it also enables people to think outside of their traditional menu of services, to think about what in their network of friends and family can be encouraged to support that person."*
- 2.61 The directing role played by such a Statement of Purpose specifically excludes the funding of certain types of support by certain types of people, and seems to lie uneasily with the promise of self-determination, choice and flexibility that underpins the personalisation agenda. Respondents seemed not yet to have identified a way of resolving this contradiction. One senior manager felt there was no real problem "as long as it meets their needs and we agree that it meets their needs" - itself something of a contradictory position. Another said of the potential contradiction:
- "I think we have a way to go on that. The Statement of Purpose has got to be a living thing if we are going to keep up with the individual budget agenda. We haven't got our heads round that yet."*
- 2.62 Much will depend here upon the approach that a council has taken in the past towards direct payments and the extent to which the personalisation agenda is being viewed with enthusiasm or resistance. In the case of the council with the Statement of Purpose, there seems to have been a fairly rigid interpretation of the nature of direct payments. According to a carer:
- "The council took a very rigid view of Direct Payments. It was 'if we give you money for half an hour of personal care between 8 and 8.30 that's what you have to spend your direct payment on'. Well, what's the bonus? Why should anyone take on the responsibility?"*
- 2.63 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 operating processes encouraged by the FACS model, and councils need to urgently understand and address these inconsistencies.

## Summary: Key Messages On Rationing By Directive

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- 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 increasing pressure upon adult social care resources came from several sources - the high cost of meeting the needs of younger people with very complex needs; an increase in demand from the rising numbers of older people, sometimes at well above the average rate for England; the high cost of intensive home care support; attempting to address the prevention agenda; and the decisions of operational staff.
- Adult social care was not necessarily a high political priority and, where this was the case, restricting eligibility to services could appear to be an attractive option. There was a strong view in some places that cutting FACS bands in this way was a strategy with surprisingly limited political consequences.
- Demand management can be secured through a multiplicity of routes other than by a change in directive about the formal rules on eligibility. The most common was to clarify and tighten up procedural guides in order to eliminate what was seen as unacceptably wide interpretations of the FACS directives by frontline staff.
- All of the sites in this study had recently developed or refined a range of procedural guides for use by practitioners in forming their decisions, typically some form of eligibility guide or grid, sometimes with a scoring system attached. In one case a 127 page manual had been produced that identifies 39 'Areas of Independence and Associated Need' based upon the FACS domains. The manual aims to identify the 'core business' of the council, describing the activities and needs that it regards as eligible and which it is prepared to provide or arrange in some other way.
- Attempts to strengthen the role of 'rationing by directive' constitute a new phase in the FACS policy journey, one in which much greater attention is focused upon policy formulation and the ways in which it is operationalised. However, several problems with the directive model can be identified: - unbundling bands and services; and problems of de-banding and re-banding.
- FACS is seen as the appropriate resource allocation mechanism for older people, but is perceived as less suitable for other groups, especially people with a learning disability. There is a potential difference in assessment approach towards the two groups of people, with approaches to learning disability more likely to be person-centred, and those with older people more likely to be service-centred.
- In more than one of the localities in this study the FACS directive linked eligibility bands to services. This approach encourages operational staff to conflate FACS bands with the allocation of 'band-specific' services, with the accompanying danger that support can be highly standardised but potentially inappropriate as well as unduly expensive.
- A FACS strategy that seeks to combine standardisation with individualisation will need to withdraw from the common mantra of '*we don't do house work and shopping*' - a shift that could be tantamount to reinstating the low and

moderate bands where these have been eliminated. The key concept here is 'contextualisation' – the acknowledgement that a relatively 'low' level of service can be critical to the individual, depending upon circumstances.

- The general view across all of the councils was that the tightening of FACS bands was neither an appropriate nor an effective strategy – inappropriate because it failed to meet legitimate needs, and ineffective because it failed to save money.
- 'Re-banding' is not straightforward. Although it may be politically easy to decide to re-open certain bands, the implementation task on the ground is complex and potentially costly, especially where information systems are poor. Overall, whilst closing a band is administratively relatively simple, re-opening it is very difficult.
- There is no clear fit between FACS and the quest for 'personalised' care in the sense of individual budgets and the principles represented by the *In Control* model. At the conceptual level 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 arms-length accountability for expenditure decisions.
- The two approaches could be seen as complementary, with FACS constituting the decision on eligibility for support, and individual budget holders then determining their own care needs and how these should best be met. In reality they represent two different paradigms with very different underpinning assumptions, values and operating procedures.
- Just as the disputes over continuing health care have resulted in increasingly tighter descriptions of what constitutes the boundary between health and social care, so there have been moves at council level to distinguish what forms of social care it is legitimate for the council to fund, and what should be the responsibility of individuals, families and other agencies. All of the councils in this study were feeling the need to address this issue, and in doing so they echo calls at national political level for a debate over funding and responsibility for social care support.
- None of the councils in this study had addressed the relationship of self-funders to FACS eligibility. One council had a strategy in preparation, most conceded little more than the right to an assessment if requested, some felt that self-funders were simply not their responsibility in any way.
- There is a danger that the personalisation agenda could end up running on parallel tracks to the FACS agenda, but that at some point the two will nevertheless collide. Any serious attempt to introduce an approach based upon the *In Control* principles will challenge the operating processes encouraged by the FACS model. In the localities that form this study there was very little evidence that the tensions between the two paradigms had been understood, let alone addressed.

## Rationing By Discretion

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- 2.64 As already indicated, rationing by discretion refers to the exercise of professional judgement in the operationalisation of the rationing process and interpretation of eligibility criteria for each person making contact with the council. There is a long-standing debate in the sociological and management literature about the nature of professional decision-making and the way in which it can be rooted in 'informal' theory<sup>35</sup> - understandings that are neither officially recognised nor formally coded, but which can nevertheless constitute the 'practice wisdom' of a profession. Unlike formal learning, informal theory is covert, implicit and taken for granted as 'common sense,' and it may co-exist uneasily with formal organisational goals. In this way, professional practice is not simply concerned with problem *solving*, but also with problem *setting* - the process by which a problem and its parameters are defined and interpreted. It is in this sense that 'rationing by discretion' can - in this case in relation to FACS - either reinforce or undermine 'rationing by directive'.
- 2.65 An additional dimension arises from the fact that the key professional group charged with the implementation of FACS is that of social workers. The concept of a hierarchy of professions differentiated by full and semi-professional status is of enduring significance in the academic literature. It has a particular relevance for social work, which has long been allocated to the category of 'semi-profession' on account of the perceived limitations of the knowledge base, training and level of autonomy.<sup>36</sup> In principle, the fact that social workers implementing FACS are located in democratically based bureaucratic organisations, implies that rationing by discretion will *not* be sufficiently influential to undermine rationing by directive. This study has helped to throw further light on this hypothesis, and suggests that in practice the picture is more complex and mixed.

### Professionalism and De-professionalisation at the Front Line

- 2.66 It was not uncommon to hear respondents in this study speak reverentially of the importance of professional judgement. A senior manager rhetorically posed the question: "*why put people through professional social work training if you are not going to let them use it?*", whilst a politician observed:
- "I think that if you start interfering with people's assessments and judgements this erodes their professional judgement and confidence, and you create dissatisfaction. Why would anyone want to interfere?"*
- 2.67 However, even for this respondent there was an issue of striking a balance between the goals of the organisation and the judgements of professionals:

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<sup>35</sup> Thompson, N. (1995), *Theory and Practice in Health and Social Welfare*. Buckingham. Open University Press.

<sup>36</sup> Etzioni, A. (1969), *The Semi-Professions and Their Organisation*. New York. Free Press.

*"When I came in we had a £3 million pound overspend. There has got to be a balance between people being aware that public money is not infinite, but not having somebody breathing down your neck with a rigid framework."*

- 2.68 Getting this balance right was not proving to be easy across the councils in this study. It has already been observed that the ways in which front-line staff were committing resources to the users of services was one of the main reasons given for unsustainable budgetary deficits, and that this has resulted in the tightening of the rules and procedures that constitute 'rationing by directive'. One of the consequences of these developments was the frequently made accusation that social work was becoming 'de-professionalised', and that this was beginning to pose some very difficult questions about the nature of the profession. A director of adult social care conceded that:

*"Long-standing social workers are questioning why they are still in the profession. The traditional approach of sitting down with somebody for a couple of hours, going over their problems and helping them to fill in forms doesn't exist any longer. It's all financial assessments, inputting information onto the computer and performing against targets."*

- 2.69 The need to perform well against the targets on speed of response was particularly frequently cited as an obstacle to reflective practice:

*"There is an anomaly between providing a speedy resolution – 'there you go, your need is met' – and the length of time it takes to do professional social work with somebody. Social workers are perceiving attendance at a day centre or receiving home support as 'the service'."*

*"It isn't that social workers want to do a bad job, but that a huge tranche of them have become deskilled by care management and the target culture – you will do an assessment within however many days if they meet these criteria."*

- 2.70 Although in principle the tenets of care management encourage a focus upon the person rather than the service, a service-led approach to assessment appeared to be entrenched in some places, often to the surprise of managers:

*"I couldn't believe that I sat there with social workers and asked 'when you assess what are you looking for? And they said 'whether someone needs to go into care'. But why do they go into care? Surely you can't be going and looking at somebody and thinking 'oh you will need care'."*

- 2.71 This issue was felt to be a particular characteristic of staff whose qualifications were NVQ based (rather than degree based) and who had often come to care management from a home service provider background rather than through a professional social work training. According to a team manager:

*"The unqualified staff tend to be very service-led. You can pick up an assessment and you are so clearly reading something written by somebody who is driven by eligible needs and trying to find out what these are – not trying to find out the person."*

2.72 It was common amongst the councils in this study for care managers to be allocated to different grades (and salaries) dependent upon their qualification status, and this did not necessarily mean that unqualified staff dealt only with less complex cases. In one council, for example, the distinction lay between cases thought to require 24 hour care (the remit of qualified staff) and those that could be supported at home (unqualified staff). All of this raises the possibility that rationing by directive is more likely to be acceptable to unqualified or NVQ qualified staff than to those who have either been through a social work degree or an earlier equivalent such as the Diploma in Social Work or its predecessors. In this study a continuum of compliance and resistance amongst care managers was evident, with people often exhibiting a mixture of the two.

### **Professional Compliance**

2.73 Earlier in this report the distinction was drawn between priority setting and rationing, and both are relevant to the issue of professional compliance. In the case of rationing, there was some support for the claim that the importance of rationing was now incorporated into professional culture to such an extent that it shaped understandings of whether needs could be legitimately met. For one senior manager this was partly a consequence of the widespread debate about rationing in health care:

*"They see the whole debate taking place about the health service – how many hip replacements can you have for a heart transplant. It has been less so about social care, but it is being debated far more publically than ever before."*

2.74 For some professionals, the attraction of rationing through FACS lay in the potential for achieving consistency of treatment:

*"When this was all first introduced we were all in a terrible state, but life is not fair, and at least this goes some way towards making it fairer."*

2.75 An acceptance of the inescapability (even the desirability) of rules for the rationing of public money can then translate into a willingness to work with the grain of FACS procedural guidelines. In some cases this was seen as an aide to making clearer judgements:

*"On the positive side you have got clear guidelines whereas before it was a bit hitty missy. With substantial-critical you would err on the side of caution and put them in critical, whereas now there is not much scope for manipulation."*

2.76 For others it was simply part of the job:

*"I know it's what I have got to do. I accept it because it is part of my job role."*

A more frequently cited reason, however, was the potential protection from complaints by service users that arose from compliance with a council code of practice – a focus upon defensible decision-making rather than the exercise of discretion rooted in professional judgement:

*"I feel more comfortable with the system because we seem to get questioned left, right and centre, something that is appearing more and more. It's quite frightening because my understanding when I came into social work was that I would be a professional in my own right, and that my judgement would be valued and accepted."*

*"Any form of complaint would just worry me sick but if one does come in I would rather it was about a decision that is out of my hands than about my professional practice."*

*"It's helpful when you have the criteria to take to people's homes to back things up. If a complaint comes in about your assessment you can justify it by reference to the criteria."*

## **Professional Resistance**

- 2.77 Not all front-line staff saw the tightening of procedural guidelines as wholly positive, and indeed some felt that the broader FACS mission was inconsistent with their professional culture. In part this was simply about a determination to put in services where judged necessary:

*"I would hate to be in the position to work for any organisation which put FACS or budgets ahead of need. I think you need to ensure that people who require a service get that service."*

- 2.78 A more fundamental objection was that FACS is inconsistent with individualisation and hence with professional ethics:

*"We are charged with treating people as individuals, yet we are also asked to slot them into pigeon holes. You can't do both. It's a subject that comes up all the time and brings great frustration."*

*"It should be about seeing the person as a person. The problem is that as soon as you start labelling people then you stop seeing the person."*

- 2.79 The key implementation dilemma here is whether professional goals end up subverting organisational goals, though even here there is an issue about whether organisations simply pass on messy and unresolved policy issues to professionals, rather than clarifying the policy itself. For example, a director of adult social care conceded:

*"We are aware that people are left with a dilemma because of grey areas. The front-line worker is left to resolve financial pressures and individual issues."*

- 2.80 This is an important reminder that whilst very tight procedural manuals might well circumscribe professional discretion, their absence leaves operational staff exercising discretionary judgement in circumstances that are not of their own choosing. Nevertheless, the power of professionals to re-shape the implementation of FACS was recognised to be a potent force by both politicians and managers. To understand the extent to which any such 'rationing by discretion' takes place requires an examination of the key point in the FACS journey – assessment.

2.81 It was noted in Section 1 that assessment is a dynamic activity that is, to some extent, privately negotiated between the potential service user and the frontline practitioner. The precise extent to which the relationship retains this 'private' dimension will depend, amongst other things, on the tightness of the rationing criteria and any associated guidance, but even in the case of tightly prescribed situations there can be some discretionary behaviour. Certainly the existence of variation in professional judgement was widely acknowledged to be an issue in all of the councils studied. For some councils this was a cause for concern, and in one case had resulted in a monitoring exercise to discover the extent of variation. This revealed inconsistencies that were felt to be organisationally unacceptable:

*"You could take the same cases who at a point of referral were similar, but the FACS bandings were miles apart. We even found the same thing within teams – two social workers go to a very similar case but the outcome will be very different. I think for some people it might actually just have been a finger in the wind."*

*"I've got concerns because we have a care manager here and a care manager there who are interpreting the same policy in different ways. How can that be? And what does that do for the customer experience?"*

2.82 The tightening up of rationing by directive has been the organisational response to this issue, but front-line staff could challenge these directives through a variety of strategies:

**Band ratcheting:** This consists of operational staff placing an applicant in a higher band than would be normally justified under the terms of the directive – a strategy that some professionals seemed happy to use and of which managers seemed to be only too well aware.

*"Sometimes something just tells you that without support there are going to be difficulties – a gut feeling – so we err on the side of caution."*

*"I am happy to 'flower' the eligibility criteria to make it look as if they meet them."*

2.83 In the case of the 'critical only' authority this was thought to be a particular issue. One care manager here commented: *"I have used my discretion to bend the rules, yes absolutely. If the majority of their needs were substantial what you have to do is find one particular need that may be critical."* Others had their own well-rehearsed techniques:

*"I can't let a sheet of paper determine how I am going to look at somebody. If I feel somebody needs such and such then I look how to get it in on the criteria. 'Significant health problems' is a very useful let out."*

**System ratcheting:** In this case, operational staff make no attempt to 'mask' the facts but simply assess as they think appropriate and pass the matter up the organisation for a decision on funding. This amounts to an acknowledgment of the necessity of rationing by directive, but a reluctance to be the hand that puts it into effect.

*"It is up to others to make these decisions. I can only do my best for the people I have seen and I will ask for whatever I want. If we put the lid on it then the real levels of need are not showing are they?"*

*"If the person needed the service I would recommend it; whether we had the resources to provide it is something totally different."*

- 2.84 **Safety valves;** This refers to the availability and use of solutions at the margin of rationing by directive which allow assessed needs to be met outside of the normal rules. In the case of the critical only council, for example, there was a caveat that where cases were assessed as 'substantial but potentially critical within six months' then they could still fall within the council's remit – a loophole that in the view of some people amounted to retaining the substantial category. A further source of support, albeit relatively inflexible, was the availability of unused provision purchased by the council via block contracts, with operational staff seemingly able to utilise this outside of the normal constraints of FACS guidelines.

### **Securing Greater Professional Compliance**

- 2.85 The existence of FACS criteria, guidelines, matrices and scoring systems was not always proving to be sufficient to ensure professional compliance amongst the councils in this study, and this had led to a search for additional means of ensuring such compliance. Curbing professional behaviour had, indeed, become a central feature of local policies, with politicians and managers committed to taking action.

*"First and foremost we are trying to get the frontline staff to accept that just giving people comprehensive packages of care is not sustainable."*

*"There is a culture of having solutions and not having to do any thinking. There is a cultural thing about saying 'no' even if needs are not eligible."*

*"When you give a social worker an inch they will take a mile. I would expect them to – I would do the same if I was out there in the field."*

- 2.86 Four broad techniques for trying to diminish rationing by discretion could be identified in this study – training programmes; peer review; supervision and management; and cultural change.

### **Training Programmes**

- 2.87 In one council an extensive training programme to prepare staff for implementing a more rigorous approach to FACS had been underway for almost a year at the time of the fieldwork. The training had been undertaken in different ways by different people in different parts of the organisation (especially in relation to older people) and some respondents felt this was reproducing the very problem that it had been set up to address. Even after such a prolonged period of training there was uncertainty as to whether 'hearts and minds' had been won over:

*"What we have been doing is trying to win over people who are deeply entrenched in their way of working...I would say about 70% of them are now with us."*

- 2.88 Despite the centrality of FACS to social work practice it is not evident that recently qualified staff are leaving their degree courses well versed in the policy and practice issues. One care manager knew nothing about FACS until her first job interview:
- "I'm not quite sure how I thought we provided services on the basis of criteria, but I had an interview here and all of the questions were around it!"*
- 2.89 Most of the localities tended to have much shorter periods of formal training to acquaint staff with new procedures, sometimes little more than a half-day event, and whilst these may be useful curtain-raisers it was widely thought that additional means of compliance had to be adopted.

### **Peer Review**

- 2.90 This strategy consists of getting professionals to act as a checking device on the judgements of their colleagues – an approach with the potential to cause conflict. In one council this took place at the point of initial assessment, with a requirement that once staff had assessed for a package of care at home (including where a direct payment had been used) this must then be passed to colleagues working in intermediate care who take on responsibility for the nature of the care package, as well as arranging delivery. These packages are determined on the basis of fifteen minute blocks that calculate exactly how long it takes to undertake specific tasks.
- 2.91 For some assessing staff this strategy was tantamount to a crude device for minimising costs which, in the process, could subvert the risks and needs identified in the assessment, especially in the case of BME service users whose expectations could not be easily accommodated within this framework. Indeed, there was also a concern that the initial assessment itself was no longer a central part of the process. One team manager, for example, related a case in which a social worker had been told that her assessment would not be used – *"they don't want to read it because it would make their life more difficult; they would have to acknowledge the individual and that would make their job harder."*
- 2.92 More commonly a peer check could come in at the point of review rather than immediately after initial assessment. Practice varied, with some councils attempting to maintain continuity of assessment and review personnel (thereby precluding a peer check), and others using different personnel precisely in order to ensure an alternative perspective. Such a prospect could heavily influence the exercise of professional discretion during the assessment procedure:
- "When a case is due for a review a colleague would go out to do that. They could come back to me and say 'you said such and such in your assessment and that's not so'. They are then going to go back to the manager."*
- 2.93 The danger here is that the purpose of a review ends up being to review the judgement of a colleague rather than to comprehensively review the needs of the service user.

## Supervision and Management

2.94 By far the most common measures being used to diminish professional discretion are supervision and management, either through a team manager or (normally in complex and expensive cases) by means of a panel of managers. There was a general view that scrutiny of professional judgement by team managers had increased in line with budgetary difficulty and the tightening of FACS criteria, often to the extent that *all* initial assessments are checked by a team manager. Along with greater team manager scrutiny, care managers were also losing control over minor budgetary decisions – in one authority the previous freedom to commit relatively small sums of money (in this case on basic equipment) without permission had been virtually stopped.

2.95 Additionally, the decisions of team managers themselves were now coming under closer scrutiny. One council, for example, held monthly 'budget clinics' in which every budget holding manager met with their 'accountancy lead' to monitor expenditure and examine any predicted variances for the end of the year. If team managers are to act as the guarantors of professional consistency then the organisation also needs to be confident that they too share a common understanding of FACS and their role in ensuring implementation. Just as front-line staff had been undertaking training to secure compliance and consistency, so their team managers were often undergoing similar exercises. This study was not able to determine how successful these exercises had been, and whilst some places seemed confident that all team managers shared a similar outlook and behaviour, there were also reservations.

