

Department for Work and Pensions

Research Report No 216

Independent living in later life

**Jane Parry, Sandra Vegeris, Maria Hudson, Helen Barnes and
Rebecca Taylor**

A report of research carried out by the Policy Studies Institute on behalf of the Department for Work and Pensions

Corporate Document Services

© Crown Copyright 2004. Published for the Department for Work and Pensions under licence from the Controller of Her Majesty's Stationery Office by Corporate Document Services, Leeds.

Application for reproduction should be made in writing to
The Copyright Unit, Her Majesty's Stationery Office, St Clements House, 2-16 Colegate,
Norwich NR3 1BQ.

First Published 2004.

ISBN 1 84123 724 8

Views expressed in this report are not necessarily those of the Department for Work and Pensions or any other Government Department.

Printed by The Charlesworth Group (Huddersfield, UK).

Contents

Acknowledgements	vii
The Authors	viii
Abbreviations	ix
Summary	1
1 The independent living in later life project	7
1.1 Background and introduction	7
1.1.1 <i>Demographic characteristics of the pensioner population</i>	8
1.1.2 <i>Older people and independence</i>	10
1.1.3 <i>The need for support at key transitions</i>	12
1.2 Research objectives	13
1.3 Methodology	13
1.4 Structure of the report	14
2 The case studies	15
2.1 The case study methodology	15
2.2 The case study areas	16
2.2.1 <i>Area one profile</i>	16
2.2.2 <i>Area two profile</i>	18
2.2.3 <i>Area three profile</i>	19
2.2.4 <i>Area four profile</i>	21
2.3 Specialised services	23
2.3.1 <i>A bereavement centre</i>	23
2.3.2 <i>Specialised residential care schemes</i>	24
2.3.3 <i>A home-from-hospital scheme</i>	25
3 Older people and independence	27
3.1 Introduction	27
3.2 The meaning of independence: autonomy and self-reliance	27
3.3 Home	29
3.4 Mobility	30

3.5	Health	32
3.6	Income and assets	34
3.7	Conclusions on independence	37
4	Lifestyle transitions and independence	39
4.1	Introduction	39
4.2	The ageing process	39
4.3	Retirement transitions	41
4.4	Health transitions	43
4.5	Domestic transitions	45
4.6	Transition case studies	47
4.6.1	<i>Older people in specialised residential care</i>	47
4.6.2	<i>Older people and bereavement</i>	51
4.6.3	<i>Older people leaving hospital</i>	54
4.7	Conclusions on transitions	57
5	Pensioners' help needs	59
5.1	Introduction	59
5.2	Patterns of service use	60
5.2.1	<i>Health services</i>	60
5.2.2	<i>Transport services</i>	60
5.2.3	<i>Home-based care services</i>	61
5.2.4	<i>Other forms and sources of support</i>	62
5.3	Factors influencing use of support and services	63
5.4	Feelings about receiving help	64
5.5	Services that help maintain independence	67
5.6	Service gaps and services that make people feel less independent	69
5.7	Help given to others	71
5.8	Conclusions	73
6	Modelling customer segments for today's pensioners	77
6.1	Introduction	77
6.2	Background	77
6.3	Proposed Customer Segmentation Model	78
6.4	Study feedback	83
6.4.1	<i>Key informants</i>	84
6.4.2	<i>Health, income and support</i>	85
6.4.3	<i>Pensioners in supported living</i>	88
6.5	Other pensioner circumstances	89
6.5.1	<i>Personality characteristics</i>	89
6.5.2	<i>Temporal factors</i>	89
6.5.3	<i>Household circumstances</i>	90
6.5.4	<i>Ethnic minorities</i>	90
6.5.5	<i>Availability of services</i>	90
6.6	Transitions between segments	91

6.7	A note on terminology used	93
6.8	Summary	93
6.8.1	<i>Issues to consider</i>	94
7	Conclusions	95
7.1	Introduction	95
7.2	Independence in later life	95
7.3	Transitions and heightened support needs	96
7.4	Negotiating support in later life	96
7.5	Interpreting differential needs: the customer support model	97
7.6	Implications for policy: promoting independence in later life	98
7.6.1	<i>Joined-up services and key points for intervention</i>	98
7.6.2	<i>Equalising accessibility and targeting services</i>	99
7.6.3	<i>The need for flexibility</i>	99
7.6.4	<i>Communication</i>	99
7.6.5	<i>Advocates</i>	100
7.7	Conclusions	100
	Appendix A Details of methodology	101
	Appendix B Characteristics of the interview sample	107
	Appendix C Notes on revised proposed CSM for today's pensioners	111
	Appendix D Research instruments	115
	References	127
	Other research reports available	133

List of tables

Table 2.1	Household level interviews across the four areas	16
Table 2.2	Individual interviews across the four areas	16
Table 6.1	Customer Segmentation Model characteristics	80
Table A.1	CSM distribution of pensioners over the course of the fieldwork	103
Table A.2	Reassignment of pensioners within the CSM over the course of the research	103
Table B.1	Age range (n = 117) Average age = 73.4 years	107
Table B.2	Self-defined ethnicity (n = 118)	107
Table B.3	Living arrangements (n = 118)	107
Table B.4	Reported weekly income bands (n = 85)	108
Table B.5	Reported health problems or disabilities (n = 57)	108
Table B.6	Benefit receipt (n = 65)	108
Table B.7	Source of social support for those who need help (n = 27)	108
Table B.8	Segment seven pensioners' health problems, support needs and movements into supported accommodation	109
Table C.1	How the revised model corresponds to the current CSM	112
Table C.2	Summary of segmentation by levels of health, social support and income	113

List of figures

Figure 6.1	Customer Segmentation Model – organisational chart	82
Figure 6.2	Mapping health transitions	91
Figure 6.3	Mapping life event transitions	92
Figure C.1	Proposed revised Customer Segmentation Model segmentation of today's pensioners – organisation chart	112
Figure D.1	Social Network Map	117
Figure D.2	Service use diary (printed to fill A4 sheet)	118

Acknowledgements

This research was funded by the Department for Work and Pensions. We are grateful to the members of the Department, in particular to our project manager Clare Talbot, for her efficiency, support and constant availability throughout the course of the research, and to Bairbre Kelly, Robert Lilly and our steering group for their valuable advice.

We are particularly indebted to the various service providers and members of the public who gave up their time to be interviewed and to help with the research in various ways.

The Authors

Helen Barnes is a Senior Research Fellow at the Policy Studies Institute and has published widely on older workers, ethnic minority groups and young people.

Maria Hudson is a Research Fellow at the Policy Studies Institute whose current research explores social and economic inclusion, with particular reference to labour markets, ethnicity minority groups and disabled people.

Jane Parry is a Research Fellow at the Policy Studies Institute whose recent research has focused on labour market disadvantage, particularly in terms of older people and ethnic minority groups.

Rebecca Taylor is a Research Fellow at the Policy Studies Institute who specialises in voluntary work and the labour market experiences of socially excluded groups.

Sandra Vegeris is a Research Fellow at the Policy Studies Institute whose research interests include how observations can be used to measure poverty and disadvantage.

Abbreviations

AA	Attendance Allowance
AC	Audit Commission
DLA	Disability Living Allowance
BGOP	Better Government for Older People
BME	Black and minority ethnic
BSL	British Sign Language
CSM	Customer Segmentation Model
DLA	Disability Living Allowance
DWP	Department for Work and Pensions
ESOL	English for Speakers of Other Languages
FAB	Financial Assessment and Benefit
FRS	Family Resources Survey
GHS	General Household Survey
GP	General Practitioner
JRF	Joseph Rowntree Foundation
LA	Local Authority
LAT	Living Apart Together (relationships)
LGA	Local Government Association
MIG	Minimum Income Guarantee
MP	Member of Parliament
NHS	National Health Service
PA	Personal Assistant
PS	Pension Service

PSI	Policy Studies Institute
QSR	Qualitative Solutions Research
RP	Retirement Pension
SDP	Severe Disability Premium
SSI	Social Service Inspectorate
UK	United Kingdom

Summary

This report brings together findings from qualitative research undertaken by the Policy Studies Institute (PSI) during 2003/04 on behalf of the Department for Work and Pensions (DWP). This explored factors influencing perceptions and experiences of independent living in later life and analysed pensioners' service needs and accessing behaviour, in turn considering the relationship between independence and service use. These issues are timely given the projected rise in the proportion of the UK's population which is over State Pension age in the near future. The research was also designed to provide refinement of the DWP's Customer Segmentation Model for Today's Pensioners, a tool depicting a sliding scale of support needs, differentiating pensioners into seven sub-segments on the basis of key demographic criteria.