*"One team manager will say to me 'I don't read any of it, if it's their judgement I just sign it'. But there is no way I am signing anything if I have not read it."*

2.96 For one team manager respondent there was still a lack of clarity about what role the organisation expected a team manager to undertake:

*"There is the whole issue of what the council wants of its team managers. Does it want them to be focused on practice and improving standards within the team? Or does it want its managers to be focusing on performance indicators at a service level?"*

2.97 The difficulty of ensuring consistency of behaviour amongst both front-line staff and their team managers has been one of the reasons for the common use of a further tier of scrutiny – the management panel. Such panels had varying size and composition but all were said to have two main purposes – to curb expenditure and to act as a quality assurance process. Typically the origin of panels has been to scrutinise recommendations for residential care, as this director of adult social care explained:

*"You need to decide if residential care is being proposed because there is an increase in demand and it's a legitimate claim, or whether it's because it's an easier option and a way of dealing with a heavy workload. That's the issue."*

2.98 The tendency seems to be to extend the role of panels beyond this focus upon residential care and into home care packages such as overnight support. Indeed, one

service manager felt that the quality assurance role had now superseded the expenditure curbing role:

*"It is turning much more into a panel which is saying 'have you explored all of the angles'. This means broadening the thinking of practitioners and team managers about what can and can't be done in relation to supporting people who have critical and substantial needs."*

- 2.99 Unsurprisingly there was less enthusiasm from practitioners and some team managers for this sort of exercise. The most common objection was the implied impugning of practitioner judgement, along with resentment of the intimidating atmosphere found in panel meetings:

*"The panel is quite intimidating. The last one I went to there were eight people round the table. I very much feel my professional judgement is being questioned."*

- 2.100 It would be wrong to suggest that practitioners are reluctant to justify their judgements – most were very keen to explain how these had been arrived at. Rather it was a case of with whom these judgements were discussed and under what circumstances.

*"I don't have a problem defending my judgements. We should be looking at what we are doing, but that already happens at team manager level. I don't think it's necessary to do it at team manager level and then have that same team manager sitting on a panel asking you the same questions they asked you in a one to one discussion."*

*"I have worked in a situation where panels didn't exist and my manager would make the final decision. That was a much better way forward. If the manager can't see a problem that's good enough."*

## **Cultural Change**

- 2.101 The final tool of compliance is potentially the most effective of all, but also the most difficult to achieve, that of cultural change. Some managers were often only too well aware of the danger of two very different cultures – professional and organisational – failing to co-exist constructively.

*"We are not making widgets. We are in the business of personal care, but if we are not careful then individuals and teams will become distanced from the way in which the business runs."*

- 2.102 The demands of financial rigour and organisational performance were certainly impacting strongly upon professional activity, and some practitioners conceded that they were finding it difficult to carry the two agendas simultaneously.

*"There is a lot of expectation for us to hit a lot of performance indicators, whereas in the past my job was to go out and assess and spend some time with service users with a view to supporting them. Everything now has a timescale attached, everything seems to be super quick. To me it feels like a level of working and a pressure that can't be sustained."*

*"For me what has happened is that the focus on practice issues has been lost in the attempt to try to meet performance targets."*

2.103 Where it has been made at all, the response has been what might be termed 'organisational co-option' – an attempt to locate professional values within organisational culture. The most common way in which this was being attempted was by sharing the financial dilemmas of the organisation with the professionals so that they would take on ownership, and hence responsibility for addressing these dilemmas. As one locality manager put it:

*"We try to bring staff with us by giving them information about what's happening in the authority with the budget, to try and understand that it's not a free world and they can't just do what they want."*

There was some optimism that this strategy was succeeding:

*"There is now an understanding that the needs of individuals have to be seen in the context of the overall budget, and we can now have that discussion without any embarrassment or lack of ownership. My first line managers used to almost apologise and dissociate themselves from budgetary activity, and now they don't."*

2.104 Front-line staff certainly do seem to accept the need for prioritisation, and are acutely aware of the dangers of 'opening the floodgates' as one practitioner put it. However, it remains debatable as to whether there has been a significant reconciliation of professional and organisational cultures, with a lot of practitioners concerned that too tight a concern for budgetary problems will distract from their prime goal – assessing and meeting need.

*"I'm aware of the budget but wouldn't take that into consideration when doing an assessment. All we can do is do our job and then it's down to the powers that be."*

*"Money is in the back of your mind but it's not a priority as far as I'm concerned. If a person needs something they need something."*

*"We are the people that go out to assess people's needs. I am qualified to do that and I am employed to use my judgement. Yes, budgetary constraints have come more to the fore but that's not my role."*

2.105 Overall, this review of the various ways in which councils seek to minimise rationing by discretion suggests that whilst there has been some increase in compliance, and possibly even of cultural change, strong differences of understanding remain.

## Summary: Key Messages On Rationing By Discretion

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- Although it was common to hear respondents in this study speak reverentially of the importance of professional judgement, there was an issue of striking a balance between the goals of the organisation and the judgements of professionals. Getting this balance right was not proving to be easy.

- A frequently made claim was that social work was becoming 'de-professionalised', and that this was beginning to pose some very difficult questions about the nature of the profession. The need to perform well against the targets on speed of response was particularly frequently cited as an obstacle to reflective practice.
- A service-led approach to assessment appeared to be entrenched in some places. This was felt to apply especially to staff whose qualifications were NVQ based (rather than degree based) and who had often come to care management from a home service provider background.
- A continuum of compliance and resistance towards FACS guidance was found amongst care managers, with people often exhibiting a mixture of the two.
- There was some support for the claim that the importance of rationing was now incorporated into professional culture to such an extent that it shaped understandings of whether needs could be legitimately met.
- An acceptance of the inescapability (even the desirability) of rules for the rationing of public money can translate into a willingness to work with the grain of FACS procedural guidelines. In some cases professionals saw this as an aide to making clearer judgements.
- Some professionals valued the potential protection from complaints by service users that arose from compliance with a council code of practice – a focus upon defensible decision-making rather than the exercise of discretion rooted in professional judgement.
- Not all front-line staff saw the tightening of procedural guidelines as wholly positive, and indeed some felt that the broader FACS mission was inconsistent with their professional culture. The power of professionals to re-shape the implementation of FACS was recognised to be a potent force by both politicians and managers.
- Assessment is a dynamic activity that is, to some extent, privately negotiated between the potential service user and the frontline practitioner. Even in the case of tightly prescribed situations there can be some discretionary behaviour.
- Front-line staff could challenge FACS directives through a variety of strategies – band ratcheting; system ratcheting; and the use of safety valves.
- The existence of FACS criteria, guidelines, matrices and scoring systems was not always proving to be sufficient to ensure professional compliance amongst the councils in this study, and this had led to a search for additional means of ensuring such compliance.
- Four broad techniques for trying to diminish rationing by discretion could be identified in this study – training programmes; peer review; supervision and management; and cultural change.
- Most of the localities tended to have short periods of formal training to acquaint staff with new procedures, sometimes little more than a half-day event, and whilst these may be useful curtain-raisers it was widely thought that additional means of compliance had to be adopted.
- Peer review was typically taking place at the point of review, but also at the point of assessment. The danger is that the purpose of a review ends up being

to review the judgement of a colleague rather than to comprehensively review the needs of the service user.

- The most common measure being used to diminish professional discretion is supervision and management, either through a team manager or (normally in complex and expensive cases) a panel of managers. Whilst the former is understood to be a normal part of professional practice, there was some resentment of the use of top-heavy panels.
- The demands of financial rigour and organisational performance were certainly impacting strongly upon professional activity, and some practitioners conceded that they were finding it difficult to carry the two agendas simultaneously.
- Some agencies have sought 'organisational *co-option*' – an attempt to locate professional values within organisational culture. The most common way in which this was being attempted was by sharing the financial dilemmas of the organisation with the professionals in the hope that they would take on ownership, and hence some responsibility for addressing these dilemmas.
- There was some optimism that this strategy was succeeding, but it remains debatable as to whether there has been a significant reconciliation of professional and organisational cultures. Practitioners were concerned that too tight a concern for budgetary problems will distract from their prime goal – assessing and meeting need.

## Rationing By Diversion

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2.106 The third and final dimension of the '3D' rationing framework is that of 'rationing by diversion' which refers to the attempt to limit demand upon one part of the system by either diverting it to other parts, or by simply re-routing responsibility back to the applicant. It consists of four chronological stages each of which will be operating at any one time in a locality: - pre-diversionary barriers to accessibility; the process of signposting; signposting destinations; and post-diversion strategy.

### **Accessibility: Pre-Diversion Barriers**

2.107 There is a potentially important 'pre-diversion' stage in which, effectively, people decide to preclude themselves from seeking social care support. This may be due to lack of understanding about the sort of help that may be available, along with a lack of accessible information. The examination of the position of people funding their own care in the previous section, for example, would suggest that they are often left to make decisions unaided (or with only the help of their family), with council social care agencies generally making little attempt to offer advice and support. In such circumstances it is unsurprising that people who self fund will tend to exclude themselves from council help by assuming that it is unavailable to them.

2.108 A different sort of pre-diversion arises where the image of local authority social care is seen as stigmatising, to the extent that potential applicants are deterred from seeking help. Several respondents felt that this was indeed the case. According to one director of adult social care:

*"In my experience, people don't really want to have dealings with social care unless they have to. I think social care isn't traditionally seen as a service that people who can look after themselves or can fund their own care come to, because it is seen as being for people who are heavily dependent."*

A care manager from a different council took a similar view:

*"Once you get involved with a social worker knocking on your door then you have got the mechanics of social intervention. I think it's very threatening for some people, and stigmatising. You can go through your whole life and never have contact with social care."*

2.109 This remoteness of social care from people's everyday experiences was precisely what needed to be changed in the view of some people – a shift from a stigmatised and selective system to a more universal service focused upon independence, health and wellbeing that is valued and used by a wider section of the population. One senior manager had just such a vision:

*"People don't particularly want to come to social services, so let's make it so that that they do. It's about open-ended access in which people have positive experiences and want to make contact again."*

2.110 Such a vision is a far cry from the trend towards the identification of core business beyond which the council will not accept responsibility. All of the councils in this study were well aware of the need to develop a more accessible image rooted in a preventive agenda around health and wellbeing, but most were unable to identify the resources to enable them to do so. It is in the absence of these resources that an alternative strategy, widespread among all of the councils in this study, was being developed – the strategy of 'signposting'.

### **The Spread of 'Signposting'**

2.111 'Signposting' is essentially what the word suggests – people who approach their council for advice or support may be advised, and perhaps supported, to seek help elsewhere. The growing importance and acceptability of signposting was commonly recognised across the sites in this study, and the term itself was in widespread use.

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

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

*"Previously we placed people in a FACS band and that determined the services they got. Now we identify eligible need, but how that is delivered is open to debate."*

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

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

2.113 The councils in this study had different positions on dealing with those people not considered eligible for council support, some more sophisticated than others. One council stuck to a firm 'information only' line, with FACS guidance stating that:

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

2.114 A different council had a longer list of actions to be undertaken when planning to withdraw or not provide a service. Staff are urged to:

- be satisfied that needs will not become eligible for lack of help
- not withdraw any service without first undertaking a review or reassessment of need;
- check any prior commitments given to the individual;
- communicate the decisions about not offering help;
- make information about other types of relevant support available;
- give details on how to make a complaint.

2.115 And in an attempt to improve the quality of its signposting, yet another council had introduced a new facility called *Starting Point* – an online directory of all social care services in the area intended to *"give the information needed to make informed choices"*.

2.116 An important issue here is whether people are completely signposted out of council systems or whether they still remain known to the council despite receiving no direct support. For all but one of the councils, signposting had generally been devised as an 'exit strategy', whereas in the case of the council that was keeping all four eligibility bands open, it was claimed that everyone remained under the council 'umbrella'.

*"We still have a consideration for those people who are deemed as in the lowest band, and we may want to review them at a later point. The difference is that we still have them in our sights and we can still offer them things as they travel on their journey."*

2.117 One respondent from the informal care sector in this authority conceded that if used in this way, FACS could be a valuable surveillance tool:

*"What FACS could be about is to say 'This is what you have at the moment, this is your contingency plan, this is your medium term plan and this is your long term*

*plan. This is what we are putting in at the moment, maybe you could do this bit yourself, but we will put more in as your needs increase'.*"

2.118 In principle this does seem to offer a way of combining signposting with ongoing vigilance of changing risk levels, but the extent to which this is indeed the case will depend upon the availability of, and commitment to, sophisticated systems for tracking and flagging those who have been signposted. In practice, there is little evidence to suggest that any of the councils in this study were in a position to undertake such a task. In the absence of any such systematic signposting, much seemed to depend upon the skills and personal commitment of individual workers, with some confining themselves to delivering a list of addresses and telephone numbers, and others attempting to support individuals along the signposting journey.

*"A lot depends on the worker. I would try to leave somebody with something positive rather than just give them a sheet of paper they could have got from yellow pages."*

*"If a person was a bit uneasy about organising things themselves then I would phone the agency for them, set the service up and monitor it for a bit to make sure things were going ok."*

### **Signposting at the Point of Referral**

2.119 It is at the point of referral that a crucial decision will be taken on whether or not to even acknowledge the case for a formal assessment of individual circumstances – in effect a decision can be taken to screen someone out from any further consideration for direct council support. In parallel with the growth of signposting as a strategy, councils have accordingly developed mechanisms for filtering people in or out of the system at the point of referral.

2.120 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. One of the most striking features of the arrangements being made by councils in this study is the extent to which this role is now being undertaken by staff *without* a professional background in social work. Such teams varied in size, scope and longevity. At one extreme, one of the councils had four Customer Relations Units containing a total of 28 staff working at the point of referral, and had been using this arrangement for over a decade. Elsewhere, the scope was more limited and more recently established – in one case a small team of four 'Customer Liaison Officer' posts, and in another council the retention and formalisation of an earlier Care Direct pilot scheme.

2.121 The background and skills required to work in these sorts of teams also seemed to vary. For the Customer Liaison posts, applicants were expected to have some experience within an adult social care setting over the last three years, and also have experience of customer service of any kind. Demand for these posts appears to be high, partly because it is an unqualified position, and also because pay compares well with administrative and customer service work elsewhere. Similarly the route into the long-standing Customer Relations Unit was from an administrative background, but postholders were expected to undertake an NVQ III qualification in Customer Care.

The least amount of relevant background and experience seemed to be required of staff in Care Direct, where the focus was upon a much broader 'one-stop-shop' model across all of the council's remit.

2.122 In all cases the imperative behind these developments has been to ease the pressure on front-line professionals by undertaking the first sift of applicants for social care support. One of the measures of success used by some of our respondents was the percentage of cases referred on for an assessment who subsequently received a service under the terms of local eligibility criteria – the implication here is that a high percentage implies an accurate initial judgement by the various intake teams. On this score some of the arrangements seemed to fare better than others, with most expressed concerns relating to the Care Direct model. Some care managers felt that the intake teams tended, on occasion, to err on the side of caution – “*we occasionally get people through and you think what on earth were they sent to us for?*” One team manager felt that the Customer Liaison Officer model was too easily open to manipulation:

*“Some people plainly just lie to the Customer Liaison Officers. They say I can't do this and I can't do that, then the social worker will go out and find they are hopping in their car and driving everywhere. They are not eligible...but my instructions are you should not chop anyone out if we have any doubts at all.”*

2.123 When councils change the availability of FACS bands, the role of these teams can become crucial as they have to change their filtering behaviour to match the new banding availability. In the case of the council in this study which had set the eligibility band at 'critical', for example, it was said that the team took some time to adjust when this band reverted to 'substantial'. In all of the localities it was commonplace for respondents to insist that everyone, regardless of their level of need, was entitled to an assessment of these needs, but it was not easy to find evidence of whether this actually occurred. The likelihood is, again, that much will depend upon the perceptions of individual workers. The observation of one director of adult care encapsulates the typically reactive stance of local councils to the issue of 'entitlement' to an assessment:

*“If people want an assessment then we will do it and give them advice.”*

2.124 The way in which an assessment is offered can also be critical, as this team manager described:

*“(Customer liaison officers) are saying to people you know 'I need to advise you that it does not appear that you are eligible for services, but if you wish to continue with a full community care assessment, if you want a social worker to come and see you, I can book that for you.' Some people still take up that offer – they have their assessment and they are ineligible – some people say 'no don't bother', but they have been given a choice.”*

2.125 These teams may serve two other important purposes in addition to passing on 'legitimate' cases to care managers – the signposting role, and the service broker role. The signposting role was considered to be an important feature of the long-established Customer Relations Unit where staff held responsibility for linking up to

community activities in their own 'patch' and ensuring leaflets were appropriately dispersed:

*"Knowing what is available in our patch is crucial because if its a low level need we know they are not going to get a service, but we may know somewhere they can get help. If someone is incapable of ringing up these organisations, then if they give us consent we can do that for them."*

2.126 The service broker role can involve setting up less complex types of support directly for people. In the case of the Customer Relations Unit, for example, the team administers the Blue Badge scheme, whilst the Customer Liaison Officers had the authority to put in one-off low level services such as meals-on-wheels and the booking of respite care in residential homes.

2.127 Opinions varied as to the appropriateness and effectiveness of these various sifting arrangements. In the case of the Customer Relations Unit the arrangement is of long-standing and relatively few grounds for concern were raised, though even here staff admitted that *"it was viewed with some trepidation by social workers at the beginning."* The greatest concerns were expressed about the models which are generic, centralised and confined to telephone or computer contact.

*"You have got help desk staff who are sat with the telephone earpiece on with the computer in front of them who will have somebody phoning up. Now people will not necessarily express their needs in terms of needs, they may just say I need a bit of shopping. The help desk need to be adequately trained to complete a basic assessment at that point."*

2.128 Indeed for some older hands, these new ways of dealing with people at the point of referral amounted to a rejection of care management principles:

*"If you go right back to the 1990 Guidance, the blue Managers' Book, which I love, it clearly states that you will have staff on intake who are sufficiently trained to be able to understand whether or not to refer on for assessment."*

2.129 All of this suggests that where councils have decided to transfer the intake role from social care professionals to other groups, then safeguards need to be in place. In the case of the Customer Relations Unit model this was approached through NVQ study, team manager supervision, regular meetings of team managers, joint training with professional staff and, at least in some cases, the co-location of intake and assessment staff. The Customer Liaison Model was said to require staff to log every phone call and electronically record the cases, each one of which is checked by a team manager or senior practitioner - an approach that may obviate much of the reason for establishing the posts in the first place. In addition, the staff can call upon advice from a social worker who is free of pre-booked appointments and can respond to emergencies. Without some such safeguards there will inevitably be concerns that people with eligible needs are being excluded from a legitimate consideration of these needs, and that unnecessary hurdles are put in their path as a disincentive to push for anything further.

## Lower Level Signposting Destinations

2.130 In all of the councils visited as part of this study the use of signposting had led to a greater reliance upon the voluntary and community sector to serve as alternative sources of support. The traditional funding of a range of organisations such as Age Concern and the Red Cross was continuing and, in some cases, increasing. However, these services were often available under market conditions without an assessment of need and based upon an ability to pay, albeit at a reduced rate. The economic attraction of such arrangements were readily conceded by council managers:

*"It is with well managed contracts with the voluntary sector that you get cost-effective activity; you have not got the staffing costs that we have got that increase unit costs. This is a way of freeing up resources that can be put back into real services."*

2.131 An alternative signposting destination for those needing some domestic support is the private sector – an alternative to council support that was felt to hold certain advantages for service users:

*"People are quite happy because they can get the support more cheaply and they are in charge of the service – it gives them a bit of independence."*

2.132 Given an adequate supply of good quality providers (and this could not be taken for granted in some areas) this type of signposting could work well for those people already paying the full council charge, but could be an expensive option for those financially assessed as needing to pay a nil or low charge. Perhaps the feeling that these 'low level' services are in some way not 'real' helps to explain the general lack of monitoring of their effectiveness - an issue examined later in this section. Although one council was anxious to re-visit the contractual relationship to learn more about user outcomes, in general little (or - in many cases – nothing) is known about the effectiveness of signposting to the voluntary and community sector. It is in this circumstance that the testimonies of individual service users become crucial, and these will be explored more fully in Section 3.

## Higher Level Signposting Destinations

2.133 One important alternative destination for higher level cases is a transfer of responsibility and funding from one statutory organisation to another. Typically this will involve the relatively small, but highly expensive, cases that may fall somewhere between the uncertain boundary of FACS critical and NHS Continuing Health Care. As one senior manager observed:

*"A first step in all of this is whether the person is eligible for continuing care. We don't even discuss FACS until we do that. That has been an interesting struggle over the years. It remains the most complex dance in the health-social care interface I think."*

2.134 The CHC-FACS critical boundary has not been the focus of this study, and here much will depend upon the ways in which the new national guidelines are interpreted and applied. For those not deemed to be an NHS responsibility there is, however, another potential destination for expensive cases, both council funded and self funded,

namely the private care home sector. It is the category of self-funders that is a particular concern for this special study. There are two key dimensions to the care journey of self-funders in the care home sector – diversion into the private sector, and redirection back to council funding.