Methods

An iterative case study approach was adopted to address these issues, deepening knowledge of the significance of key demographic characteristics upon perceptions of independence, while exploring the effect of local factors upon pensioners' experiences. Four contrasting case study areas were selected to provide a range of geographical and service delivery circumstances, which were purposefully revisited in successive fieldwork phases. Qualitative interviews were conducted with 98 pensioner households (118 individuals) to examine experiences within and across a range of socioeconomic groupings which proxied for 'customer segments'. Three successive tranches of fieldwork have focused upon emerging issues and explored patterns of service use and non-use, with the final stage of the research concentrating upon key transitions in later life: bereavement and leaving hospital. Additional key informant interviews, which preceded those with pensioners, have augmented local knowledge of the case study areas and enhanced the range of sampling strategies employed.

Making sense of independence in later life

Older people's understandings of independence in later life encompassed a number of interrelated elements, reflecting their circumstances and changes in these over time. **Notions of autonomy and self-sufficiency underpinned interviewees' perceptions of what it meant to be independent.** The balance between an emphasis on 'doing what you want to do' and 'doing things for yourself' shifted to reflect older people's capabilities, social context and expectations.

Intersecting these priorities were a series of sub-components to independence. These included the importance older people attached to staying in their own homes, maintaining personal mobility and

good health, and having sufficient income to live comfortably. **Independence is thus subjective, shifting and multi-faceted, and the relative weight older people attached to particular elements reflected their circumstances, as well as individual values and preferences.** Crucially, even when older people's ability to do things on their own was compromised, they were able to maintain their sense of independence if they felt a sense of autonomy over how and when help was received. There were also subtle gender, class and cultural differences in terms of how people understood their independence, and in the strategies they employed to manage their situations. In particular, income in later life often informed the way interviewees framed their independence, and was tied to the kinds of choices they were able to make.

Most of those interviewed thought about and explained independence in much the same terms as when they were younger, and their priorities changed little in later life. However, **a sizeable proportion explained that the meanings they attached to independence changed as they got older**, and that in response, they both saw things and acted differently. These **shifting perspectives were particularly related to health**, in that disabled pensioners and those with long-term health conditions were more likely to regard independence differently in later life, in both dramatic and more subtle cumulative ways. Those who displayed the most stable ideas about independence tended to have experienced little recent household change, being married, or else widowed or divorced some time ago. By contrast, **more recently bereaved people**, who had experienced dramatic changes in their social networks and expectations about mutual support, correspondingly **reassessed what independence meant to them and how they might best achieve it.**

Transitions and heightened support needs

Significant events (particularly recent ones) and changes in the life course had an important impact on older people's sense of self and the way they viewed and prioritised their independence. Later life is often associated with periods of great change, which involve adapting to both anticipated and more unexpected circumstances. These include the general ageing process, retirement, health deteriorations, and changes in the domestic sphere (such as bereavement, divorce and moving house or into supported accommodation). Domestic transitions, in particular, tended to be relatively unsupported. Transitions may also occur singularly, simultaneously or consecutively, which has implications for the pressures they exert upon older people. They are mediated by a range of socioeconomic, demographic and personal factors, which influence pensioners' perceptions of independence over time and inform their support needs, which in turn are influenced by their relative distance from transitions. For example, the proximity of extended family can have an important influence over how older people cope with bereavement, and people with higher incomes have improved access to obtaining the kinds of mobility aids and care likely to help them adapt to deteriorating health.

Three common transitions are presented in terms of case studies of pensioners who received institutionalised support at this time of change in their life: people moving into residential care and other forms of supported living; those coping with bereavement; and older people who had recently been discharged from hospital and who had returned to their homes. While the former of these provides illustration of a holistic lifestyle service, the latter two draw attention to more crisis-driven services. These **case studies provide evidence of the value of specialised services in supporting older people through periods of acute adjustment**, and of the interconnection between independence and finding the forms of support through key transitions that worked on an individual basis. **Given the difficulty in planning for many of the transitions associated with later life, it is important that services are targeted to meet pensioners' needs at key anticipated crisis**

points, and that these are accessible, easy to navigate, and offer multiple points of contact – where any one agency could jumpstart the facilitation of access to a wider host of relevant services.