## **Diversion into the Private Sector**

2.135 The trend towards tighter procedural guidelines for FACS based council funded care has not been echoed in the case of self funders diverted into private sector care homes, where the data provided to (and collected on) entrants is relatively flimsy. Despite the magnitude of the decision to enter a care home, councils generally offered little support to people who self fund their care. Some thought this a perfectly reasonable stance to take, others seemed to have minor doubts. One director of adult social care conceded that:

*"If people are asking for information and advice about residential care – and it's usually self funding for a relative – often we just send them the book of information Where people are struggling to understand the system we should be taking a more active role, and I don't know to what extent we are...we refer them to the CSCI website."*

2.136 This sort of attitude was, in the same council, reflected at the care manager level:

*"We do get people contacting us and we can send out the directory which has local homes in it. People can contact CSCI about homes, but we don't facilitate this."*

The consequences of this sort of approach - which was common across all of the sites – can surface at a slightly later point in the care journey, as this private care home owner observed:

*"I have seen people come to us who have a typed sheet with a ring round certain homes. That's about it really."*

2.137 It is doubtful that such an approach is of much value to self-funders and their families who are on the cusp of the decision to enter a residential setting. The findings of this study reinforce those of the recent CSCI study on the experience of people deciding to enter residential care<sup>37</sup> which found, *inter alia*, that:

- 50% of people who fund their own care do not have a care assessment
- 40% of councils acknowledge that support is lower for people who fund their own care than for other older people
- People were generally critical of the written information they had received from both councils and care homes.

2.138 Respondents in this special study generally acknowledged that once someone was known to have savings above the level that gives the council some funding liability, then they were generally left to their own devices both in terms of entering and residing in a private care home. In general the councils in this study were struggling

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<sup>37</sup> CSCI (2007), *Op cit*

to even keep up reviews for the residents they were funding, let alone self funders, and this can leave self-funders feeling powerless, with no-one to turn to for independent support. Indeed, even if a care manager wishes to offer support to a self funding resident, there are other potential obstacles:

*"We have got no legal power to look at the notes of the people we don't fund. In some cases the homes don't even bother keeping notes for self-funders. They will keep them for the council because they know we are going to ask to see them as part of their contract."*

2.139 It is perfectly possible for an individual, usually an older person, to end up in a care home through a combination of reasons, none of which is to do with the *need* for this particular option. In part this may sometimes be down to an individual choice, however ostensibly misguided, as our analysis in Section 3 will demonstrate. It was possible, for example, to discern some individual predisposition to regard private residential care as an extension of hotel living that at the same time obviated the need for contact with what was seen as the stigmatised public sector. There is, however, also a *systematic* predisposition to move people precipitously into the private care home sector. Care home owners seeking to maximise occupation, hospital staff seeking to release beds and GPs looking for a quick solution to complex cases, were all cited as bearing some responsibility for the growth of self-funding residents.

### **Redirection to Council Funding**

2.140 Although the diversion of self-funders into the private care home sector may offer an immediate financial solution for local councils (albeit not necessarily the most appropriate outcome for individual service users), the issue of redirection *back* into council funded care is a growing concern for local authorities. In this study three related concerns were raised – resource depletion, council fee structures and FACS eligibility criteria.

2.141 Resource depletion – the situation in which the resources of self funders fall to the level at which councils have funding responsibility - is the basic issue upon which other problems rest. Councils in the study were well aware of the danger of resource depletion, but none of them appeared to have a developed strategy in place for dealing with it.

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

2.142 Any such strategy involves close liaison with private care home owners. Although a stronger relationship would be in the interests of both parties, it was not an easy task to accomplish. One private home owner expressed a reluctance to inquire about the savings of residents:

*"When self funders come to us I will say to them 'I don't want to know what your resources are, but when you think they are coming to a close, say a year away, it is in your interest to talk to the local authority'. But they may not remember to do it. I*

*have two or three cases where someone finishes on Friday and they have no money."*

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

*"We try very hard but they say they don't know themselves, so they are clearly not asking."*

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

2.143 Better identification of resource depletion forms the basis for a strategy but does not resolve two further issues. First, the inflexibility of fee structures on the part of many councils. The problem here is that self funding residents are often paying fee levels that exceed those normally paid by the council for its own funded residents. In such circumstances there will be difficult pressures on all three parties – on councils to pay at the higher level, on home owners to continue with occupancy at the lower council level, or upon individuals to find some 'third party' top up payment.

2.144 Councils, in pursuit of market efficiencies, are increasingly setting locality wide fee structures which they are then unwilling to break for self funders whose resources have depleted. Some felt the home should accept responsibility:

*"In my opinion the test of a good home will be that it is committed to making sure that person is going to be looked after, and it will negotiate a different fee level in order to facilitate this."*

*"The problem is that homes are not being upfront about what the council can do. In all good faith a family can place their loved one in a home that is above our rates and then they have a very stressful time when the capital is depleted."*

One council respondent went so far as to see such a solution as rooted in the principle of equity:

*"We depend upon self funders to subsidise the others. Isn't that how it's meant to be?."*

2.145 On occasion, councils do break their own fee structure in order to maintain an existing resident in a familiar setting, but this brings its own problems:

*"We have paid the higher rate in some cases and that's not fair on the contract we have with other providers. Word gets out, and if people see us doing that then there is no incentive for them to work within our fee structure. It's a very difficult situation to manage."*

It is common for private homes to charge less for council funded residents than for those who fund their own care – 58% of homes do so according to the CSCI study<sup>38</sup> - but a key factor here is that those paying higher rates do not get a substantially

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<sup>38</sup> CSCI (2007), *Op cit*

different service. Indeed, in some respects those paying the higher rate receive a worse service, in that - unlike council funded residents - they have no independent surveillance and support.

2.146 Finally there are those people who, having depleted their resources, find that they do not even qualify for *any* council support because they fall outside of the FACS criteria being operated by their council – another consequence of entering the residential sector without having first undergone an assessment of need by the council. It has not been part of the brief of this study to quantify the numbers of people in (or potentially in) this situation, but it was of sufficient frequency to concern several respondents.

*"This happens quite a lot actually, I have seen two or three people like that. They put themselves into residential care at quite an early age because they don't want to live on their own. When their capital is used up they come to us and even after all that time, they still don't meet our criteria."*

*"The ones that make their own decision to put themselves in care, that is a concern. They've sold everything to pay for their care and at the end of their money the council will not take them on. It's soul destroying."*

### **Post-Diversion Strategy**

2.147 If rationing by diversion is 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. Some respondents were well aware of this necessity:

*"Everyone focuses on assessment and eligibility criteria and not on what the objectives of the intervention are meant to be and how effective the intervention is. But this is what the original Community Care Act talked about."*

2.148 For the most part, however, councils had taken relatively few steps to measure and understand the consequences of their policies. The most frequently mentioned approaches were complaints procedures, aggregate monitoring and re-entry to the council system.

2.149 *Complaints Procedures:* Formal complaints are best regarded as the 'long stop' of any dissatisfaction with services and support – when all else fails an individual may feel that there is no alternative other than to activate formal complaints procedures. Many people, especially when they are at vulnerable points in their lives, will lack the skill, energy and motivation to go down this route, yet the councils in this study often equated a low level of complaint with satisfaction with signposting. In the view of one elected member:

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

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

2.150 Another example of a long-stop approach was to have infrequent meetings with community representatives to check out their views. One portfolio holder noted:

*"Once a year I invite the Director of Age Concern and the carers organisation in and say 'right it's your turn to put your problems on the table' and we'll see what we can do about them."*

2.151 *Aggregate Monitoring*: If reliance upon complaints procedures is the most basic reactive form of monitoring, then aggregate monitoring constitutes the minimal mode of proactive monitoring. The strategy here is to try to estimate the aggregate number of people who have been diverted into other types and sources of support, without knowing the circumstances of any individual cases. The evidence from this study is that this strategy tends to be half-hearted in execution and statistically crude in terms of output. Although councils may well be increasing their financial support to the voluntary and community sector to support people who are signposted out of the statutory sector, they are generally unaware of the fate of the individuals who are supported.

*"There has been very little feedback about tangible outcomes. They will say 'we saw so many people, we did 'x and y', and we don't know if that was with our priority group or an easy group."*

*"We haven't any idea what is going on with the low level contacts. We don't know what is going on with each excluded FACS band because it hasn't come through our assessment process."*

*"We grant fund a whole range of voluntary groups but these are not assessed services. We know that folk are out there and they avail themselves of that, and that keeps them away from our door, but they don't keep information in a way that is useful to us."*

*"We know how many people are receiving these services but we don't have a mechanism for noting who they are – that would be a bit intrusive."*

2.152 *System Re-entry*: One other measure of the effectiveness of signposting – but one that is too belated to be of proper value – is re-entry into the statutory system after signposted support has failed to meet individual needs. Even here there may not necessarily be an indication that the individual has approached the council in the past:

*"When you get a new referral it will often show any contact history we have had so I guess you could know if people bounce back a bit."*

One care manager conceded that such a 'bounce back' occurred relatively infrequently and could not be used as a reliable measure:

*"If I had asked for help and somebody just gave me a bit of paper then I would be reluctant to go back again and say would you help me."*

2.153 The reality seems to be that most councils actually make no attempt to ensure that vulnerable individuals who are signposted out of their own system are receiving some support. Some respondents appeared to regard this as simply an unremarkable fact of policy life:

*"If it was just a signposting then there wouldn't be any follow up, so we wouldn't know what happens to them."*

2.154 In the case of another council there did seem to be a procedure for recording unmet need, but it appeared to be little more than a dormant bureaucratic chore:

*"We used to have a form that recorded unmet needs and used to go to somebody in commissioning – somebody who left. I'm not sure what happened. I had colleagues who were looking for the form and they were unable to locate it. They found an old one but there was no way of passing it on."*

2.155 Only one of the councils in this study seemed to even have any aspirations for changing this situation. Here it was felt that where the voluntary and community sector is funded by the council then it has an obligation to account more fully for how effective the expenditure has been.

*"We need to have a much better idea of the needs of our population and the option of contacting them again to make sure they did get the services they need and that they didn't just drop out of the system."*

2.156 Not only was this new approach seen as vital for service users, but it was also thought to be important in helping the council to demonstrate to central government that it is meeting performance management targets:

*"What would be happening in the future is that we will be redefining the nature of our contracts and relationships so that these organisations understand that we live in a world where the numbers count...clearly some of them have been less than comfortable with this approach."*

2.157 For any such strategy to work it will be crucial to have sophisticated information management systems in place that are capable of capturing relevant data on individuals, but the councils in this study did not generally have this capability. And even if the right hardware and software was in place, there is likely to be a cultural issue about getting care managers to identify and record presenting, as well as eligible, needs.

2.158 Overall, in this special study, rationing by diversion has resulted in a system in which people whose needs are deemed to be ineligible for direct council support are - at best - 'signposted' into an alternative system. Once in this system it is not generally possible to ascertain whether people get any help at all, or whether such support as they do receive is right for meeting their needs. Monitoring procedures and mechanisms are crude or non-existent, and staff are pre-occupied by the demands arising from meeting eligible need. Rationing by diversion is in danger of fulfilling the

description of community care made by Sir Roy Griffiths in the 1980s – “everybody’s distant relative but nobody’s baby.”<sup>39</sup>

## Summary: Key Messages On Rationing By Diversion

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- There is a potentially important ‘pre-diversion’ stage in which, effectively, people decide to preclude themselves from seeking social care support. This may be due to lack of understanding about the sort of help that may be available, along with a lack of accessible information. A different sort of pre-diversion arises where the image of local authority social care is seen as stigmatising, to the extent that potential applicants are deterred from seeking help.
- All of the councils in this study were well aware of the need to develop a more accessible image rooted in a preventive agenda around health and wellbeing, but most were unable to identify the resources to enable them to do so.
- ‘Signposting’ is essentially what the word suggests – people who approach their council for advice or support may be advised, and perhaps supported, to seek help elsewhere. The growing importance and acceptability of signposting was commonly recognised across the sites in this study. Although the reasons for developing a signposting strategy are essentially economic, it was also seen as having other virtues such as responding to user preference and strengthening a sense of individual responsibility.
- An important issue here is whether people are completely signposted out of council systems or whether they still remain known to the council despite receiving no direct support. For those councils operating at less than all four FACS bands, signposting had generally been devised as an ‘exit strategy’, whereas in the case of the council that was keeping all four bands open, it was claimed that people signposted to other services nonetheless remained under the council ‘umbrella’.
- The nature and quality of signposting appeared to depend upon the commitment and skills of individual workers, with some confining themselves to delivering a list of addresses and telephone numbers, and others attempting to support individuals along the signposting journey.
- It is at the point of referral that a crucial decision will be taken on whether or not to even acknowledge the case for a formal assessment of individual circumstances – in effect a decision can be taken to screen someone out from any further consideration for direct council support. In parallel with the growth of signposting as a strategy, councils have accordingly developed mechanisms for filtering people in or out of the system at the point of referral.
- 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. One of the most striking features of the arrangements

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<sup>39</sup> Griffiths Report (1988), *Community Care: An Agenda for Action*. London: HMSO.

being made by councils in this study is the extent to which this role is now being undertaken by staff *without* a professional background in social work.

- Opinions varied as to the appropriateness and effectiveness of these various sifting arrangements. Without some safeguards there will inevitably be concerns that people with eligible needs are being excluded at an early stage from a legitimate consideration or assessment of these needs.
- In all of the councils visited as part of this study the use of signposting had led to a greater reliance on the contribution of the third sector to serve as alternative sources of support. Little was known about the effectiveness of signposting to these voluntary and community services.
- The trend towards tighter procedural guidelines for FACS based council funded care has not been echoed in the case of self funders diverted into private sector care homes, where the data provided to (and collected on) entrants is relatively flimsy. Despite the magnitude of the decision to enter a care home, councils generally offered little support to people who self fund their care.
- Respondents in this special study generally acknowledged that once someone was known to have savings above the level that gives the council some funding liability, then they were generally left to their own devices both in terms of entering and residing in a private care home. In general the councils in this study were struggling to even keep up reviews for the residents they were funding, let alone for people funding their own care, and this can leave self-funders feeling powerless, with no-one to turn to for independent support.
- Although the diversion of self-funders into the private care home sector may offer an immediate financial solution for local councils (albeit not necessarily the most appropriate outcome for individual service users), the issue of redirection *back* into council funded care is a growing concern for local authorities. Councils in the study were well aware of the danger of resource depletion, but none of them appeared to have a developed strategy in place for dealing with it.
- If rationing by diversion is 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.
- Rationing by diversion has resulted in a system in which people whose needs are deemed to be ineligible for direct council support are - at best - 'signposted' into an alternative system. Once in this system it is not generally possible to ascertain whether people get any help at all, or whether such support as they do receive is right for meeting their needs. Monitoring procedures and mechanisms are crude or non-existent, and staff are pre-occupied by the demands arising from meeting eligible need.

## Policy and Operational Issues: Conclusion

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2.159 This section of the report has examined policy and operational issues surrounding Fair Access to Care. It has identified three modes of rationing – by directive, by discretion and by diversion. These modes are not mutually exclusive and each will be

in use to a lesser or greater degree at any one time in a locality. The intention in this section has been to explore both the formal and informal processes at work in the rationing of social care, and to gain a better understanding of the tensions between them. There is an inherent tension between rationing by directive and rationing by professional discretion, with the former based upon explicit rules that should ensure consistency of treatment, and the latter dependent upon individual judgement. Rationing by diversion may combine elements of both formal and informal rationing.

2.160 In principle, FACS has the potential to act as a guarantor of equity across a locality (though not across the country) and to match changing levels of support to changing levels of risk and need. In practice it tends to be used as a means of reducing budgetary demands upon the council, limiting professional discretion, and legitimating the diversion of demand away from council funded services. All of the councils in this study were experiencing financial problems in respect of adult social care, and felt the need to review both their priority setting and rationing policies.

2.161 This section of the report has identified a number of key trends, notably:

- all councils are developing tighter rules and procedural guidelines for FACS regardless of whether FACS band availability is reduced;
- reducing the availability of FACS bands does not resolve demand-side issues;
- the trend towards identifying the 'core business' of adult social care is not easy to reconcile with the growing personalisation agenda;
- care managers continue to exercise some discretion in determining eligible needs, but this discretion is diminishing and professional reactions vary;
- all councils are increasingly using 'signposting' as a way of diverting demand;
- people who fund their own care tend to be left without any form of independent review and support;
- councils rarely know what happens to those whom they signpost out of direct support.

2.162 Perhaps the key message in all of this concerns those individuals who for various reasons are 'lost' to adult social care, and about whom very little is known. With the numbers of such people increasing, it is important to discover more about their lives – in effect to examine the impact of policies and procedures. This is the purpose of Section 3 of the report.

# Section 3: Outcomes and People's Experiences

## Introduction

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- 3.1 The previous section of the report has examined the policy and operational approach to determining eligibility for social care. In so doing it has explored how eligibility criteria are intended to operate as a rationing device to ensure that resources are directed towards identifying and supporting people with the greatest needs. The policy position (or what we have termed 'rationing by directive') is mediated by the behaviour and practice of operational and front line staff who introduce an element of professional judgement ('rationing by discretion'). For those they are unable to accommodate within eligibility criteria there is typically a practice of 'rationing by diversion' through which people are directed to other potential sources of help and support.
- 3.2 What impact do eligibility criteria have on people seeking social care support? In Section 1 we introduced some of the voices and stories of people who use social care services. As we discussed, there is national evidence of eligibility thresholds being progressively raised to address critical and substantial levels of need (and sometimes critical only), and there are growing concerns about what happens to people who fall at this hurdle, but who nevertheless have a range of support needs. In addition to the group of people who might approach councils for help with social care but find their needs are insufficient to warrant support, there is another group who - for a variety of reasons - tend not to approach the council and simply make their own private arrangements. It is to the experiences of all these people that this section now turns.
- 3.3 People's experience of using social care organised by local councils depends entirely on whether their needs meet local definitions of eligibility. The most critical test of eligibility is that which takes place on initial assessment. People who are accepted as eligible enter the system and rarely leave it (although their level of support may be reduced); for those who don't gain access the story is a very different one, and they remain on the outside unless there is a substantial change in circumstances *and* they have further contact with social services leading to a new assessment. The people we spoke to in the course of this study all told a similar story of how their contact with social services typically arose as the result of a crisis or trauma.
- 3.4 In working with the six councils who agreed to take part in the study we set out to identify different types of people. In particular:
- People who are assessed and judged to be just below some of the thresholds for eligibility;
  - People who no longer meet the eligibility criteria at review and have support withdrawn;
  - People who have received intermediate care and are no longer eligible for support at the end of this period;

- People who buy their own care and support privately. This includes people who have made their decisions without contact with social services; those judged ineligible for publicly funded services and who have no option but to buy their support privately ('self-funders'); and those who are eligible for publicly funded services but choose to privately fund their care rather than pay the charges for council organised support.

3.5 We were reliant on the councils to identify people in these categories. Contact with the people themselves was contingent on them agreeing to participate and giving consent to their file notes (where relevant) being examined and their case discussed with the care managers or social workers responsible for decision making. Relatively few people declined to be involved with the study and we are particularly grateful to people for allowing us to spend time with them in their homes, and for patiently answering our questions. Many of the people we spoke to expressed their hope that participating in the study might improve the experience for others in the future. In the analysis which follows we draw heavily on our interviews with people who use services (and with those who have tried unsuccessfully to get access to services), and of family carers in order to allow their voices to speak and their stories to be heard. In addition to using direct quotations from our transcribed interviews, we also present a number of case studies to illustrate particular experiences.

### **Outcomes Framework**

3.6 The framework for analysis in this section is derived from the seven outcomes dimensions identified in the 2005 consultation document *Independence, Well-being and Choice*,<sup>40</sup> and reiterated in the 2006 DH White Paper *Our health, our care, our say*,<sup>41</sup> that is:

- Quality of life.
- Exercising choice and control.
- Making a positive contribution.
- Personal dignity and respect.
- Freedom from discrimination and harassment.
- Improved health and emotional well-being.
- Economic well-being.

3.7 This framework has been further developed in work by CSCI looking at how it relates to regulated social care.<sup>42</sup> It is evident that the dimensions are often inter-related – in particular it could be argued that *all* the dimensions relate to aspects of quality of life. Moreover, it is also the case that not all dimensions are always relevant to all people seeking support from social care, or that different aspects become of lesser or greater importance at different times. Despite these caveats, the framework is

<sup>40</sup> Secretary of State for Health (2005), *Independence, Well-being and Choice: Our vision for the future of social care for adults in England*, Cm 499, London: The Stationery Office.

<sup>41</sup> Secretary of State for Health (2006), *Our health, our care, our say: A new direction for community services*, Cm 6737, London: The Stationery Office.