Negotiating support in later life

The older people interviewed drew upon a range of support packages, reflecting their needs, the type of support that was available to them, and individual preferences about receiving help from particular sources. There was an issue about asking for help among many pensioners, who would like to have received particular services but who felt uncomfortable or unconfident about seeking these out, and who were sometimes also uncertain of their eligibility. Some interviewees felt that there was a stigma associated with claiming statutory services. There were also perceptions that asking for help was an admission of failure, in conflict with a strong personal ethos of self-sufficiency, and some expressed concerns about not becoming 'a burden' upon friends and family. Often older people commented that they would feel happier accepting help that was offered to them proactively, **and it seemed likely that worries about asking for help reduced take up of support services**. Past negative experiences about trying to access services also deterred people from future service use.

High quality informal social support was considered a particularly important aspect of people's support mechanisms in later life, and support preferences were influenced by older people's expectations about family and kinship obligations, which were, in part, the product of their class, gender and cultural background. While support needs in later life varied according to pensioners' differential and changing circumstances, in particular, with relation to their health and social support networks, so too did the ways in which these were met. These might comprise any one, or a combination of, informal support networks, statutory services, the voluntary sector, and where income was available, private agencies. **A well-managed package of support played a vital role in helping pensioners maintain their sense of independence.**

Priority services felt to help maintain independence in later life, included transport, health and home-based services. These supported older people, in particular, through health transitions, and were felt to be important in rebuilding their confidence. Older people also valued being able to help out friends, family and partners where they could, and these activities played an important role in maintaining their sense of independence. **Interviewees often relied upon tried-and-tested support services, and preferred a single point of contact that directed them to broader support services.**

Older people therefore want to have one point of contact that can access the range of services on their behalf. Given the preferences of some groups of older people to use particular routes into services, it is important that a wide range of organisations that could potentially be the initial point of contact are able to take on this role.

Interpreting differential needs: the customer support model

A significant component of the research has involved analysing how pensioners' experiences reflect the conceptual categories identified in the DWP's Customer Segmentation Model for Today's Pensioners. This has classified the pensioner population into seven categories according to differing levels of health, social support and income. These are anticipated as reflecting a sliding scale of 'independence', which can be used to target support services. In broad terms, the research confirmed that the model identifies credible groups and subgroups of pensioners, in terms of distinctive help needs and accessing behaviours, and it thus has value for identifying groups, and in potentially anticipating the help needs of the pension age population and targeting interventions. The pensioner

interviews indicated that being independent necessitates not only having help needs met, but that this is achieved in ways that respects individual autonomy and choice. The strong value attached to autonomy by pensioners with a range of health, income and social support characteristics clearly has important implications for the model.

The model was less suited to reflecting the support needs of pensioners who sat on the boundaries between 'segments', who were commonly going through some sort of a transition, and who represented a significant element of the pensioner population – those with fairly urgent and often unmet support needs. Complex interactions between health, income and social support occur in reality, which it is problematic to capture in a linear model. Its conceptual underpinning, a continuum of dependency, cannot map straightforwardly onto interviewees' own values and priorities in terms of independence, which were far more differentiated. The research has drawn attention to the wide range of experience that can sit within a single segment, often with quite diverse support needs, and to the relative vulnerability of pensioners to move without warning between segments. This issue was particularly identified for segment seven pensioners living in supported housing.

The model would therefore benefit from being applied in a more dynamic way, recognising the interplay between changed circumstances brought about by life events, help needs and independence. Independence in later life means having needs met through a seamless flow of supports. The implication for the model is that services need to be responsive to events over the whole course of later life.

Conclusions and policy implications

This research has provided evidence that strong, well-managed support systems that complement pensioners' own priorities, play an important role in maintaining independence in later life. These may consist of informal social support from partners, extended family and friends, or more formalised services from the statutory, voluntary and private sectors. Some of the most successful packages of support drew upon a combination of these sources, which has advantages in terms of flexibility in responding to crises. The most important issue in terms of independence was that older people were able to negotiate (or have negotiated for them) a package of support they felt comfortable with, which reflected their unique needs, values and priorities.

These findings have a number of specific implications for policy, in terms of ways in which services could be delivered to enhance access and promote independence in later life. These include:

- promoting integrated cross-sector services with multiple entry points, that identify key points for intervention;
- equalising accessibility by investing in the multiple targeting of services, to include non-traditional and specialised routes;
- prioritising flexibility in the ways that services are provided to reflect the diverse and changing needs of the pensioner population;
- placing an emphasis on developing forms of communication that are appropriate to older people's needs, particularly during times of transition when multiple contact may be necessary to ensure that people have the support they need; and
- making a commitment to ensuring the availability of advocates to older people who may have difficulty accessing services, with particular attention being devoted to ensuring that pensioners' desires are correctly understood and communicated.