<sup>42</sup> CSCI (2006), *Inspecting for Better Lives: A quality future*, Consultation Document.

important in exploring how services impact on people's lives, and the analysis which is presented here should help in developing CSCI work on judging the outcomes of regulated services.

- 3.8 The outcomes framework reflects the dimensions which people have identified as important in a range of different research and consultation exercises over some years. In many ways the core objectives of social care have changed little from those stated in the 1989 White Paper *Caring for People*<sup>43</sup> which emphasised enabling people to 'live as normal a life as possible' in their own homes and community; helping people achieve maximum possible independence; and giving people a greater say in how they live their lives. Improved choice and independence were underpinning principles. The fact that there is such continuity between the outcome objectives identified over this period of time emphasises both that these *are* core values which continue to be valid, but also that achievements have been limited. Criticisms of progress have identified the poor development of outcome frameworks beyond the simple listing of core objectives, and the often misconceived focus on process factors, or a confusion between ends and means.
- 3.9 In the analysis which follows we follow the original outcomes framework set out in *Our health, our care, our say*, and we draw on the further work which has been undertaken jointly by CSCI and by the Healthcare Commission to align their frameworks and develop joint indicators.
- 3.10 Many of our findings highlight the negative consequences for people's lives; it is important to remember the focus of the study which is essentially on people who often fail to get the support from social services which they had hoped for or expected. We turn now to the seven outcome dimensions; we consider what these mean for people's daily lives, and how eligibility and ineligibility for social care services impacts on these outcomes.

## 1 Quality of Life

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- 3.11 'Quality of life' refers to that disparate collection of variables and circumstances which we all recognise as integral to our satisfaction and contentment. The 2005 Green Paper (*Independence, Well-being and Choice*) described the outcome in terms of:

*"Access to leisure, social activities and life-long learning and to universal, public and commercial services. Security at home, access to transport and confidence in safety outside the home."*<sup>44</sup>

### Keeping Independent

- 3.12 Work by CSCI in developing the outcomes framework for regulated social care services suggests this outcome variable is about the active promotion of people's

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<sup>43</sup> Secretaries of State (1989), *Caring for People: Community care in the next decade and beyond*, Cm 849, London: HMSO.

<sup>44</sup> Secretary of State for Health (2005), *Op Cit*, P.26.

independence, and supporting people to have a fulfilled life. The vast majority of people we interviewed about their experiences were elderly, and indeed many were in their 80s and 90s. For most of these their sense of independence and fulfilment was about being able to 'keep going', and to remain in their own homes, for example:

*"But you have to put up with it don't you? I'd rather be home than anywhere."*

And

*"With all due respect to homes, I have been in a few to visit and it's not for me (...) Like I say, if you have got to physically, then you have to make the best of it."*

- 3.13 For some people the desire to remain independent and in their own home is accompanied by the fear that this might not be possible in the longer term, as this person remarked:

*"You do get worried when you are on your own, you think how long am I going to be able to keep this up? But I would like to be able to stay here if I can, but they are such big places, you know."*

- 3.14 For people who have moved into care homes the concept of independence also has meaning. For some this is about continuing to do as much for themselves as they are able to, and avoiding being seen as 'a nuisance'. For example this person explained that she could access the garden if she asked for help:

*"Well, I could if I rang the bell. But they are so busy, and some of the people are quite difficult you know. But oh they are so good!"*

This resident was also reluctant to ring the bell for assistance in getting up and down during the night:

*"I can get on the bed, but as soon as I go to get my leg up – this leg is awkward – and it's a job to get it up and I nearly fall off. I did one night, so I have to ring them to get me back into bed (...) but some nights you can hear that bell ringing all night – people ringing and ringing, and they need people and the girls are up and down, up and down all the time. If I can do it, I will do it."*

- 3.15 By contrast, other residents who also try to do as much as they can for themselves have problems with care staff "getting a little bit picky and choosy about what they'll do and what they won't do." As this resident described, she would only ring for assistance if she couldn't manage alone, but she often received short shrift in response:

*"Well if I ring the bell and somebody comes they might say 'oh you're alright – you can do it!' and they're off out the door. I have already tried to do it; I wouldn't have rung the bell otherwise! If I can do it, I do it. I said 'look, perhaps you don't know that I've already tried to do this and couldn't and that's why I rang the bell.' It's more the younger ones."*

This may also be an indication of care staff absorbing the message that residents should be encouraged to do as much as possible for themselves, but interpreting that

in a rather blunt and inflexible manner which fails to take account of individual circumstances.

### **Lifestyle and Social Networks**

- 3.16 It is evident that normal habits and life style become harder to maintain as people become older and less mobile, as the following comments indicate:

*"There is a club I belong to – the Con Club down the road – I used to go down there with a couple of the lads every Sunday, but I packed that up because I don't feel like going around with that damn thing [walking frame], and I can't carry a pint."*

*"I used to go out every night to play dominoes (...) I used to enjoy myself."*

*"I used to go out a lot. And people are surprised that I have settled so well in the house. But I have. I have no desire to go out. And yet I was always out at one time."*

- 3.17 Normal activities – such as going out in the car – become harder to do but at the same time people are reluctant to give up their cars which still represent their independence and lifeline to the outside world:

*"I'm still driving! I'm 89 now – but I can drive alright; I'll go up the road for milk and so on."*

*"I could drive, I could – the trouble is getting out and getting the car out of the garage; it is an awkward job, well it is hanging on to a Zimmer frame."*

At least one person (aged 84) who had given up her car was now thinking of buying another.

- 3.18 A number of people had electric scooters to help them in getting around, and while these were useful they also have limitations not least the fact that they are open to the elements. Various people also remarked on the hazard which these scooters represented when they were driven by people who were either not fully in control of the vehicle or used it irresponsibly. One of the people we interviewed had been badly injured in an accident when she was run over by one of these scooters. Some people who had given up their cars (either by choice or because they were no longer fit to drive) recognised that the money they saved on running costs could be used to pay for taxis so that they could get out and about. Despite the fact that people would have access to free – or subsidised – public transport it was apparent that taxis were often a much better solution.

### **Access and boundaries**

- 3.19 For people who are rarely able to get out of their homes, their world becomes very small. It is in this context that the condition of the house can be especially important (as we will explore later under the heading of personal dignity and respect); the view from the window can also be crucial. For some people it makes such a difference that it becomes the most important criterion when thinking about where to live. An elderly person living in warden controlled accommodation had rejected a ground floor

flat (despite limited mobility) in favour of the first floor so that she could see more from the windows, watch the world going by and have a glimpse of a sea view. Another who was living in a residential home similarly explained how she chose her room:

*"I saw this little room and a much bigger one, but this one looked over the garden and I thought it was nicer for me."*

- 3.20 Another elderly person who was receiving minimal personal care in her own home had expressed a wish for the home carers to feed the birds in her garden. Her file notes record:

*"At review it was explained that this task could not be prioritised and may only be possible if time allowed. In addition, during inclement weather carers could refuse access to the garden if Health and Safety issues were apparent."*

- 3.21 What might have seemed like an unreasonable request from the perspective of social care made perfect sense to this person who spent many hours looking out of her window into the garden, and for whom the visiting birds were an enormous source of pleasure, not least because she had been "a country girl" and seeing the birds reminded her of those times in her life.

- 3.22 While some people become housebound because their mobility is so impaired that they cannot easily leave the house, or because they disengage from the outside world and have less interest in going out, others are effectively captive in their homes because of the absence of essential equipment or adaptations. This was vividly illustrated in the situation of a young man who had undergone amputation of his leg and was discharged from hospital apparently without any assessment of his home situation. Without a wheelchair and with no ramps to facilitate access, he was unable to leave the house. In desperation his father built a ramp himself but this did not meet health and safety criteria and the local council could not offer an alternative because it was claimed a safe ramp could not be constructed in the space available.

*"They can't give me one – because the door is too steep for the ramp, or something (...) they won't give me one for the back door even (...) I can get out of the backdoor and I'd end up in the middle of the lawn."*

- 3.23 Not only was this person confined to the house unless there were people who could physically lift him out, but he was also stuck downstairs unable to access toilet and bathroom facilities until he managed to drag himself up the stairs. He explained how he managed:

*"On my bum. I don't go very often. You see I have got stronger now, everything's getting stronger and back to normal. So I can lift myself. And everyone else seems to do it. At the hospital, everyone's crawling on their bum like."*

This man was determined to attain some independence – to move out from the parental home he had returned to, and to get back to work. However, while he was recovering from the recent trauma of amputation and complications he was limited to using a wheelchair. His needs under the FACS criteria had been assessed as 'low'.

His quality of life – on any reasonable assessment – was very poor indeed and could easily have been enhanced with a little support.

### **Isolation and Resignation**

- 3.24 In addition to the physical limitations on people's mobility and activity there are also social barriers. In particular, people's social networks often become smaller with consequent risks of increasing isolation and loneliness:

*"They have all died; that is the trouble see? At my time of life you find that all your friends that you knew are not around and you don't make any more because you can't get around, plus the fact you don't feel particularly like making friends with people you don't know."*

*"I want to be gone! All my friends are gone!"*

*"That's the trouble – you go on too long these days. You feel that you have not got much going for you, you sort of dread to be a nuisance to people."*

And

*"I get very lonely and unless my grandson comes to see me I don't see anybody; everyone I know around here has either died or moved."*

- 3.25 The risks of isolation and loneliness were well recognised and many people work hard at maintaining their social networks in order to ensure they don't become reclusive. One person, for example, described how she continued to play bridge regularly with friends:

*"And that keeps my brain a bit more active (...) and you have to, I think, otherwise – well I'd sit and watch those walls all the time if I didn't."*

- 3.26 Some people view their situation – rightly or wrongly - as purely temporary; it is associated with ill health or disability and if they can only get that resolved, everything will be fine once again. For those people who have made the decision to move into residential homes, quality of life is defined in different ways. For them it is about coming to terms with a new pattern of life. For example when a (self-funding) resident was asked whether she was happy in the home she had chosen she replied:

*"Let me say at once that you make your own happiness. But 'happy' is the wrong word for anybody in a home."*

For this person the best she could hope for was to be 'comfortable'; happiness was something that sadly belonged to her previous life.

- 3.27 Some other residents were more positive, and while most were 'making the best of it', others were more fulsome in their praise:

*"I like the people here, I get on well with the staff and they are always pulling my leg – and I give as good as I get, and they don't mind."*

*"They're such a wonderful crowd here; you couldn't wish for anybody better."*

And

*"Oh yes, they're very good. It's one of the nicest really. I can't complain, I really can't."*

However, even for this resident who stated several times that everything was alright, he also observed:

*"..but you get used to it; you can get used to anything."*

- 3.28 Another person who had made the decision to move into a care home was altogether less content with her situation and was planning to move as soon as she could (*"I want to get out now"*). Because of poor mobility and with a leg in plaster, she had become virtually stranded in an upstairs bedroom, and was determined to get her leg better so that she could find another home to move to and *"get out of here."* Other residents she had been friendly with had already moved out to other homes because of growing dissatisfaction, and for this person the only glimmer of hope was the belief that once she had the plaster removed,

*"I can get more mobile and get out by next month."*

And

*"I don't want to stay here. It's not a nice atmosphere; you notice when you come in here."*

- 3.29 This introductory examination of people's experiences has highlighted the poor quality of life on offer to many (indeed most). Few people described their lives entirely negatively; most expressed a level of resignation and acceptance (*"I get by the best I can"*) and had low expectations and modest desires about what might be offered to them. However, most of the people who participated in the research had either been turned down as ineligible for social care, were receiving less support than they felt they needed, or were simply trying to find their own way in the system.

## 2 Choice and Control

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- 3.30 'Choice and control' has become the key mantra of social care. Improving the choice and control people have over the services and support they receive, and how they receive it, were central objectives set out in the 2005 Green Paper, and the 2006 White Paper on health and care. Central to this was the further promotion of Direct Payments and of models of self-directed support and personalisation, particularly through the piloting of Individual Budgets (IBs). For people who are not yet making use of DPs or personalisation, choice and control should still have meaning. The Green Paper described the objectives in these terms:

*"Through maximum independence and access to information; being able to choose and control services and helped to manage risk in personal life."*

- 3.31 This implies a number of features, in particular:

- People have access to information and services.
- Services are responsive to individual needs and preferences.
- People have the information they need to make decisions and choices.
- People are supported to make informed decisions about risks.

Below we explore how people experience these and other aspects of choice and control in their daily lives.

### **Assessment, Information and Signposting**

3.32 As we have already discussed in Section 2, the assessment process occupies a pivotal position in determining whether and how people gain access to council arranged social care support. The significance of assessment was widely recognised by people who had sought help from social services. The people we interviewed who had been told they did not meet the eligibility criteria for social care nonetheless *did* have needs which they (or family members) had identified. The initial approach to social services was often a matter of chance; people were frequently reluctant to contact social services or had not thought about doing so until it was suggested by friends or family. Some elderly people described the difficulties they had in trying to contact services (struggling with telephone systems) or being told that they had to have a referral.

3.33 Because most of the people we spoke to had been judged by social services not to meet eligibility criteria for support, the most common experience that was reported was of making contact, having an assessment and then getting little or no help. Many expressed their surprise and bewilderment that social services were unable to offer any assistance, particularly where people were coping *but with obvious difficulty*. Some people also misunderstood the reasons why they were ineligible and thought it was not about their needs being insufficiently urgent or intense and more about them having their own financial resources. The following comments were typical of many that were made:

*"My daughter used to be a health visitor and she said that we needed to get Social Services involved to help us because of all our medical problems (...) as you can see we can do things, but my daughter said we are too brave for our own good."*

*"Well she asked me all these questions and then decided that none of it applied to me."*

*"They said I didn't seem to be doing so bad."*

*"Because if you have got any money at all with a pension, they don't want to know!"*

*"Well, I did not know who to ask anyway, because you don't."*

*"They said you are not entitled to anything."*

3.34 At the same time, many people readily accepted that others were in greater need and recognised that resources had to be prioritised:

*"Well I always think there is someone worse off than me that needs it more than I do you know (...) I mean, I try the best I can."*

People who were self-funding often remarked that they had never even considered contacting social services, partly because they did not believe it would be appropriate for their needs, for example:

*"No I did not! And I didn't think about it either way, I didn't need anything, let them get on with those who do need them!"*

- 3.35 People who were deemed ineligible for social services support were often provided with Occupational Therapy equipment (trolleys, walking frames, bath boards etc) to help them cope more easily in their home. While these aids and adaptations were generally seen as helpful, they often did not address the main support needs which people had identified for themselves. Moreover, even the supply of equipment was not always straightforward and there could be considerable delays as the following comments indicate:

*"Nobody has ever come in from social services, only a letter, and two turned up with the bath board."*

*"We asked her (the OT) could she get a rail for the back garden because there are four steps up and it is difficult going up there and she said she would put it forward, but we have not heard anything."*

- 3.36 As we have described in Section 2 the general response of councils to people who do not meet social care eligibility criteria is to offer 'signposting' to other sources of help and support, and then – as our analysis of case files indicated - frequently to close the case and record that 'no further action' is required. In none of our six councils was there any systematic attempt by social services to follow up what happens to people directed towards non care-managed services in this way. Even when contracts or service level agreements exist with third sector and other organisations to respond to 'low level' support needs, there appears to be no mechanism that allows councils to link activity to individual referrals. As Section 2 described, signposting can be interpreted in many ways from a passive provision of a list of contact addresses, to a more active role in helping people to identify and contact particular organisations or agencies. People using services who we interviewed described a range of such experience. Signposting can often put considerable onus on people themselves to take the initiative in seeking further help, and at times it is evident that signposting leads people into a cul de sac in which they remain with no further assistance, for example:

*"They gave me [a voluntary organisation] to contact, and [that organisation] said they don't know if they can help us or not because they have got so many people on the books."*

*"I contacted them as soon as we came back and he just said it in a way that was – I think – you'll be very lucky to get somebody, you will have to do it yourself."*

*"I don't know who she was and (...) she gave me a list of where I could contact different sorts of people and I contacted [this organisation] (...) they said they would be in touch with me (...) I waited five weeks (...) the following week I had a letter (...) and it was to say that at this moment in time there was not any likelihood of me getting any help."*

- 3.37 Not surprisingly, such experiences reduced the likelihood of people feeling that they could get help or seeing any point in going back to social services in future. People who had run into a dead end when trying to follow signposting were likely to throw away any list of contacts and to see little point in asking for further assistance. In the absence of any offer from social services, it is evident that some people are resourceful and find ways of organising support for themselves. Typically this is a combination of using informal sources of help, together with privately arranged support. However, these arrangements are fragile and liable to break down and, most importantly, not everyone has a network to draw on or the financial resources to support private choices.

### **Finding Solutions**

- 3.38 People needing support in their daily lives do not automatically look to social services as their first port of call. On the contrary, most of our interviewees told us about their neighbours and family members who were willing to help out and who often went out of their way to do so. These comments are typical:

*"Oh if I want anything I just have to say to my neighbour, she is very nice. Well she calls in every day (...) she says if I want anything just ask her, ring her up and ask her (...) I couldn't get a better neighbour."*

*"As for my meals – I cook dinner one day; my mate cooks it the next and we do that between us because some days she isn't well and another day I don't feel well."*

*"So he has got the key and he comes in nearly every day and we have a chat."*

*"I have a friend round the corner and she does all my shopping and everything. She comes in every day to see me (...) she is very kind."*

*"Oh well my neighbour used to come up, but she's busy working now, but oh she was a wonderful person, when my husband was ill she did all my shopping."*

*"My niece comes once a week to do my shopping."*

- 3.39 For some people these informal arrangements with friends or relatives are more than just 'popping in' and have been put on a more regular footing, as this person described:

*"Well I have a god-daughter who is a hairdresser and she does my hair (...) and one day a week she does the flat. And then this morning I've had the other lady who I have known for donkey's years as well, she does the flat for me. And next Thursday her sister-in-law comes."*

- 3.40 While friends and family can be invaluable in helping with little jobs around the house or with the practical demands of shopping (even though people often remarked that 'you don't like to ask'), people were less keen to have help with personal care in this way because of the obvious embarrassment. Sometimes (such as when home care staff did not arrive) there was no choice, as this person described:

*"I felt awful when I had to get my daughter back home from work and so she had to come home and help me get washed and dressed, and I mean it is more embarrassing if you have got your children trying to dress you than a stranger."*

- 3.41 When people are living with a spouse or partner, mutual support plays a key role in helping them to manage. Walking to the shops and back, and having to stop "every few yards" to "have a little lean on the wall" is clearly very difficult, but a couple might manage it together more easily than a person attempting it alone. As this couple described, managing by helping each other is a way of coping:

*"(my husband) has been very good since I had my heart attack, he hasn't let me carry any heavy shopping. And in fact I can't do it now; so he sorts out the shopping. We manage indirectly."*

However, such arrangements are fragile and deterioration in the fitter partner's health is all it takes for a crisis to develop.

- 3.42 Informal networks and word of mouth play a central role particularly in finding people who can provide practical help. People recommend cleaners to their friends; adverts are seen in local shop windows. Typically these services are provided at a price that is below the rate that would be charged by social services (if they provide such support) or by private care agencies. Some people choose to discontinue support organised through social services because they can find it more cheaply for themselves, as this comment illustrates:

*"I got a cleaner from a recommendation; I pay £10 an hour. Social services have a lady, have a cleaner – when they have got one spare – which is £13 an hour. So I said, well thank you very much I am not paying that!"*

- 3.43 Not only can private arrangements be cheaper, but many people also pointed out that such arrangements are more flexible – some had previous experience of help through social services where there were many restrictions on what they were and were not able to do. While cleaners arranged privately will "do anything – you know, the windows, the floors", those arranged by social services are much less responsive to people's preferences:

*"Oh, but they can't do this; they can't do that – they won't even carry a vacuum cleaner upstairs (...) that is their regulations!"*

### **Experiences of people who are self-funding**

- 3.44 It might be assumed that people who fund their own care and support have the greatest choice and control since they can use their money as they please – to help them to stay at home, to move to more suitable accommodation, or to move into a care home. However, this greatly over-simplifies the situation, and in many respects

it is clear that self-funding people can be just as disadvantaged as people relying on public funding.

- 3.45 We encountered considerable confusion about the meaning of 'self-funding'. While most people understood that it referred to people who made their arrangements completely independently of the council, others included within the definition people who have their support arranged through social services but pay the full cost of their care because of the level of their capital and savings. These two groups share some characteristics, but also differ in important respects.

**a) People paying the full cost of care**

- 3.46 What is striking is that – far from making active and considered choices about their lives – people who are funding their own arrangements often appear to end up in their situation by chance and through an unfortunate combination of circumstances. For example, the daughter of a person who had moved into a nursing home explained how her mother had ended up doing so much against the wishes of the family. The daughter and her family had been looking after the mother who had moved into her daughter's home after developing dementia (but still had her own house which was then rented out). She had been admitted into hospital for respite and assessment when the daughter was unable to cope. The daughter's plan was to have her mother back home and to continue to care for her, although this was clearly very demanding:

*"I would see to her in the morning, get her up, sort her out, give her breakfast and get her settled. Go to work and by lunchtime – running my own business I could fit it in – go to work for the afternoon and then come home teatime. So she would only be on her own for a couple of hours at a time."*

- 3.47 However, following the period in hospital it appeared that this could no longer continue, as her daughter recounted:

*"And the doctor said, no – she can't do that; she must go into a home. She must have a lot of other people around her, she needs 24 hour care. So reluctantly I said okay. They gave me a list of homes."*

- 3.48 This situation was not unique. On occasions people seem to be fast-tracked into residential care before all other options have been explored (the CSCI study on people in care homes had similar findings)<sup>45</sup>. In this case it seemed that a doctor effectively made the decision without reference to social services, or indeed without considering what support might be available to enable the family to continue to look after their mother as they wanted:

*"My point that I have tried to get through to everybody was that I wanted to take her home; the doctor said she wasn't fit to come home. They insisted she went in a home and yet we had to pay for it. Which doesn't seem right."*

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<sup>45</sup> CSCI (2007), *A Fair Contract with Older People?* London: CSCI.

- 3.49 The fact that the person needing care had a home that could be sold seemed to be a factor which led to residential care being presented as the only way forward. The daughter who was trying to do her best in a difficult situation commented that she was surprised by what happened but did not know what to expect, as she explained: *"A lot of things have happened over the years because I have no experience of all this. I didn't know any different. I thought that's what happened."*
- 3.50 Being 'thrown in at the deep end' and left to make their own way was a challenging experience. This particular carer was an articulate and intelligent person who set out to find out as much as she could about the care home her mother was in (including making use of the CSCI website and reports). Many people would not be able to cope with making such decisions, or to negotiate with care home proprietors, without advice and guidance.

Mrs A is 91 years old; she was widowed for the second time in 2003 (having lost her first husband in 1942). Following the death of her husband Mrs A's son and daughter-in-law came to stay with her and decided they would move in with her permanently. Relations became strained particularly between Mrs A and her daughter-in-law and in 2005 it was suggested that Mrs A might like to move to a care home. Mrs A agreed to have a look because she "was beginning to feel uncomfortable" with the situation in her own home. Despite these unpleasant circumstances Mrs A is happy in the home and feels well looked after.

However, there are financial concerns. Mrs A is self-funding but her savings are running out. Her home cannot be sold to pay for her care because it is occupied by her son and his wife and they are aged over 60. Mrs A has come under pressure from her family to move to another home or to a cheaper room within the home she is living in. She is understandably reluctant to move.

Mrs A has problems with her mobility and has diabetes which is well managed and she is visited weekly by a nurse to monitor her condition. Her sight is poor and she uses a hearing aid. Social services are aware of Mrs A's situation and of her money running out. They do not believe that her needs meet the eligibility criteria for residential care as she could be supported in the community. They have offered Mrs A alternative accommodation in sheltered housing but this was turned down by her son. It was expected that something would have to be arranged when Mrs A's money ran out and the home would need to evict her.

- 3.51 Other interviewees (particularly family carers of people who had since entered care homes) told similar stories of people having to go into residential care because insufficiently intensive support was on offer in the community. The decision to move into a care home in such situations was rarely a planned and considered one, rather it seemed to be the only option. In another of our sites we interviewed a family carer who told us how family members had rallied around to try and support their Mum at home. Between them the siblings (particularly one daughter) managed to do the shopping, cleaning and cooking and visit their mother on a daily basis. This arrangement became more difficult when the person's needs increased merely from needing help because of poor mobility, to becoming confused ("her memory was going") and unsafe to be left alone. Social services were approached for help which led to an admission into emergency respite for two weeks.

3.52 Social services subsequently offered four brief visits a day by home care staff. The family were concerned that this would not offer sufficient care and support for their mother who could not safely be left alone, and decided on their own initiative to organise a 24 hour live-in carer for two weeks for which they made their own private arrangements (with an agency located through the internet). During this period the family understood that the social worker involved in the case “was going to come up with some plan”, as the daughter explained:

*“..so we made a decision that we would keep her (the live-in carer) on for another week and see if (the social worker) could come up with an alternative to the four carers. And of course to us it would have to be 24 hour care at home, or a residential – which is what we really didn’t want for her (...) we had another meeting (...) and my younger brother said to him what can you offer us? He said, I can offer you four carers or she goes into a home. Four carers! Which we had already said wasn’t going to work.”*

3.53 The family tried to negotiate a compromise:

*“So I said what about if we find somebody to do the night shift while you pay for the day shift? No! (...) they weren’t prepared to do these little things – it only added up to two hours (...) he was going to leave Mum alone, and she could end up blowing the house up or falling over and nobody knowing about it all the time.”*

3.54 It was impossible to find a solution which would provide the necessary support to help this person remain at home; the maximum support available was four half hourly visits through the day – or admission to a care home, which was ultimately what happened. The family continued to be involved and funded a top-up to allow their mother to move into a care home they felt happier with, as the daughter explained:

*“If your mother and father have saved and done their finances and got themselves to a certain standard where they’ve got a nice airy bungalow and three bedrooms, everything up to date, then why should they have to go into a residential care home that’s dingy and dark and is grotty and stinks? (...) so this is why we decided as a family to put her in a home which OK we are going to self-fund, but I would rather do that while she has still got some social skills, knowing that she can look out of the window and actually see what’s going on.”*

3.55 The fact that the family had sufficient resources and were willing to pay extra for their mother’s care *did* give them some choice over where she was living. They were able to choose a home which they felt “was much nicer” and which was conveniently located and where the staff appeared to be accommodating:

*“If we want a family get-together we could get a wheelchair and bring her out (...) they are not averse to the dog going in, because she misses the dog, and you know I can take her out perhaps onto the field with the dog and with a buggy.”*

3.56 What was clear, however, was that this choice was a compromise, rather than what the family really wanted, which was help in maintaining their Mum in her own home.

3.57 There were exceptions to this pattern of poor choice between minimal support or residential care. Additional help could be provided on occasions through social services having access to further funds – notably through the POPPS (Partnerships for Older People Projects) grant introduced to support independence for older people. One person, for example, described a range of help that was provided under POPPS which included an emergency pendant alarm and extra day care which managed to provide cover for six days a week. In this situation the extra help enabled a person to continue living at home with her husband for longer than would otherwise have been possible. Ultimately she *did* enter a care home (which was funded from savings), but the family were satisfied that everything else had been tried.

## **b) People making their own private arrangements**

### **A positive choice?**

- 3.58 It is important not to assume that the decision to enter residential care is something negative and always to be regretted. As the Wagner report highlighted almost two decades ago, residential care must be considered as part of a continuum of care in the community. More than that, *"people who move into a residential establishment should do so by positive choice and living there should be a positive experience."*<sup>46</sup> Unfortunately, it was evident from our fieldwork that this was by no means always the case. People are likely to enter residential care for want of any alternative option, and - for some - the experience of living in a home can be utterly isolating and miserable.
- 3.59 People who were entirely self-funding and had simply made their own arrangements for social care had different experiences from those people we have described above. As in the CSCI study of people moving into care homes,<sup>47</sup> any contact with social services was the exception rather than the rule, and none of those people we interviewed had experienced a social care assessment prior to entering a care home. It is important to understand what leads to the decision to move into a residential home. For some people the decision was made following a crisis – often leading to hospitalisation - or a significant change in circumstances (such as the loss of a partner). There is a risk – acknowledged by service managers – that once a hospital patient needing on-going social care support has been identified as self-funding they may be directed straight into residential care, as this comment indicates:

*"I think in terms of self-funders there is potentially more of a variance, but that may be more a reflection of individual practitioners. And I can think of some practitioners who would take exactly the same approach for a self-funding inpatient as they would for somebody who was likely to need local authority funding. There may be others who would maybe not go quite the same sort of distance (...) I think sometimes the hospitals are anxious to discharge somebody and then they are aware obviously that they are self-funding, they may intervene themselves and make some arrangements that we are not even a party to."*

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<sup>46</sup> *Residential Care: A positive choice*, National Institute for Social Work, Chaired by Gillian Wagner, London: HMSO.

<sup>47</sup> CSCI (2007), Op Cit.

Miss B has been living in a care home for eight years; she is self-funding. Miss B has rheumatoid arthritis and osteoporosis; ten years ago she had three major operations in a year when she broke her leg, underwent a knee replacement and had a new hip. Following the last of these episodes Miss B decided to move into a care home because she felt everything had become too much and her doctor advised her that she would have to go into a home.

Miss B was initially living in a small home with only 12 residents (which she liked very much) but had to move to a larger establishment (with 32 residents) when the first home closed.

Miss B has poor mobility and had her leg in plaster as the result of another fracture. She had a first floor room in the home and was effectively confined to the room because of her mobility difficulties. Her mood was extremely low at the time of the fieldwork and she was talking of moving to another care home because of the poor quality of care she was experiencing. Other residents have already left and a person with whom Miss B was friendly has moved to another home nearby and has encouraged Miss B to try to move there too. Miss B has had no contact with social services and chose her care home from a booklet she was given in hospital.

3.60 In one case (Mrs A) we found a person who had effectively been forced into a care home by her family who had taken over her house and no longer wanted her living with them. People described how they lost confidence, or simply became more concerned about the future – especially if they found themselves alone. The generation of people in their 80s and 90s also represents the cohort that were young adults during World War Two. For women this often meant the loss at a young age of a husband or sweetheart, and many of these subsequently remained single. Many of our interviewees were in this situation and having never married they lacked many of the natural networks of support that might otherwise have been available to them.

3.61 The following comments are typical of many in the course of the fieldwork:

*"The only decision I made at that time was that I definitely would not buy again. I didn't want to get back on the housing ladder; I didn't want problems, and I didn't want aggravation, but I wanted a residential home which was near my friends (...) so I decided that I would look at one or two, and then in fact I only looked at this one."*

*"I came of my own volition; I was not forced to come – it was my own idea. My friends were shocked. They said what are you doing putting yourself away in a home!"*

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

*"It was my decision."*

3.62 Some of those people who were self-funding had moved into homes in a gradual process and had 'tried them out' on occasions by organising periods of respite or short breaks that they would spend at a home before making the decision to move permanently:

*"Well when I was on my own, I began to think – what's going to happen to me? So I started this business of having respite."*

3.63 What is surprising, perhaps, is that most people making the decision to enter a care home in this way did not explore other options such as having support at home (either through contacting social services for advice or by making private arrangements). The observation that "I've never really had anything to do with social services" was made repeatedly and indicated not only that people able to pay for their own support did not think social services was for them, but that they were not aware that social services might be able to offer them any help or advice. Some people were quite affronted by the idea that they might have sought help from social services:

*"I beg your pardon? No of course I didn't! I did everything privately when we lived in our house."*

3.64 The decision to move permanently into a care home is a major one; it is the last move that many people will make and getting it right is important. The self-funders we spoke to seemed to rely heavily on word of mouth and 'feel' of homes rather than on any independent advice, or by researching what was on offer from different homes. Our findings on the poor information made available to people making private arrangements, and lack of promotion of assessment, are consistent with those reported in other recent research, notably by the Office of Fair Trading<sup>48</sup>, and in work by CSCI on people moving into residential care.<sup>49</sup>

3.65 Several people funding their own care home placement had lived in more than one care home and had moved because of homes closing (or being closed). Some residents were also considering moving elsewhere; sometimes this was to find better value, on other occasions – as noted previously – it was because of dissatisfaction with the standards of care on offer or about the manner of staff. One person who was desperate to leave and find another home explained her sense that the only thing the proprietor was concerned about was making money:

*"You see they're getting all the money they can out of you (...) they talk down to you all the time."*

*"When I went to hospital, after I came back he brought me the bill, so I said well I haven't been here half the time, so he deducted 25% from it. He knew what he was doing. He wasn't going to do that! (...) I had to ask (...) well he said that's how it is. He was quite abusive (...) well it upset me."*

3.66 This person was waiting until she was well enough to make alternative arrangements to leave, but in doing so there were few people she could call on for advice or support:

*"I've got friends – but they're abroad at the moment (...) but you can't depend on them because they've got their own lives to live. They'll help me as much as they can."*

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<sup>48</sup> Office of Fair Trading (2005), *Care Homes for Older People in the UK. A Market Study*, London: Office of Fair Trading.

<sup>49</sup> Commission for Social Care Inspection (2007), *Op Cit*.

- 3.67 Several people paying for their own care commented on their confusion about the fees being charged and the lack of clarity about how these were calculated, as the sister of a person who was self-funding remarked:
- "The care here is £1,722 – I think – a month. I've just got a bill. Last month it was £1,658.58. The month before it was £1,400. So every month that I am getting it up to now, it's gone up."*
- 3.68 Ultimately people who are paying for their own care *do* have the option of exercising choice and moving elsewhere. However, for people who are alone and with little or no access to outside help, actually doing so can be very difficult or impossible to achieve. When asked who they could turn to for information or advice, people in this situation were most likely to identify solicitors, bank managers and financial advisers, rather than anyone who might know anything about the care market.
- 3.69 As we discussed in Section 2, only one of our six sites claimed to have a policy on support for self-funding people, and even the sole exception was only aspirational at the time of the fieldwork. *All* sites claimed that they would offer an assessment if one was requested, but none practised any outreach to identify people who were self-funding and potentially vulnerable, and some social workers were baffled by the idea that social services might be involved, as this comment illustrates:
- "I think they sort of fall through the net a lot of the time, and I don't think anybody is to blame for them falling through the net. Obviously the local authorities have a threshold that is a set of financial means. So if you have £70,000 in the bank and a property that is worth £400,000 (...) why would you need to have somebody come in and interfere in your life?"*
- 3.70 The very process of undertaking this study alerted some social workers and service managers to the issues – often for the first time - and caused them to reflect on the possible implications for their own practice. Indeed, some were intending to make follow-up visits following our fieldwork. However, in general terms it was evident that councils usually become involved with self-funders only if a home is closing or there is an investigation, or when people come to their notice because they have depleted their savings and could face eviction.
- 3.71 Many care managers were personally uncomfortable that they were not doing more for self-funders, but did not believe it was possible to do so under current resource conditions, for example:
- "Whether they can self-fund their care or not, if it looks like there are issues with the quality of their placement and they look like they need help to move or whatever – my belief is that we should be doing that. I believe we are probably not adequately resourced to do it."*
- 3.72 One care manager described how it was standard practice if a home was being investigated for any reason to try to offer assessment to *all* residents, but persuading some people (and their families) who were self-funding can be difficult. Nonetheless, when such assessments *are* undertaken, the results tend to reinforce concerns:

*"And invariably, in fact without exception, you will come out of it with something. Whether that's the fact they have actually not been having chiropody regularly, it can be a tiny thing. Or it can be, quite often I've said 'you realise your mother had a fall last week?' 'No, nobody told me she had a fall'."*

- 3.73 When social workers *do* become involved with self funders, they often realise that people have entered care *"because there were no other options for them at that time."* As we pointed out above, people who are self-funding may not know what options there are and do not automatically have access to the information and advice they need. We were told of successful outcomes in a few cases where people had been identified as inappropriately placed and had subsequently been supported to move back into the community and to live in sheltered housing. However, proprietors are often resistant to social workers trying to work with residents in this way since they are reliant on self-funders who may make few care demands and pay higher fees which – it was acknowledged – cross-subsidise publicly funded placements.

### **Avoidance of social workers**

- 3.74 Most of the people in the study who were self-funding simply didn't consider having any contact with social services. However, some people were actively hostile to the idea of social workers having anything to do with them and strongly resisted any attempts at contact which they found highly intrusive.

*"That blasted social worker!"*

*"I said don't tell me you're a social worker? I said I don't like them! I said you don't look like one or act like one!"*

- 3.75 It is highly likely that this was a reaction to previous poor experiences which had coloured their perceptions and led to a general mistrust of all social workers. For some people it is likely that they were keeping away from social workers as much as possible because they were concealing something about their past (such as a history of mental health problems), or about their personal life (such as homosexuality), and they feared being 'discovered.'

- 3.76 Some people had contact with social services as the result of other circumstances. In one of our sites there had been a fire at a care home necessitating the evacuation of all residents to emergency social services accommodation. This included residents who were self-funding and had been previously unknown to the local council which then became involved in finding them alternative homes. Locating suitable placements within the price bracket that people were able or willing to pay was difficult, as this person described:

*"And then this social worker came along and said that we were going to be moved, you know, and we went to see a couple of places and one I just didn't like. And then the social worker said that she couldn't find anywhere (...) she quoted a price and I said I can't afford to pay that, and she more or less said we'd have to take it or leave it!"*

- 3.77 The actual choice of home was made with the help of a relative of another resident. The file notes on this case record:

*"As he is self-funding his placement, NFA required. Case to be closed."*

More worryingly the file also indicated that this person had less than £21,000 in savings, and would therefore be eligible to apply for support from the council. It was difficult to be sure if this was the case since the person was secretive about their savings and reluctant to accept an assessment even if it might lead to getting some help with the funding. This case also highlighted the problem for self-funders of depleted savings more generally (an issue already raised in Section 2), and we will return to this topic when we examine outcomes associated with economic well-being.

## **Direct Payments**

- 3.78 Direct Payments (DPs) and Individual Budgets (IBs) are being promoted by the Department of Health as the key mechanisms "that will allow individuals to keep control and choice over their situation and the support they actually receive."<sup>50</sup> In many ways these models are seen to offer people who use services the same options and autonomy as people who fund their own arrangements. Very few of the people we interviewed had experience – or indeed knowledge – of Direct Payments. One person who *had* made use of such arrangements described how they had struggled to understand what was on offer:

*"We didn't really get our heads around this Direct Payments thing properly. Your need is assessed but how you meet the need is up to you. And we are kind of stuck on the old carer who comes or doesn't kind of thing. And if we haven't used it we could use it in some other way (...) We thought it had to be spent on exactly what it was provided for. So in other words, if you are getting an hour and a half in the morning to pay for your carer and we somehow managed to do that ourselves, we couldn't just pay ourselves, you know what I mean? So, what else would we spend it on? So we couldn't sort of work out how to redirect it."*

- 3.79 However, what these people who had used DPs *did* benefit from was the flexibility and direct control to vary the support they were receiving as they needed it, and to be free to purchase care from the most appropriate provider, for example:

*"We got the Direct Payments sorted out, which was good because that agency had not been signed off with social services so we couldn't have used them in the normal course of things, as we were with other agencies. But because of the Direct Payment we could. They were, in fact, a reputable agency, it was just that they didn't have a contract with social services."*

- 3.80 While there was little take-up of Direct Payments among people we interviewed (and not surprisingly given that many were ineligible for support from the council), there was also poor understanding of the model on the part of many social services staff. For example, the idea that DPs could offer greater choice was thought to be limited because of the way in which the payments were calculated:

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<sup>50</sup> Secretary of State for Health (2005), Op Cit, para 4.21.

*"Well it is not technically up to them how they use it because the assessment is based on care, the fact that the lady chose not to receive the care [but to use it for other things] you then have to say does she need the care if she can manage without? So technically the direct payment would not be offered to that level in the first place."*

And

*"If you look at a basic package for an average client from our team: a 30 minute visit in the morning and perhaps a 15 or 30 minute visit in the evening. One in the morning to help basic washing and dressing and vice versa in the evening. Now with the best will in the world, how creative can you be with that amount of time per week?"*

### 3 Making a Positive Contribution

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- 3.81 People have many different identities; they may be wives or husbands, partners, siblings, sons or daughters; they may have had a professional life, and in other ways had a sense of who they are and their place in the community. These dimensions of identity do not cease to be of importance simply because people use social care services. How people are supported to participate in their community, and how their contribution is valued were issues we explored.

#### **Participation and inclusion**

- 3.82 Almost without exception the people we spoke to who were living in care homes had little or no engagement with the wider community. Most were very elderly and frail and the idea of participation or social inclusion had little meaning. However, a minority of people were able to maintain their sense of self and to feel they made an important contribution in their life within the home. For example, a person who was self-funding and had moved into a care home following the death of her husband had found a niche for her skills and interests, as she explained:

*"They have confidence in me, they have given me the front door key – nobody else has got it – and they don't allow me privileges more than the others, we all get the same, but they pick on me if I can help in any way. So they ask me to do the entertaining quite a lot – the introducing and thanking, and that's nice because it gives me something to think about."*

- 3.83 Another person who had returned to live in his own flat following a period of intermediate care remarked:

*"I'm lucky in as much as the only trouble I've had is from the waist down – bone trouble with arthritis. I've kept my marbles and everything, I can still deal with most things on the financial side, so – I'm fortunate in that respect."*

- 3.84 Prior to retiring, this person had been a successful businessman. He continued to draw on his skills and experience in running the management board of the flats where he lived:

*"Oh that's another thing that keeps me rather occupied – with these flats, it's a limited company and we've all got so many shares. Chappie over the other side of the road and myself, we're directors – it sounds a bit pretentious, but we have to be because we have to have it registered you see."*

- 3.85 Another elderly person (in her 90s) who was also back in her own home following a period of rehabilitation had recently decided to buy a computer to help with her hobby of writing children's stories. She had organised lessons for herself and using it was helping her remain engaged with the wider world, as she explained:

*"Well I send emails – that's what I have had it for. Because I have got friends abroad in Canada, I have got god-children in Canada and Australia and India, and really it's the best way of doing it, because all you have got to do is send it (...) you haven't got to go round the Post Office and queue up have you?"*

- 3.86 In all of the examples cited here, people were continuing to exercise their autonomy and to participate in wider roles purely of their own volition; these roles had nothing to do with the services and support they were receiving. However, there were a few examples where support had been provided to assist people in their wider social inclusion and participation, but all of these instances involved people who were younger disabled adults. For older people there appeared to be no recognition of the value of participation or social inclusion. One person who had received intensive rehabilitation following a debilitating illness had benefited not only in recovering his functional independence, but also from support to rebuild his confidence and capacity to access the wider community. Achievement of objectives and personal outcomes enabled a planned reduction of the care package over time. Support had also been provided to enable the person to develop computer skills for the first time which he was using in working as a volunteer in helping other people learn to use computers, and which might be the first step to undertaking some paid employment in the longer term.