In summary, it provides a strong argument for joined-up services, which offer multiple legitimate routes into a broader host of services, which cut across a variety of sectors and which reflect the diversity of pensioners' circumstances and expectations. The report has also drawn attention to **older people's heightened vulnerability during times of transition commonly associated with later life**. While the research illustrates a range of ways in which pensioners' support needs may be met during such times, these will enable older people to maintain their sense of independence only to the extent that **critical aspects of life course continuities** are prioritised. Older people emphasised that the same things mattered to them as had done throughout their lives, and hence services need to be aimed at supporting them in maintaining this balance, particularly in relation to remaining in the family home and continuing to live as a couple as far as possible. It is also important to recognise symbolic markers, such as continuing to take part in valued leisure activities, or providing help to friends and family, in terms of preserving older people's sense of independence.

1 The independent living in later life project

1.1 Background and introduction

In April 2003 the Department for Work and Pensions (DWP) commissioned the Policy Studies Institute (PSI) to carry out qualitative research exploring the factors that influence perceptions and experiences of independent living in later life. The Pension Service is an executive agency of the DWP (the latter being formerly known as the Department for Social Security (DSS)), and the Department is responsible for delivering the State Pension and benefits to pensioners. Throughout the life of this research, the Third Age Programme has been undergoing development, and it is anticipated that the findings will be used to help in the future development of the programme. The Third Age Programme concentrates on working with partner organisations in more joined-up or holistic ways, rather than offering new services. Its overall aim is to provide simple accessible services that treat pensioners with dignity and promote independence.

An additional aspect of PSI's research has been that it was designed to provide refinement of the DWP's Customer Segmentation Model for Today's Pensioners. This Customer Segmentation Model (CSM) was developed as a tool within the DWP to help with the development of policies and The Pension Service. It depicts a sliding scale of independence, differentiating pensioners on the basis of key demographic criteria, namely health, social support and income. Older people are, therefore, categorised into three broad groupings – 'independent', 'assisted' and 'special needs', and further classified into seven subgroups on the basis of the more detailed demographic information (see Chapter 5 for a detailed review of this tool).

This chapter introduces the research by outlining the policy background and relevant literature on the subject. Only an overview of the literature is provided here, since the DWP commissioned separate research to conduct a more thorough review of the ongoing debates (Leeson *et al.*, 2004). The aims and objectives of the current research are then presented, and these are contextualised in a discussion of the research methods used. The chapter concludes by providing an overview of the report's structure.

Despite the impending equalisation of men and women's pension ages between 2010 and 2020 (set out in the Pensions Act of 1995), the proportion of the UK's population over State Pension age is predicted to continue to rise from 10.8 million in 2000 to 12.3 million in 2021, and alongside this, dependency ratios will also increase (Shaw, 2002). The gendered profile of the ageing population is

well established (Bernard and Phillips, 2000), with women progressively outnumbering men at later ages due to their greater longevity. Characteristics of the UK's ethnic minority populations also ensure that in the future the pensioner population will comprise significantly more Black and Minority Ethnic (BME) groups, particularly in terms of Afro-Caribbean and British Asian pensioners (Atkin, 1998). This ageing profile raises a number of increasingly pressing questions for policy-makers regarding how best their needs can be anticipated and met.

The recent Audit Commission (AC) and Better Government for Older People (BGOP) report *The Challenge for Public Services* (2004) sees older people's services in a state of flux, recognising that as the baby-boomer generation enters retirement, new demands will be created, not only in terms of volume, but also in terms of a shift in expectations, '*from the prevention of dependency to a much more proactive and positive promotion of wellbeing and successful ageing.*' Through its research with pensioners, and working with organisations such as the Local Government Association (LGA) and Association of Directors of Social Services, the AC and BGOP have recommended a holistic approach to the delivery of services for older people, which promotes 'control and interdependence', in contrast to a more market-driven emphasis on 'choice and independence'. This alliance promotes an active ageing agenda, emphasising the need to focus on later life as a period of growth, autonomy and enjoyment, and decrying the previous more reactive emphasis upon older people's needs and crisis points. Thus the agenda has been set for multi-sectoral preventative action that promotes active and fulfilling ageing, and which focuses on the needs of the individual from a long-term perspective, a perspective that has been viewed increasingly sympathetically by policy-makers. Although PSI's research was concurrent with this activity and was not designed to feed into the process, in many senses its policy implications are complementary.

1.1.1 Demographic characteristics of the pensioner population

Disability and its severity increases with age, and is, therefore, a particular issue for pensioners; a quarter of couples and a fifth of pensioners living on their own are in receipt of incapacity or disability benefits (Summerfield and Babb, 2003). Over two-thirds of disabled adults are over 60, and the incidence of disability is particularly marked among the over 80s age group (Grundy *et al.*, 1999). Disability may affect pensioners in a variety of ways, for example, in terms of dementia, mobility, sensory or visual problems, which may vary in their degree of intensity, and require a range of forms of support. For instance, pensioners may require support with personal care, household tasks, or healthcare, which may be provided through various formal and informal forms of care, either separately or in some form of combination. Furthermore, over half of those over age 75 live alone (Matheson and Summerfield, 1999), and as pensioners age they are more likely to need to draw on support outside their immediate household. Those lacking such support are likely to enter some form of residential care at younger ages (Netten *et al.*, 2002). Declining levels of fertility and increased divorce rates also affect the quality of social support that pensioners can expect to be able to draw upon in later life (Aykan, 2003, Wenger *et al.* 2000). Grundy and Shelton (2001) have identified a positive relationship in terms of the frequency of contact between adult children and their parents and gender (particularly in terms of mothers and daughters), but a negative association with age.

Pensioners' socioeconomic circumstances differ markedly (Hayden *et al.*, 1999), affecting the ways in which they draw upon the private/public sector in accessing support services. However, pensioners are more likely than those in other age groups to exist close to or below the margins of poverty, particularly if they live on their own (DWP, 2003a). Furthermore, women's access to non-state pensions falls dramatically behind men's (Ginn and Arber, 1996). UK pensioner incomes currently stand at 78 per cent of the average income, compared to 83 per cent for other OECD countries (Disney and Whitehouse, 2001). Gender differences in access to and contributions into occupational

pensions partly explain women's disproportionate representation among the elderly poor. Pensioners are over-represented among groups residing in 'unfit' dwellings or lacking basic amenities (Summerfield and Babb, 2003), and deprivation is regionally patterned, with those on low incomes most likely to live in inner London (DWP, 2003a). The link between poverty and ill-health is well-established (Payne, 1991), contributing to women's greater chronic ill-health compared to men's more acute health problems in old age, with all the implications this has for use and cost of healthcare services. There are also class differences in caring, with women married to (former) manual workers being twice as likely to be caring for a disabled partner as married women married to men from social classes I and II (Glaser and Grundy, 2002). These social problems look set to be accentuated as life expectancies continue to rise (Dunnell, 2001).

Ethnicity and its effect upon service use and demand is a relatively unexplored aspect of ageing. Pensioners living in households headed by someone from an ethnic minority group are more likely to live on a low income (DWP, 2003a). Recent research has challenged the popularly held assumption that the care needs of pensioners from ethnic minority groups will be universally contained within the family (Chiu and Yum, 2001). Turnbull (1985) has emphasised that some ethnic minority extended families are characterised by loneliness and conflict. Other research has revealed that within ethnic minority communities, carers tend to be women, who are often isolated and unsupported, just as they are among white groups (Netto, 1996; Katbamna *et al.*, 1997). These problems may be exacerbated by communication difficulties (Yu, 2000). Relying upon untested assumptions of shared care may therefore leave the support needs of ethnic minority pensioners under-addressed and vulnerable. Despite some innovative schemes, such as sheltered housing for particular ethnic communities (Butt and Box, 1997), the first ever SSI (Social Service Inspectorate) inspection of community services for black older people found most local authorities' social services departments' responses inadequate (Murray and Brown, 1998).