- 3.87 Another young adult had received temporary support with her personal care needs (because of an acute illness and disability), and while this had been withdrawn support was being provided to enable her to continue to maintain her role as a parent, which was of the utmost importance to her. Getting help to get back into life and normal social participation was important, but was also proving challenging as she described:

*"My biggest problem is that I don't like facing people and I don't like going out, and I have always been – I mean this is not unusual – I do tend to be a home body anyway (...). I just want to do things in my own time; I don't have to go out you know, and to be honest with you I am quite comfortable just hibernating for a while."*

- 3.88 While people who use services may need support and encouragement to participate in society, this comment does raise an important point and having choice and control does mean that people should also be able to choose to lead a quiet life if that is their preference.

## 4 Personal Dignity and Respect

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3.89 Maintaining dignity and respect are fundamental to people's sense of self worth and personal identity. The White Paper (*Our health, our care, our say*) described the outcome in terms of not being subject to abuse; keeping clean and comfortable; enjoying a clean and orderly environment; and having appropriate personal care available. This rather stark interpretation arguably fails to reflect the multi-dimensional nature of dignity and respect. Work by CSCI in applying the outcomes framework to regulated social care extends the definition in these terms:

*"People are treated in a way that helps them feel confident and secure. Their privacy and dignity are valued and protected. People are free from abuse and neglect and their human rights are protected.*

*Respect for individuals is a priority in every part of the service. The environment is good. The process and procedures support respect. The way people are treated shows respect.*

*The uniqueness of each individual is acknowledged and appreciated."*

3.90 Many of the interviews with people who use services raised issues associated with dignity and respect. The most frequently identified themes were the following:

- The home environment.
- Flexibility and responsiveness.

We examine both of these below.

### The Home Environment

#### a) Housework and gardening

3.91 In all our sites the operation of FACS eligibility criteria meant that certain needs were deemed eligible while others were not. The exclusion of what are often termed 'lower level needs' was evident in all the sites. When asked what support they needed but were not getting people were most likely to identify help with housework and other practical tasks.

3.92 The policy on providing help with housework in all our sites was *not* that it could not be provided, but that it *did not stand alone*, and could only be delivered as part of a wider personal care plan. A social worker described the situation in these terms:

*"The thing is if you look at the criteria it specifies, doesn't it, being unable to manage five aspects of maybe personal care and/or essential domestic routines. Now, if you can't find somebody to do your shopping for you then that becomes essential if you can't do it yourself. So that is where it still remains within the care package, so there are still people that have it, but it is not an automatic service any more."*

3.93 This subtle distinction was often lost on people seeking help; they often knew of other people who *were* getting help which they had been refused, and the unfairness of this situation was a source of considerable discontent, as this comment highlights:

*"If you don't qualify for personal care, you don't get home care – and I think that is very wrong. I think personal care is one of the last things you want to give up and yet you can't have some help in the home if you won't accept personal care and I think that is very wrong. Because providing somebody could do the housework it could keep that person in their own home, whereas if their house goes to pot social services walk in and say you can't live like this and away you go (to a care home)."*

- 3.94 Other people also had experience of being turned down for home care because they were 'not bad enough', as this person recalled:

*"I wasn't eligible for a home help because I am not an invalid and I can go up and down the stairs and I can get in and out of the bath. I sort of thought to myself I should have said I have some aches and pains and put the agony on! He said he was ever so sorry about this. He was very polite but he didn't solve my problems."*

- 3.95 In some cases it is possible that people had needs for services other than home care. In this particular instance the person was agoraphobic, very lonely and with a low mood. Her needs were assessed as moderate or low, but no attempt appeared to have been made to redirect her towards befriending services or to offer anything else that might help with her needs. In some cases it was argued that people use home care services inappropriately. A social worker described how she monitored the contact sheets of care workers:

*"If it is recorded that they have done such and such and then 'had a chat' I always pick up on that. And if it is a long chat and it is on a daily basis then I might think that they only need half of that visit because we cannot really afford to pay for people to go and chat, and it is just a way of the carer using their time until it is time to go onto the next person (...) We are always told that we don't pay for social time; the Council can't pay for social time."*

*"What we say is we don't provide people to come and sit with you unless there is a need because of cognitive impairment (...) There are other ways that we can perhaps signpost if they are lonely."*

- 3.96 Keeping the house looking nice is important to most people. For those who spend a great deal of their time inside the house it is often of the utmost importance; however, people who have chronic health conditions or who are simply frail and unsteady may be unable to cope with housework, as this person explained:

*"The thing that I really, really want is help with the housework because it is exhausting (...) I am willing to pay but I do need it desperately because it really is exhausting."*

- 3.97 In this case – as has been described previously – the person was signposted to services which did not appear to respond to the request for a service. When this case was discussed the social worker concerned remarked:

*"My view (...) was that she was managing her personal care, it was not wearing her out, but all she wanted was help with housework and we don't provide that, do we? So I had to advise her how to get it, but what struck me about her was that her house was absolutely immaculate; it was totally spotless, and I am thinking – if it*

*looked like that table up there [covered in clutter from a previous meeting in the room] I would understand perhaps there was a need for help with housework, but I could not actually see the need, if you see what I mean."*

- 3.98 What this perspective might have missed was that although the house was kept in good order, this was only achieved with considerable difficulty by the person concerned. It may also be the case that there is a generational difference in the importance attached to housework and that many older people apply different standards, as this 92 year old remarked:

*"I was brought up that way; I can't help it. So if I see a little bit of paper and up there, there is a lot of crumbs – well (the carer) is coming today so she can Hoover so I did not bother, but another morning I got me little thing and put it there to pick the crumbs up. Because if I sit down and I see them I shall go over and pick that up; I can't help it – it was the way I was brought up."*

- 3.99 Another couple (see box below) who had been turned down for help and signposted (unsuccessfully) to alternative sources of support wanted help with the garden which had become overgrown. They had already paid £150 to have the garden cut back when they had moved into the property, but it was getting out of hand once again, and

*"..the thing is to get a gardener is nigh on impossible."*

As another person concerned about the state of their garden remarked:

*"Well I could do it until last year – I could get out there and do the digging and I would put plants (...) and all that, and now it is all overgrown and I have just given it up. I asked them and they said oh yes we will send a bloke in at £10 an hour, and I thought yes but he has got at least 5 hours there and that's half me pension gone!"*

Mr and Mrs C are in their late 70s and have recently relocated from the north of England to live near their daughter. They are very happy with the town they have moved to (as local authority tenants), but their accommodation is very small and poorly suited to their needs. The local authority has been informed of problems that need attention in the house, including hand rails which are required for the garden, but there was no sign of this being attended to.

Neither Mr nor Mrs C is in good health and they are struggling to manage housework, shopping and gardening. They requested an assessment from social services to see if they could get any assistance. Because they are strangers to the area they are keen to meet other people of their age and have inquired about having access to a day centre.

Mr and Mrs C were turned down by social services because their needs were judged to be below the eligibility threshold of substantial and critical. They were given information and advice about other possible sources of help, but on following these up they were informed that they were unlikely to be able to have any help. Mr C is planning on tackling the gardening himself – including cutting a very large hedge, and his wife is very concerned about him as he has previously had a heart attack and has COPD as well as other chronic problems. Mr and Mrs C have help from time to time from their daughter but other than that they are struggling to cope on their own and are fearful of not being able to continue to do so.

- 3.100 The risk for these people was obvious; if they don't get help with practical tasks they will probably try to do them for themselves, with potential risks of falls or other problems. There was a view – implicit in the statement from a care manager quoted above, but sometimes stated more overtly – that some people try to 'trick' the council into providing them with support that they don't really need or are not entitled to receive (*"some people like being waited on don't they?"*).
- 3.101 Other comments made by care managers about people's eligibility revealed assumptions about other sources of support that people should draw on first. When told about the difficulties a couple had encountered in trying to arrange gardening help through a service they had been signposted to, the social worker remarked:  
*"Well their daughter lives in the same town so – I mean normally families help out."*
- 3.102 It was clear that people – such as this couple – who had been signposted to services were then left to their own devices to follow up on their own. This couple (newly moved to the area) had also enquired about using day care services (*"somewhere where people are where we can meet them and have friends of our own age"*). No day care opportunity was offered, as the social worker explained:  
*"I think I have followed up all that I can; I mean that was an inappropriate referral. Someone put them down for day care, and they have a car! You don't give day care to people who have a car and that get out and about on their own."*
- 3.103 As we explored in Section 2, judgements about eligibility *do* take account of all the resources that people have available to them, including support from family and friends. As the portfolio holder in one of the sites remarked, this should be uppermost in the minds of social workers undertaking case reviews:  
*"Nobody has got an open-ended purse. And I think that in these re-referrals and re-assessments when they sit people down and talk to them, there could be some of that – especially taking domestic stuff out. The main principle of some concern (...) isn't the takeover from the family; it's there to assist the family to manage their responsibilities. That sounds harsh and it sounds brutal; but that's the principle of it."*
- 3.104 Social workers and other staff working in care managed services were reluctant to acknowledge that people with lower level needs were not being appropriately supported. The following justifications were offered:  
*"I found that those that have got low level needs don't seem to have a need for a service – they might have referred themselves, I have lots of people who refer themselves because they want to see what the Council can offer. But if you say to them that at this point in time we can't actually offer you anything but if your needs change we can, they are quite happy with that – there is nothing specific that they want (...) they are just testing the water. Some people think they need to make themselves known to social services in case – get their foot in the door as they would put it and they don't anywhere near meet the criteria."*

And as another observed:

*"I would say I have come across unmet wishes, wants and desires, but not unmet needs."*

- 3.105 Not one of the people using services, or trying to get support from services, who we spoke to in the course of the study could have been described in these terms. None of them identified frivolous needs and wishes, and none approached the council without considerable forethought. Being told they were ineligible for support was both a surprise and a considerable worry for some people who did not know how they would be able to continue to cope unaided.
- 3.106 Not everyone we spoke to was unable to get help with housework; in some cases signposting worked well and people were able to make arrangements for housework and practical support that they required. People recognised that they could use Attendance Allowance (which they were often encouraged to claim by social services) to help make privately arranged home care or other services more affordable, for example:

*"[I pay] £40.25 each week (...) I think that is about the average price I understand (...) it saves me doing the floor, it saves me doing the kitchen, it saves me making the bed, and he has cleaned the shower out for me."*

And

*"I've brought in, just in the last week through (social worker's) recommendation, I've brought in a cleaner (...) she's very good, she's coming in again next week. She was marvellous! (...) I do get Attendance Allowance for that you see (...) so I'm paying her privately so that's a great help. I can sort of feed myself and do odd jobs around, but she goes around all the top curtains and everywhere I can't reach so I'm managing fine myself."*

- 3.107 Being able to manage some jobs around the house is important to people in keeping their sense of identity and control over their lives, as these people remarked:

*"When I get the help I feel as though I don't want to take everything up; you know – I feel as though I want to do some jobs."*

And

*"(this young lady) comes every Monday afternoon; I mean it is not a lot of work as it is so small – she cleans it through once a week and apart from that I don't do much you see, only flick a duster around."*

*"And the social services had been up to see me because I live on my own; they said they would try to arrange things for me (...) they said did I want somebody to do the housework and get my shopping in? and I said I didn't want them to do it all because I thought if I get it to do the housework and do my shopping, I'll be sitting here and just vegetating. So I have got a girl who comes tomorrow and she does my shopping, but I do my own housework. But I do it when I feel up to it."*

## **b) Equipment and Adaptations**

3.108 Maintaining a suitable environment is about more than keeping a house clean and comfortable. While many people struggled to get help with housework or odd jobs around the house, they were far more likely to be provided with equipment and aids for daily living to help them remain in their homes. Such equipment was clearly useful to people and helped them remain independent with their personal care, and for social services it was a straightforward and functional response – equipment could be provided through Occupational Therapy without any need for on-going or care managed support.

*"I have got a trolley (...) she said I could keep it for as long as I wanted. And I have got a wonderful stool in there where I can sit and get washed (...) it takes all the weight off your legs. And I can sit and reach everything, oh yes – it's very good."*

3.109 Another person had been provided with a seat for the toilet and other equipment to help with standing up and sitting down because the arrangement they had been using was clearly unsafe (in this case the equipment had been delivered – probably coincidentally – the day before our interview took place).

*"The seat for the toilet – you see they put me a thing on the wall and to help me get off the toilet. I have got to take hold of these. But I have also got to hold on to the wash basin to help myself up and she said, 'no way (...) that will come loose in time.' It's good."*

3.110 Where people needed major adaptations to enable them to remain in their own homes, they usually had to pay for these themselves. A person whose mother had recently been admitted to permanent residential care recounted the story of how her parents had tried to cope:

*"They provided us with a stand for the toilet and also for a sit down shower seat, because my mother had lost the ability to get in and out of a bath. We had – at our expense – to change the bathroom to a shower room. Which was an expense obviously and was a necessity."*

The equipment offered initially by social services was unsuitable and did not seem to take account of the circumstances of the elderly couple where the wife had dementia:

*"Social services said they would pay for a sit down shower seat. At first they came with a little wobbly seat once we had this bathroom transformed to a shower. The wobbly seat – which she obviously couldn't sit on, it was dangerous for her and for my father who was trying to shower her, he was worried. So we enquired again and they did come back and put a fixing to the wall which has been a god-send."*

3.111 It was possible for this couple to afford to pay for the adaptations, but this was not the case for everyone. Another elderly couple who had recently moved to local authority accommodation would have preferred to have a bath rather than a walk-in shower (which they had) because a bath in their previous accommodation had been beneficial and it had been possible to use it with help of a bath-lift:

*"When the pain comes on I used to get in the bath and it used to really relieve my pains."*

*"It's good that I have got (husband). Because in a bath – you can get in a bath and sort of do yourself, but in a shower I have got to rely on (him)."*

The Council refused to replace the shower because they had changed it for the previous resident *"and they said the cost was too great to be doing what they had already done."*

- 3.112 For two years this couple had been making a weekly telephone call – without success - to the Council to enquire about a bungalow with a bath, which they believed would better address their needs and help them remain independent.

## **Flexibility and Responsiveness**

### **a) Personal care**

- 3.113 We have already explored some aspects of this topic under the heading of choice and control. However, there are also other dimensions which relate to the way in which support is (or is not) provided, and the contrast between a personalised response, and a task-based and mechanistic approach. A social worker in one of the sites (meeting critical and substantial needs) highlighted the distinction between these models in an example with somebody who needed a shower to be installed:

*"I have got somebody at the moment who is having problems and has been assessed to have a shower put into the property and it has been agreed but there is a long wait and her condition is deteriorating. And she cannot climb into the bath any more and it was actually – it was the OT that said locally, they said well you can have a strip wash in the meantime. And the OTs look at it in terms of your access to maintain your personal hygiene (...) it is not about how do you feel, the broader issues – how are you coping if you are unwell. Thinking of how hot and sticky it was last night – if I could not have got in the shower last night, I would have been – you know, my mental well-being would have been affected."*

- 3.114 Another social worker commented on a similar case where a person was only able to have a strip wash which she was "really unhappy" about; the social worker had sorted out interim arrangements with a day centre where she could make use of the shower facilities. Similar arrangements had been made for another person where day care was being purchased by the Council from a nursing home for a person with a debilitating condition:

*"(he) has Huntington's Disease and his movements are so bad now that even with the right equipment at home in the confined space it is difficult, and he goes there 4 days a week, and they have offered to give him a shower every day if he would like that as part of his care."*

- 3.115 Not everyone was so lucky. People who were funding their own care sometimes had very poor experiences. A person whose leg was currently in plaster and who was considerably disabled by arthritis and osteoporosis remarked:

*"I find it very difficult (...) you see I need so much help (...) I haven't had a bath since last year! Wouldn't you think they would give you a bed bath?"*

3.116 Another person (living in warden controlled housing) who had been turned down as ineligible for support from social services had previously had some personal care following a period in hospital. That had been withdrawn ("when I felt better and I was able to cope"), but had left the person unable to manage bathing because she could not get in or out of the bath unaided. Eventually a shower had been installed in a communal bathroom close to her flat and she was able to access it on her own, but had spent the preceding 12 months "having to strip wash every day to keep myself clean."

3.117 It was clear from other cases that many people judged ineligible for social care support, or who are deemed to be coping with their personal care, are actually managing with extreme difficulty or are using arrangements which are far from ideal. One such person explained how he managed with bathing:

*"They put a thing across the bath for me – a seat, but I don't use it because if I got in the bath I couldn't get out. So I devised something myself. I have a baby's 1980s plastic bath, and what I do is I fill that with water, not to the top, I fill that with water and I stand in it. I use the thing at the side of my bath and I stand in it. And then on where I am supposed to be sitting, I have another little plastic bowl and I wash the upper part of my body and when I have done that I pour that water, because it's only come off my body, in to the thing for my feet. Then I turn around and sit on the seat and then I do my bottom part."*

3.118 Some people who were caring for a spouse or other relative recounted the difficulties they had in getting any support. In retrospect some people believed that they had appeared to be coping too well. One person – who was herself acutely ill – had tried repeatedly to get day care for her husband (who had dementia), but with little success. The social worker who was dealing with the case was reported to have a different approach to respite care from the one that the carer was seeking:

*"The social worker, she did suggest respite care (...) but she had this thing about respite care, when you are on the bottom, we will take him away (...) where you were saying 'why should I have to be on the bottom, crying on the phone? Why can't we just set something up once a week?' To stop getting into that state."*

In this situation the relationship with the social worker was described as at 'loggerheads'. It was only later when this person requested a carer's assessment in her own right and said that she was unable to cope with bathing her husband any longer that things changed.

*"I have got another social worker and I have been treated so well lately I am pleased (...) since I asked for my husband to be showered once a week, they did send a girl to like go over my finances and see if I was due anything. And I was due quite a lot of money wasn't I? But how do I know that?"*

3.119 Another person who had been caring for his wife who had dementia only succeeded in getting help because of needing care for himself. Following a fall which necessitated a period of residential intermediate care, other family members stepped

in to look after his wife but could not cope with her needs. A very distressing situation developed with the mental health team and Social Services arguing over who should assume responsibility, ultimately leading to the person being sectioned under mental health legislation and admitted to hospital. Earlier support from social services might have led to different outcomes, or even if the outcome was the same – the route to it would have been quite different. If the husband's own illness had not occurred there would have been no change of circumstance triggering a response and he may have been left to struggle without help for even longer.

### **b) Timeliness and pace of visits**

3.120 A recurrent complaint of many people who had used services concerned not knowing when home care staff would turn up for appointments. This is a theme which has been identified repeatedly in the research literature on people who use social care services. Unreliability or uncertainty over home care visits was a particular issue for people who were reliant on getting support to get washed and dressed, as these comments from people who had used intermediate care indicate:

*"(...) the carers used to come to help me get dressed. The only thing with that lot was that they did not come until dinner time and I used to get so annoyed because I was there from 6 in the morning – in your night clothes, wanting to get washed and dressed (...) I would get out of bed and just be sitting around in my night clothes. I had visitors come one morning at 11 o'clock and I was still in my night clothes!"*

3.121 Other people told very similar stories of their experiences, although as these comments indicate people recognise the difficulties of trying to arrange multiple visits within a short period of time:

*"The only thing about the caring is it's the time. You have got to get up in good time, breakfast, in case they come early. And sometimes they came early and sometimes they came late. But I don't think you can do much about that because they have a lot to see to. And one morning it was about 10 when she came at breakfast time and she said, 'I am sorry, but all the men wanted a shower.' (...) but she can't help that at all."*

3.122 Discussions with care managers confirmed that they are also frustrated by short and hurried visits (*"I don't think you can do anything fully for anyone in 15 minutes; I mean by the time you have gone into an older person"*). However, the logistical reality was that multiple visits had to be managed within a fixed time slot:

*"We have got three girls out tonight and they have all got 16 clients each, and I don't know how they get round unless they were sort of in and out really."*

It was recognised that this was far from ideal, "but we have not got an answer". For many people using social care services a hurried visit is not just a matter of inconvenience, it is undignified and distressing. As this social worker observed:

*"To go and put someone on the commode who needs to go to the toilet, and who is maybe not quite ready to go, you have not got the time to wait for half an hour have you?"*

3.123 Not knowing which care worker will turn up can be a further concern, and for people with a level of confusion having new people come into the house can be distressing. The same person described how a regular care worker was on holiday and a replacement was sent:

*"Nobody informed me from the office that somebody different would be coming, or what time they would be coming. So they sent somebody strange that had never done a shower in our house before. And (husband) will not have him back again, and I don't know why; he got so agitated, no way, no way, no way! (...) I don't know whether it's the way they handle him or what, but he certainly wasn't happy on Tuesday when they did that."*

3.124 This experience had been so difficult that the carer cancelled the next visit, preferring to wait until the regular care worker returned from leave. People get used to their regular carer workers, and – particularly where a person has some confusion – it is important that people carrying out personal care understand the individual needs and preferences of the people they support. If they have never met them before it may not be possible to offer the personalised support required. Another carer (now self-funding a placement for herself in a care home) similarly described how she had nursed her husband when he was terminally ill and had tried to get help with his care which had turned out to be unsatisfactory:

*"Well I did ask for someone to come to help me to bath him, and she came three times in one week, and my husband said to me 'don't let her come anymore, she's too rough with me'. His skin was very thin. She charged me £14 per week for it, and I ended up doing it all."*

## 5 Freedom from Discrimination and Harassment

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3.125 The concept of equality of access to services goes beyond merely requiring services not to *overtly* discriminate against people on the basis of faith, beliefs, sexuality, colour, ethnicity, disability, or indeed any other criterion. It must also be the case that in practice the eligibility criteria for social care do not operate in a way which discriminates implicitly.

3.126 None of the people using services (or trying to get access to services) whom we interviewed indicated that they believed they had been treated badly because of any personal characteristics. However, as we have noted previously, some people kept the details of their private lives to themselves at least partly because of their concerns that they might encounter prejudice. It is likely that these beliefs were indicative of a generation that had grown up in a society which was less accepting of diversity than would be expected today.

3.127 However, there are two aspects in which eligibility criteria for social care *can* have an unequal, or discriminatory, impact on people:

- Differential impact on client groups.
- Impact of financial circumstances on eligibility.

## Impact on client groups

3.128 The way in which eligibility criteria for social care are worded determines how inclusively eligibility is defined. Not all people have a similar experience of trying to obtain social care services. As various social services staff also acknowledged, much depends on how articulate a person (or their family) can be in arguing their case. Commenting on the learning disability service, for example, this service manager observed:

*"That's the other dilemma because you might have somebody who is actually, in terms of their needs, their needs are not that great, and based on just their needs you might only give them a couple of days service a week. But because the parent will not have them in the house on their own, and they have got to go to work, you do ten rounds with them and have complaints and in the end they get five days a week."*

3.129 Within the learning disability service this was creating a highly inequitable position where some families got a lot of support and others got little or nothing:

*"We had the short breaks unit but a lot of the people who went in there went in with no assessment; they didn't have a care plan, they weren't known to the social care services, and it's whoever shouted loudest got the most service (...) So we have a collection of 12 families who are receiving in excess of five months a year; we have 22 families who are receiving nothing."*

3.130 This council recognised that the situation was untenable and was attempting to introduce a more systematic approach through a personalised points system (adopting the model of In Control).

3.131 Another group of people who were identified as being particularly at risk of falling outside eligibility criteria are the 16 and 17 year olds in transition between children's and adult services:

*"It's just beyond what I can do in adult social care, where the decision is actually they are not eligible. But at 16 and 17 they are incredibly vulnerable and they get nothing from children's services."*

3.132 The reality of this experience was confirmed in a focus group with carers which took place in the same fieldwork site:

*"My son – he is autistic – he has just turned 16, basically he has not been accepted in the grown up process (...) we are now at the stage that we cannot get any help from the child and adolescent psychiatry unit."*

3.133 In failing to identify this group of young people in transition there are risks that they simply disappear from the system. As the service manager observed:

*"We never hear about them, or we don't hear about them until they're 25 and their Mum has got ill (...) they may have been sitting at home for 10 years."*

3.134 A service provider in another of our sites also confirmed that some people are more able than others to get what they need from social services:

*"What we noticed is that if a client of ours was quite articulate and they were having their care cut, we'd find we were told one day to drop it and the next day they had written to the Council or they had written to someone and it was actually going back up again. Someone who is maybe alone and didn't have an advocate, you find that nothing happens."*

- 3.135 The issue of equity between people also raises questions about wider cultural norms and what is regarded as acceptable. Several of our interviewees remarked that the inherent ageism of society is such that older people are often expected to accept a different – lesser – quality of life from everyone else, for example:

*"That doesn't mean it's under-funded; it means it's different. And I think age and cultural (differences) are important things to reflect on. And we might argue whether it's right or wrong, but I think it's a fact that other people moving into homes with 30 or 40 other people – older people, that seems to be culturally acceptable to society. They don't see it as a bad thing. Forty people with a learning disability living in a hostel has long been regarded as outrageous."*

And

*"(...) in terms of people with learning disability we are putting in the kind of services that are quality of life services (...) the whole well-being agenda is what we should be aiming for. I think we are still on the journey; we are probably doing that for people with physical disabilities as well and maybe to a lesser extent in terms of people with mental health (...). The older people's agenda in terms of (...) a well-being and holistic approach, I think again we are on a journey to get there."*

- 3.136 The contrasting approach to different adult client groups can also be evident in the approach taken during assessment. A service manager, for example, highlighted the contrast between information that might routinely be gathered during assessment of an older person compared with a younger disabled person:

*"Less information so it's more difficult to form a full picture, and I am not getting a sense of who Mrs Jones actually is. Whereas in the disability services, you don't just get a picture of who Mrs Jones is, you know that she likes to get up at 7 am and she likes to listen to Radio 4, you know, so you get all of that information."*

- 3.137 As another Team Manager remarked, if the quality of assessment information is inadequate, or is service-led rather than focused on the needs of the person, the offer of support will be based within the narrow constraints of existing services which will often fail to address their particular needs or well-being. It was believed that this was more likely to disadvantage older people. Commenting on assessments undertaken by colleagues:

*"They will put down 'needs socialisation' or whatever. And I will say OK, what do they like to do? Well I thought we could take them to the day centre. Tell me what things do they enjoy doing? I don't know we didn't ask! Well to come out of an assessment not knowing what makes someone tick, to me you have not done an assessment (...) So there are real issues there, particularly for older people. I think there is more acceptance that you take somebody who is under 65 and you might accompany them to the pub."*

- 3.138 There was some hope – and expectation – that the extension of personalisation (through DPs and IBs) will be helpful in making implicit and explicit discriminatory practices more transparent and open to challenge.
- 3.139 In other sites social services staff also believed that older people were disadvantaged by the system, not least by the fact that other people (notably younger adults with physical disabilities or learning disabilities) often received much higher cost care packages. Such inequities were often especially stark where a person was benefiting from additional funding from the Independent Living Fund (ILF):
- "Where it causes issues is where there is somebody with a big ILF package, and they maybe got that in their 65<sup>th</sup> year, so they get to keep it, and then they transfer to the older people's services team. And you have got one older person who is getting a lovely package which gives some choices and lifestyle additions, and the woman next door gets 15 minutes for a toilet call."*<sup>51</sup>
- 3.140 Even without eligibility criteria which are implicitly or explicitly discriminatory, it is still the case that people *experience* the criteria differently. In particular, it is older people who are most likely to be in the position of funding their own care simply because they are more likely to have accumulated assets over their lifetime. As we explore below, this was widely perceived as unfair.

## **Financial Assessment**

- 3.141 Economic well-being is the final dimension of the outcomes framework which we will examine later. However, in terms of equity and the discriminatory impact of criteria it was evident that some people believed they were treated unfairly. For some this was a moral argument and a general resentment that having been thrifty and saved throughout their lives, they were now being penalised, for example:
- "And it's hard lines to think she is sitting there on that table and she has to pay it all herself. And there could be somebody sitting on this table that has drunk, smoked, gambled all their lives and spent every penny they had, and is getting identical care."*
- 3.142 For others it was a belief that they (or more often their elderly relatives) should not have to pay for what appeared to be health care.
- 3.143 A woman whose mother had recently entered residential care because of advanced dementia, and who was paying the full cost of her care remarked:
- "I do feel strongly that my mother shouldn't be a burden on their finances as far as the recognised medical nature of her condition goes. Perfectly willing to pay for hotel services, her food, her heating, her social care and all of that. But I strongly believe that there should be some assistance at all levels of ability to pay – that the condition is recognised and there should be some help."*

Moreover

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<sup>51</sup> This and other issues about the operation of the ILF have been examined in depth in a review: M Henwood and B Hudson (2007), *Review of the Independent Living Funds*, London: Department for Work and Pensions.

*"It is a huge amount of money. For people who have saved in the hope that they would probably pass some money on to their children, it is a huge amount to pay (...) But it really galls people I think to pay for a recognisable illness."*

- 3.144 Similarly, other relatives identified the unfairness of a situation when a house has to be sold to pay for care, and money that was intended for the next generation disappears:

*"My mother worked hard for that money. She worked hard to pay off [the mortgage] and of course they hadn't got a lot of money."*

- 3.145 At the same time, however, some people also recognised that if money needed to be spent to ensure the comfort of a parent or other relative, then it should be:

*"At the end of the day, all that money that she has got for the house is her money. So it is spending it on her, it's spending her own money. I have got no rights for it. My sister has got no rights for it. So as long as it's her money and it's paying for her to be looked after, what else can I do? It seems to me the only thing you can do."*

And as another person commented:

*"My children are her god children, and they were like a second mam and dad to my children, they were there for them as well. And that was what they wanted for my two to have everything. And they are not going to. And yes, it does make you a bit bitter when you think about it. But at the end of the day, if this gives my sister the quality of life and if that's the price that has to be paid, then so be it."*

- 3.146 Many people remarked to us that they believed there was no point in saving because they would just end up having to pay for everything. When people needed major alterations or adaptations to help them remain in their own homes this could be especially costly, as this carer remarked:

*"So we weren't going to get any help from social services or anywhere towards alterations. So we had to pay for it all ourselves, which cost us thousands."*

- 3.147 Other people who had been told they were ineligible for support from social services sometimes misunderstood the reasons for this decision and thought that it was because of their savings (which should never be the case as this should just mean that people are charged according to their means rather than denied a service if it is required to meet their support needs).

*"I did not think I would need social services because I had earned enough to get by I thought (...). If you've got more than £15,000 or £20,000 you get nothing, which I just have; I've got just over that, and I'm not going to spend it just to get down to that level and then have a means test! I don't want it (...) It is humiliating, because I think we are due it by right."*

- 3.148 The impact of means-testing was seen as unfair by other people using services who reported that there was an 'all or nothing' situation whereby:

*"I think it is always the borderline people who are hit – below that you get everything, and above you get nothing. It seems a pity that somewhere along the line there can't be a bit more levelling out."*

3.149 Sometimes younger people also find themselves bearing all or most of the cost of their care. In one case a person was disabled following a road traffic accident which necessitated considerable social care, however, this person reported that they were self-funding because of the amount of money they had received in compensation through an insurance claim. In other sites there was a maximum ceiling imposed on charges for people using social care services in the community which ensures that people who have had large financial settlements are still able to access support and may have very costly packages of care. It was also evident that social services do not seek out such people, and they may end up paying for care which they could get help with. For example:

*"I think there are probably a lot of people out there in the community who are eligible for services who don't ask for them and who are not getting them. And if they did all come forwards it would really kind of make a mess on our budgets (...) the person I am working with at the moment was awarded money for the whole of her life – she is tetraplegic – and money to help pay for care and holidays and everything, housing – the whole lot. But she is still eligible to have services from us."*

## 6 Improved Health and Emotional Well-being

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3.150 Support from social care has an important contribution to make in improving people's physical health and emotional well-being. The objectives are to address people's needs appropriately and ensure that their quality of health is maintained for as long as possible, and improved where feasible. For people judged ineligible for social care support there are risks that underlying health needs are overlooked. One of the sub-groups of people we focused on was those who had received intermediate care for a specified period and were no longer eligible for support when this ended. In many ways it might be argued that a criterion for judging the success of an intermediate care service is that people no longer need on-going support when it is complete. If rehabilitation goals are achieved people are able to return to their daily lives with little or no support. While many of the stories we heard in the course of this study were about people struggling to cope without help, there were also some contrasting success stories of people having services withdrawn because they no longer needed as much support and could manage independently. It is important that both dimensions of these scenarios are examined.

Mrs D is 90 years old but is very independent. She lives alone and manages without support apart from private domestic help and some help with shopping from her niece. Mrs D has a moderate disability resulting from having contracted polio in her twenties; one leg is in a calliper and she walks with the help of sticks. In 2007 Mrs D had a fall which necessitated her being admitted to hospital. Following her discharge Mrs D received two weeks of intermediate care in a nursing home and further support with activities of daily living when she returned home. This assistance lasted for two months and was

then removed on review (although equipment has been left for as long as it is needed). Mrs D is happy with the situation and is glad to be independent once again; she has resumed driving and is coping well.

## Risks to health and well-being

3.151 Some of those people who had been turned down for support from social care had obvious health care needs and their condition could become worse without adequate support. Sometimes the response of social services was – as with 'low level' care needs - to signpost people elsewhere. For example, a person who struggled to manage her personal care and to keep her home in order primarily because of COPD was recommended to contact the community matron:

*"I did feel with her I had to refer her on to choose or make her own private arrangements but I was concerned about her physical condition and I did contact the community matron because I thought there was a pilot project running (...) for people with COPD and (...) I wrote to the lady but she never contacted me about it."*

3.152 The file notes record "Nothing further heard. Close case." Another couple who had also been turned down for social care and who had multiple health issues between them were in some danger because of their physical environment and housing conditions. The social worker had sent an email to the housing authority but did not seem to regard this as a priority for action or indeed a social services responsibility:

*"I have been in touch with them but again we don't have much sway with housing (...) we don't have any influence over housing I'm afraid (...) we try very hard but we don't."*

3.153 Another person whose health needs were being poorly addressed has also been introduced previously in this section; a young adult who had lost a leg, but who also had other chronic health needs including dependency on dialysis, had been unable to get the help or equipment needed at home, as his mother described:

*"I rang (them) and said I don't know whether it's health or if it's social because we never know who to go to (...) I said I needed a trolley to put (his) machine on. I said we have been to the aid shop (...) because what they had in the hospital was a stainless steel trolley (...) they have only got one which is no good. I said I wondered if you could get me one or suggest someone. Anyhow she said no, she couldn't help me. So we went along and we bought this computer trolley (...) it fell to bits."*

3.154 Help with dialysis was eventually provided for this person on a temporary basis when alternative support was needed to cover for his parents (with whom he was living) going away on holiday. Money had been made available under the POPPS scheme to facilitate this support, although it was recognised that this was intended to help with keeping older people living independently.

3.155 Sometimes the help that is provided to people enables them to make a good recovery. On occasions this help comes too late. An elderly person who had recently entered permanent residential care on a self-funding basis had been put back on her feet by the support from the home, as her sister recounted:

*"They got her back on her feet to enable her enough to walk, with a view to possibly going home (...) during the time [at the home] she did progress and she was walking. And the company in there made a difference, she had somebody to talk to."*

3.156 It was agreed that the best thing was for this person to remain in the care home rather than returning home where she was alone 24 hours a day, but if other support had been put in earlier it was believed that she would not have needed to enter a care home:

*"In fact, if my sister (...) had been this well six months down the line, she wouldn't have been here. She would have gone and she would have been able to have carers going in, because we would have requested this 4 times a day. And I would have insisted she did go to the day care because it's the company, the company has made her a lot better. If you had seen her 6 months ago, this is not the same person (...) the company has made the difference to her."*

### **The position of self-funders**

3.157 We have already examined the situation of people who are funding their own care, particularly those who are living in residential care homes. We have discussed the lack of information which people have in making decisions about their care and about their choices of home. The relative isolation of people living in care homes, and the absence of anyone advocating on their behalf can mean that health needs go undetected. Many people would also be concerned about having too many health requirements if this might mean they would have to move to a home registered to provide nursing, rather than being able to remain in a residential care home.

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

### **Improved health and well-being**

3.159 The provision of intermediate care – whether through intensive support at home or in a dedicated rehabilitation facility – appeared to be a highly successful intervention which enabled people to recover functional independence and manage with reduced or no further social care support. However, for some people this owes most to their personal determination and taking control of the situation rather than to the model of support arranged by social services.

3.160 One person who had become paralysed as the result of a degenerative neural condition and had spent many months in hospital was discharged with a poor prognosis and a medical view that he had "reached the end of the road" and at best could only hope to maintain his situation but should not expect any recovery. On discharge from hospital he was unable to walk, dress, or do anything for himself without help. The involvement of the community intermediate care team for 6-8

weeks was then handed over for on-going support. A committed (and well-informed) wife was instrumental in organising a direct payment for this person, and between them they arranged the care they needed and that appeared to work for this particular situation. When rehabilitation support was withdrawn after a period of time this couple replaced it with visits to the gym which they were able to organise using their direct payment. As the carer commented:

*"Good as they were at the rehab unit – and they were very good when he was there – it wasn't enough, and it was short-term."*

3.161 Quite by chance one of the care workers had an interest in alternative and complementary treatment and it was believed that her intensive input (including massage of hands and feet) was very important in helping this person recover his mobility and independence. Without the personal determination of the couple to see progress, and without the availability of a direct payment which facilitated access to different services and support, it is unlikely that the outcomes would have been so positive (certainly his neurosurgeon had predicted that the person would be unable to ever walk again). Instead it had been possible to reduce the level of the direct payment over time as less and less support was needed. The fact that this couple was now receiving no social services support was an achievement, as the carer remarked:

*"That's not a negative; it's very positive (...) we've got what we needed and we were quite happy to let it go when we didn't and to work our way up because that was his goal. He wanted to be able to do it for himself."*

3.162 Most intermediate care is not concerned with such major rehabilitation challenges. Typically we found people using intermediate care following traumas such as hip fractures or recovery from other injuries or operations. In one of our sites intermediate care was focused around a specialist residential unit. Most people had never heard of intermediate care before they needed it and were pleasantly surprised at how it operated. These comments were typical:

*"Absolutely independent, I have never had any help! The first time I have ever been anywhere was to [rehab facility]. Free! They didn't charge me anything!"*

*"I liked it there; you know I was very happy there, they were all very nice and the staff were nice."*

*"Beautiful. And you can have your hair done as well. I was quite surprised. Actually though if you had to pay for that you couldn't afford it. Well probably not – it would be quite a lot wouldn't it?"*

*"You have got to show improvement in 8 weeks (...) you get up and make your own tea if your friends come. I think it is a fantastic place (...) I'd go back there tomorrow if I had to; I should protest at going anywhere else. But I think they have got the right attitude; they have got the right staff which is important."*

*"I couldn't speak highly enough, because the staff are so kind!"*

*"I left notes of thanks down there for all the team who worked with me and on the physio side, and there were too many of them to thank individually. Ladies would help you get in the bath, and dry between my toes and everything."*

*"I just can't believe how marvellous they have been, they are so efficient, they are kind – the food is lovely."*

- 3.163 While intermediate care can be marvellous for people while they are receiving it, some people were anxious about what would happen when they reached the end of the 6-8 week period of support, for example:

*"I could not have had better care; the only thing that is worrying me is I hope they don't send me home too soon because I have nobody at home. I live alone and that is just worrying me a bit when they said we will go and have a look at what you have got there today."*

- 3.164 Other people similarly recognised that they had a long way to go in recovering not only their physical capacity but also their confidence to return home, as this person observed:

*"I am alright within four walls but the minute I step outside I shake, so now they are going to start taking me for walks around the garden."*

- 3.165 In our other sites, people's experience of intermediate care was largely of short term support provided to them at home rather than intensive specialist rehabilitation, and was focused on providing practical help with personal care until they were able to cope alone. Most people were glad to get back to managing on their own and saw it as a sign of their progress and recovery that they no longer needed social care, for example:

*"I had that for 6 weeks – morning and night (...) just bathed me, got me dressed and they came at night to undress me. In the beginning because I could not get about they used to get me my breakfast – do me some cereals and tea (...) just for the six weeks until I was able to do things for myself."*

*"I had somebody that used to come in the morning and help me get washed and dressed (...) and she did it for a few weeks and then she said, you know – do you think you could manage? And I could, I could manage to get myself to bed at night and that you know. So they just said well if you do need any help let us know, but I can manage things like that alright."*

- 3.166 The withdrawal or reduction of support at the end of the period of intermediate care was not generally something that people were concerned about. On the contrary, being able to feel that they were better and able to manage relatively independently was generally viewed very positively. Such examples indicate that the FACS eligibility system can work well and target help to people when and where it is most needed and then reduce it when the need no longer exists. These positive experiences are in marked contrast with the situation of people whose needs are assessed as below the threshold eligibility and who are unable to get access to the

support they feel they need, or people who have some level of support which is subsequently withdrawn on review when they do not feel able to cope.

## 7 Economic Well-being

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3.167 In almost every interview undertaken with people using social care services, concerns were identified about money. People worry about not being able to afford care, or about having to make do with less support than they need because of cost. For people who no longer have any source of income beyond their pensions, other benefits and savings, the fear of their money running out is very real. We have already examined the impact this had on people who used a combination of informal and recommended sources of help in order to under-cut the rates charged by social services. Where people have been assessed by the council and are deemed eligible for services, it is common practice for any charging regime to be accompanied by a benefits check and an attempt to maximise the income which people are entitled to in order to off-set the impact of charging. Some social workers and care managers took particular care to ensure that people understood their entitlements and received any money they were due, as this person described:

*"And I say (...) but do you get an Attendance Allowance? Well no! Well, why not? (...) And they turn around and say because I've got x amount of money, and I say – my favourite saying is – you could win the lottery tomorrow and you'll still be entitled to Attendance Allowance (...) You need care and that's what Attendance Allowance is for."*

3.168 However, people who are funding their own care arrangements typically do not benefit from the Fairer Charging policies of councils, and – as in many other areas which we have identified – self-funders were potentially the most vulnerable and fearful about their savings running out.

### **Worries about money running out**

3.169 When people make the decision to enter a care home they rarely think about it being a long term arrangement. People expect it to be their final move and to spend their last days in one place. However, many of those people we met who were self-funding had been living in care homes for a number of years and had spent a large proportion of their savings in that time. The unspoken questions in many of our interviews were 'how much longer will I last?', and 'will my money be sufficient?' In a few cases these issues were addressed head-on.

3.170 One 95 year old who was considering moving to a new care home because of dissatisfaction with her current arrangements explained the calculation she was going through in deciding whether the move was affordable, and wondering what information the private company developing the new home would need access to:

*"I've been trying to find out if they can decide whether I have enough money. I spoke to my solicitor yesterday and I said 'how are they going to assess this?' In the short term – I'm 95, in two or three years I'll be gone. But do they know that I had the aunt who lived to 101, because that is considerably longer? I don't want to*

*go there and pay their terms and find out that the money won't last, because if the worst came to the worst I would have to come back here. Hopefully by then they would have sorted the food out!"*

3.171 Another self-funding resident was wondering about moving to a cheaper room within the same care home:

*"Well at the moment I'm paying £575 a week. So that's quite a lot and of course my savings have gone right down, and that means I will only be able to stay in this room for about five more months and that will be that (...) If I move downstairs it will be £100 a week cheaper."*

3.172 In this case the care home proprietors were well aware of the person's situation and tried to offer reassurance that she would be safe, as she described:

*"They keep saying, 'now don't worry!', because I say about this financial business and they say 'don't worry' (...) I say to them here when are you going to throw me out? They said they are not going to throw me out, they've got no reason to."*

3.173 Some residents had a vague idea about the existence of a savings threshold and that once their savings reached a certain level they might be able to get some assistance from social services. However, none of the self-funding people we spoke to were well-informed about this and some were wary of going down this route, for example:

*"So I think there is something that you can get them to – but I haven't been able to contact the people yet. I was given the wrong telephone number and I just went on to social services; they weren't any use and I'm afraid they gave me the wrong information."*

And

*"Well she told me that if I couldn't manage I could live on Social Security; and I've never lived off Social Security! I've always paid my way."*

3.174 Another person who was funding residential care for his wife had been provided with better information, but even in this case he was worried about the possible funding gap between what social services might pay and what he believed his wife needed:

*"The assessment officer came around (...) she said well the system is that you get down to £21,500 (...) and they then can kick in when it's down to a certain level. They'll pay £492 and I'll pay the top-up. But then of course it could come to the stage that is she gets upgraded or she has to have more and more attention, that could require more staff, which requires more fee paying which would be another £55 per week, which could leave me looking for £85 per week, but we'll meet that when we come to it (...) I suppose we could one way or another, I could even go onto equity release (...) we can get by. I want her to stay there."*

3.175 In another site the son of a person who was living in a residential home also described how he had been advised by social services to contact them at the point when his mother's savings had reduced to £3,000 above the savings threshold. Some people who were funding their own care had *already* dropped below the threshold

where support should be provided through social services funding but were not receiving it. In part this might be due to people being secretive about their savings and feeling that the involvement of social services in their financial affairs was too intrusive and unacceptable. This was particularly likely with people who were secretive about their personal background or who felt that they had something that they didn't want social services to know about – such as a history of mental health problems – and who therefore tried to avoid all contact with social workers. Section 2 has shown that interviews with policy and operational social services staff indicating that the process for identifying people who were depleting their savings was - at best – hit and miss. While it is unusual for people to 'slip through the net', social services staff acknowledged that it *does* happen on occasions.

- 3.176 Even when social services are aware of a person's financial situation their approach is a reactive rather than proactive one. This social worker described a person whose case has been discussed previously who was concerned about her funds running out, and commented:

*"(...) there will come a point at which she will be evicted (...) if it had come to the point where he [her son] had let them evict her, he would be in contact with me again, either [the proprietor] at the home would contact me, or the son probably. I think that's the point at which we would be back in again (...) In the meantime, as a worker I have been told to close that case."*

### **Depleted Savings**

- 3.177 Social services appear to rely on care homes alerting them to self-funding people who may be running out of money, while those homes – in turn – rely on residents telling them of their position. What happens to people whose savings *have* depleted varies. Very often people who are self-funding will have been paying a higher rate for their care than the local authority is charged, and are effectively used to subsidise publicly funded residents. When the case is referred to the council to pick up funding they are unlikely to pay at the higher rate. This same provider described how they tried to operate a humane approach:

*"So what we often find is that Mrs X perhaps has been with us at a certain level, the local authority say well we are only going to fund it up to the current level. And what we find is we've got that sort of position well we don't really want to be showing them the door because it looks as though we are being harsh. So they can stay, and they have gone on with the rate."*

- 3.178 Other service managers also described how in such situations they would try to negotiate a compromise rate with a care home in order to allow a person to remain living there, but:

*"Homes can't just expect us to kick in public funding at private funding rates!"*

- 3.179 However, if people are resident in homes that are charging substantially above the normal social services limit, alternative provision may be offered. Deciding to move someone is a difficult and potentially risky judgement. What happens to anyone in this situation appears to be a matter of happenstance, as this social worker observed:

*"It's a lottery! I think it's a lottery as to who your team manager is, who – what worker you get!"*

3.180 An added difficulty for people who are self-funding is that once the council becomes involved because their savings have been depleted, assessment may indicate that they do not meet eligibility criteria for residential care. In some situations this leads to the person being moved to other accommodation, often with highly damaging results. This is clearly something which causes distress to all concerned, including social services staff:

*"(...) they just do not meet the criteria, do they? And then they get to the end of their money and more often than not, the borough will not take them on. Thank God I never had much dealings with those people."*

3.181 Even if people *could* be maintained in the community, or would not have been admitted to a care home with the level of need they display, some people have become institutionalised by their care arrangements and are unable to adapt to anything else:

*"(...) one lady did not meet the criteria for residential care and they put her into this high grade warden controlled accommodation, but then she spent the whole night wandering the corridors, because she could not live in a flat on her own again (...) she had been used to a room this size and someone being there 24 hours."*

3.182 Social services staff acknowledged that there are human rights issues to be considered in deciding to move someone from a place they have made their home, and many were reluctant to deal with the adverse publicity which can arise from such cases.

3.183 In all of our sites it was apparent that awareness of self-funders – particularly in care homes – was a matter of chance. When people approach the council for help because their money is running out, this is often the first contact the council has ever had with them:

*"We still get the surprise of people knocking on the door (...) they say we can't pay this month's bill and that's about it."*

As another care manager observed:

*"We used to have a system to keep a good track of people who are self-funding and living in care homes, but I am not quite sure what has happened to that now."*

## Summary: Key Messages on Outcomes for People

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- A poor quality of life was experienced by the majority of people seeking help from social services or paying for their own care who were interviewed for this study. Few described their lives entirely negatively and most expressed a level of resignation and acceptance. People had low expectations and modest desires

about what help they might get, but most had been turned down as ineligible for social care, were receiving less support than they felt they needed, or were simply trying to find their own way in the system with little or no help.

- Improving 'choice and control' has become the key mantra of social care. In order for people to exercise such choice and control a number of features need to be present. People have ready access to information and services; services are responsive to individual needs and preferences; people have information to help them in making choices, and they are supported in making decisions. These features were typically absent.
- Contacting social services was often a matter of chance, and the outcome often one of disappointment following assessment. Many people expressed their surprise that social services were unable to offer any assistance, particularly where people were coping *but with obvious difficulty*.
- People judged ineligible for social services support are typically signposted to other services. For many people this leaves them to take the initiative in following up and at times it is evident that signposting leads people into a dead end, where they remain with no further assistance.
- Such experiences reduced the likelihood of people feeling that they could get help or seeing any point in going back to social services in future. In the absence of any offer from social services, it is evident that some people are resourceful and find ways of organising support for themselves. Typically this is a combination of using informal sources of help, together with privately arranged support, and many such arrangements are fragile and liable to disintegrate.
- Informal networks and word of mouth play a central role particularly in finding people who can provide practical help. People recommend cleaners to their friends; adverts are seen in local shop windows. Typically these services are provided at a price that is below the rate that would be charged by social services (*if they provide such support*) or by private care agencies.
- People who fund their own care and support should, in principle, have the greatest choice and control since they can use their money as they please – to help them to stay at home, to move to more suitable accommodation, or to move into a care home. However, in practice it is clear that some self-funding people can be just as disadvantaged as people relying on public funding.
- Far from making active and considered choices about their lives – people who are funding their own arrangements often appear to end up in their situation by chance and through an unfortunate combination of circumstances.
- On occasions people who are self-funding seem to be fast-tracked into residential care before all (or indeed any) other options have been explored. The decision to move into a care home is rarely a planned and considered one, rather it seems to be the only option.
- There *were* exceptions to this pattern of poor choice between minimal support or residential care. Additional help could be provided on occasions through social services having access to further funds – notably through the POPPS (Partnerships for Older People Projects) grant introduced to support independence for older people.

- For people making their own arrangements for residential care any contact with social services was the exception rather than the rule, and none of the people we interviewed for this study had experienced a social care assessment prior to entering a care home.
- Most people making the decision to enter a care home in this way did not explore other options such as having support at home (either through contacting social services for advice or by making private arrangements).
- Several people paying for their own care commented on their confusion about the fees being charged and the lack of clarity about how these were calculated.
- Ultimately people who are paying for their own care *do* have the option of exercising choice and moving elsewhere. For people who are alone and with little or no access to outside help, actually doing so can be very difficult or impossible to achieve. People in this situation were most likely to identify solicitors, bank managers and financial advisers as sources of information and advice, rather than anyone who might know anything about the care market.
- It was evident that councils usually become involved with self-funders only if a home is closing or there is an investigation, or when people come to their notice because they have depleted their savings and could face eviction.
- Direct Payments are being promoted by the Department of Health and are seen to offer people who use services the same options and autonomy as people who fund their own arrangements. Very few of the people we interviewed had experience – or indeed knowledge – of Direct Payments, there was also poor understanding of the model on the part of many social services staff.
- In some cases people living in the community were continuing to exercise their autonomy and to participate in wider roles purely of their own volition; these roles had nothing to do with the services and support they were receiving. However, there *were* some examples where support was assisting people in their wider social inclusion and participation, but all of these were with people who were younger adults.
- In all our sites the operation of FACS eligibility criteria meant that certain needs were deemed eligible while others were not. The exclusion of what are often termed 'lower level needs' was evident in all the sites and people had particular difficulties getting support with housework and other practical tasks.
- People unable to get help elsewhere struggled to continue doing things for themselves with obvious risks of falls or other problems.
- There was a pervasive view among social services staff that some people try to 'trick' the council into providing them with low level support that they don't really need or are not entitled to receive. Our study did not find that this was the case.
- Not one of the people using services, or trying to get support from services, who we spoke to in the course of the study identified frivolous needs and wishes, and none approached the council without considerable forethought. Being told they were ineligible for support was both a surprise and a considerable worry for some people who did not know how they would be able to continue to cope unaided.

- While many people struggled to get help with housework or odd jobs around the house, they were far more likely to be provided with equipment and aids for daily living to help them remain in their homes.
- The way in which support is (or is not) provided, and the contrast between a personalised response, and a task-based and mechanistic approach was evident on occasions, particularly in relation to personal hygiene. This approach might meet people's basic needs but with inadequate consideration of the impact on people's dignity and emotional well-being.
- It was clear that many people judged ineligible for social care support, or who are deemed to be coping with their personal care, are actually managing with extreme difficulty or are using arrangements which are far from ideal and at risk of breakdown.
- The way in which eligibility criteria for social care are worded can be important in how inclusively eligibility is defined. It was acknowledged that people who 'shout loudest' tend to fare best, while groups of people relatively disadvantaged by eligibility criteria included young people in transition, and older people where cultural and institutionalised ageism was likely to lead to a poorer package of support.
- There was some hope – and expectation – that the extension of personalisation (through DPs and IBs) will be helpful in making implicit and explicit discriminatory practices more transparent and open to challenge.
- Older people are most likely to be in the position of funding their own care simply because they are more likely to have accumulated assets over their lifetime. This was widely perceived as unfair, and as a penalty on savings.
- While many of the stories we heard in the course of this study were about people struggling to cope without help, there were also some contrasting success stories of FACS working well in targeting help on people needing short term intensive support who were subsequently able to manage independently.
- People who are funding their own care arrangements typically do not benefit from the Fairer Charging policies of councils, and – as in many other areas which we have identified – self-funders were potentially the most vulnerable and fearful about their savings running out.
- None of the self-funding people we spoke to were well-informed about the existence of a savings threshold and understood that once their savings were depleted they might qualify for some assistance from social services.
- The process for identifying people who were depleting their savings was - at best – hit and miss. What happens to people in this situation is a lottery.
- On occasions people do 'slip through the net', and continue to spend down their resources below the point at which they should have been referred for public support.
- In all of our sites it was apparent that councils' awareness of self-funders – particularly in care homes - was a matter of chance. When people approach the council for help because their money is running out, this is often the first contact the council has ever had with them.

## Conclusions

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- 3.184 In this section we have examined the impact of FACS eligibility criteria on people's lives. We have done this by analysing our findings through an outcomes framework. In the final section of the report we will draw together the overall conclusions from our analysis. One conclusion which emerges strongly is that there is a tension – and often contradiction – between the pursuit of FACS (which, as we have seen is essentially a rationing device), and outcome-focused objectives for social care support.
- 3.185 The experiences of people seeking help from social services are varied. People who are most disadvantaged are those who are deemed ineligible for support, and those who are self-funding and make their own arrangements often with no advice or help whatsoever. People who succeed in getting over the eligibility threshold for social care reported the greatest satisfaction of those we interviewed, and even if services were subsequently reduced or removed many felt that they had received the help they needed when they needed it. People who don't meet the criteria but who have a range of needs deemed to be of low or moderate severity are typically left to find their own way. Signposting to alternative sources of help is highly variable and effectively places considerable onus on people to show some initiative and seek out what they need. For some people this is feasible, but for many others who are already feeling disempowered, vulnerable and unhappy it is too much and they are unable to access the help they need.
- 3.186 People who are funding their own care – particularly residential care - are unlikely to be offered any advice or assessment by social services. Any contact self-funders have with the council is random and is likely to occur only when there is an investigation of a home they are living in, or when their funds become so depleted they can no longer continue to pay for their care.
- 3.187 Analysis of people's experiences through the framework we have adopted reveals outcomes for many which are poor, and certainly of much lower quality than people might reasonably expect. Moreover, these outcomes could be considerably improved with relatively minor inputs. The focus on eligibility thresholds sits uneasily alongside the new model of social care which is supposed to address outcome-based commissioning and personalised support. Focusing on achieving the best possible results for people in ways which address their particular needs and circumstances would arguably have led to very different outcomes for many of the people we met.

## Section 4: Conclusions

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- 4.1 Throughout this report we have highlighted the key findings and it is not the intention here to repeat in full the many points already established, but rather to briefly reflect upon the narrative that emerges from the findings. The impact of the tightening of FACS eligibility bands has attracted a great deal of publicity and general expressions of concern, but to-date has been the subject of relatively little empirical investigation. Although this report is confined to the experiences in six areas in England, it has involved well over a hundred interviews at a range of levels – policy, management, practitioner and individual users and carers. In addition it draws upon other published material, both academic and official, and sits alongside a parallel quantitative study undertaken for CSCI.
- 4.2 What this amounts to is a fuller understanding of FACS implementation in a wider context. It is important to be clear that councils are rationing adult social care in order to ensure they keep within their budgets. The difficult financial circumstances facing councils, combined with the growing need for support arising from an ageing population, means that service rationing has a higher profile than in the past. None of the councils in this study were comfortable about undertaking the rationing role, and the council in the ‘critical only’ camp felt this to be a stigmatising and self-defeating situation from which it duly escaped relatively quickly. In the report a conceptual distinction is drawn between three types of rationing – by *directive*, by *discretion* and by *diversion*. It has been emphasised that these three modes of rationing are not mutually exclusive and each of them will not only be operating simultaneously but also interacting in complex (and often unpredictable) ways. Responsibility for putting priority setting and rationing into practice at local level falls to a range of constituencies – politicians, managers and practitioners.
- 4.3 In principle, policy implementation is based upon a simple transmission belt model – politicians (national and local) formulate decisions, managers set a framework for implementation, and practitioners put it into effect. In reality, these three constituencies can often be pulling in very different directions, and this will shape the different ways in which FACS rationing is practised in a given locality. Notwithstanding such variations, this report has identified some common policy and operational trends:
- all councils are developing tighter rules and procedural guidelines for FACS regardless of whether FACS band availability is reduced;
  - reducing the availability of FACS bands does not curb the demand for support;
  - people with ostensibly eligible needs are not gaining access to services;
  - councils are increasingly attempting to define the ‘core business’ of adult social care;
  - councils are increasingly using ‘signposting’ as a way of diverting demand;
  - councils rarely know what happens to those whom they signpost out of care-managed support;

- care managers continue to exercise some discretion in determining eligible needs, but this discretion is diminishing;
- there is still a tendency on the part of front-line staff to assess for bands and services rather than to address risks and needs;
- people who fund their own care rarely have access to assessment and tend to be left without any form of independent review, advice or support;
- the trend towards tightly circumscribed council help is strikingly at odds with the personalisation agenda and with wider conceptions of health and well-being.
- the precise point at which councils establish the threshold for FACS eligibility is not necessarily a predictor of how criteria operate in practice. On balance, more restrictive criteria are likely to be more restrictive in application, but the major issue is that of *policy implementation* rather than merely formulation.
- existing performance measures appear to reveal relatively little about how councils behave towards prospective users of services who are judged to lie outwith their criteria.

4.4 In Section 3 of the report the experiences and voices of people who use services and of their carers are put at the forefront, for it is here that decisions on priority setting and rationing unravel into individual lives. Sometimes these are good experiences; too often they are dismal.

4.5 There is nothing inherently wrong with rationing in general, or even with FACS specifically. All governments are concerned about levels of public spending, and all societies limit access to social care in some way. FACS consists of several risk-related bands and, in principle, these could be adjusted in a sensitive and flexible way to match the changing needs of individuals. In practice the temptation is to use FACS bands as a crude means of curbing demand, and the evidence of this investigation is that this occurs too readily, and with potentially risky consequences for vulnerable people.

4.6 It is at this point that council members and officers must take some responsibility for sometimes making a difficult situation worse in several respects:

- by making unrealistic and damaging decisions about the sorts of help that the council will fund;
- by formulating unclear or unrealistic rules and procedures that fail to win the backing of professional staff;
- by diverting people to other sources of possible support but failing to check whether these are available or effective in meeting those needs;
- by conceptualising self-funders to be outside of council responsibility and capable of making all of their own arrangements for care, when in fact they may be highly isolated and vulnerable;
- by failing to recognise tensions between the tightening of rationing criteria and the developing agendas on personalisation and health and well-being;
- by failing to understand the effects of their policies on the lives of individuals.

The clearest expression of the consequences of funding and rationing is to be found in the lives of service users and their carers. This report identifies many cases where

the absence of any help, or of inadequate levels of help, is resulting in some very poor individual experiences which are both damaging to the individuals concerned and self-defeating in terms of system-wide demand management. Action is needed to give greater priority to social care backed up with sufficient resources and to develop more sophisticated and sensitive approaches to service rationing. The question raised is whether the present situation is sustainable and - in the context of an outcomes focused personalisation agenda - defensible.

## How to contact CSCI

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