Boaz *et al.*'s (1999) literature review highlighted that pensioners from ethnic minority groups felt neglected in consultation processes, and that even where they had been consulted, they often perceived that their views had not informed the design and implementation of the policies which affected them (Butt and O'Neil, 2004), and that this was likely to have knock-on effects upon the subsequent development and accessibility of services. Research into mental health services in Liverpool (Boneham *et al.*, 1997) highlighted a number of factors particularly associated with elderly ethnic minority people's experiences, including cultural issues relating to pride, a lack of support from extended families, a reduced knowledge of available services, the cultural inappropriateness of services, and language barriers. Barnard and Pettigrew's (2003) recent qualitative research on the service needs of older people from ethnic minority groups, conducted during the period of transition between service delivery through the Benefits Agency and The Pension Service, has reiterated and further probed these barriers. They developed a more comprehensive understanding of the factors that affect the accessibility of services to older people from a range of ethnic minority communities, including a lack of familiarity with systems and entitlements, language and literacy issues, and a suspiciousness of statutory services. Evandrou's (2000) analysis of GHS data has illustrated significant differences both between and within ethnic minority elderly populations (with particularly high levels of deprivation amongst Pakistani and Bangladeshi elders), which, in the context of the expected increase in the proportion of elderly people from these groups, requires greater consideration by policy makers.

1.1.2 Older people and independence

A great deal of existing research has suggested that 'independence', in particular the positive sense of self which may be derived from exercising control over support received (Abbot and Fisk, 1997; Tanner, 2001), is fundamental to pensioners' hopes for the future (Boaz *et al.*, 1999; Hayden *et al.*, 1999). However, older people's ability to access health, benefits, care, housing, transport and information services has often been frustrated by a lack of service delivery co-ordination and integration at the local level (Boaz *et al.*, 1999; Chang *et al.*, 2001; Kempson *et al.*, 2002), despite their being the greatest users of health and care services (Dunnell, 2001). It seems likely that increased tendencies to contract out, privatise and ration services have exacerbated existing inequalities and muddied the waters in terms of pensioners' understanding of their entitlements. Chang *et al.*'s (2001) evaluation of the Better Government for Older People prototypes confirmed the need for a holistic, integrated service. Recent changes in health, welfare and social services have signalled a heightened policy concern with facilitating independent living, particularly with reference to disabled pensioners. Government initiatives have demonstrated a growing concern with needs of the UK's ageing population, including the establishment of the Royal Commission on Long Term Care and the Foresight Programme, which has an Ageing Population Panel.

This research has been conducted in the context of a particularly active policy context, at both the local and national stages. The Pension Service, created in 2002, was designed to enhance the way benefits and information are delivered to pensioners, particularly in terms of vulnerable and 'hard-to-reach' groups. The Pension Service is delivered through a network of pension centres. These centres are supported by local service teams, who work with a range of partner organisations, including local authorities and voluntary organisations. However, some concerns have been expressed about these developments. Patterson (2004) has argued that a phone-focused Pension Service must rely on partnership working with local authorities, the voluntary sector and other agencies to provide a face-to-face service for those who prefer to deal with their benefit claim in person. He reflects that the initial moves away from home-based visiting by the then DSS in the mid-1980s made it more difficult for pensioners (particularly those from ethnic minority groups) to claim their entitlements, and anticipates that The Pension Service's reduced level of contact with elderly people will limit the scope for preventative work, keeping them '*out of sight and, ultimately, out of mind.*'

Recent research on The Pension Service has shed early light on these predictions. Kelly *et al.* (2004) surveyed over 4,000 users of The Pension Service. While around four-fifths reported being happy with the service they had received, and only six per cent had made a formal complaint, there was evidence that those with the greatest needs were being the least well served. Almost a quarter of those claiming Minimum Income Guarantee (MIG) found the forms hard to complete, as did 20 per cent of those aged 75 and over. Of those with special needs, one in twelve needed help to complete forms, but were unaware that this was available. Significantly, among those who did make a formal complaint, older pensioners, those who were disabled, and those claiming MIG were over-represented.

Relationships between Pension Centres and local agencies were in the process of being developed over the course of the research, in preparation for implementation of the Service in April 2004, and significantly there has been no one fixed model for local service delivery. Simultaneously, there have been developments in the Third Age Programme, which started with the rollout of joint teams in the South West, building on the lessons of the 2001 Care Direct pilots, with the aim of further

harmonising service delivery and promoting independence. There are plans to rollout joint teams¹ nationally in the coming year. A Public Service Agreement (PSA 6) has committed to providing Pension Credit (the replacement for MIG, which went live in October 2003²) to a minimum of three million pensioner households. This is supported by a Service Delivery Agreement objective to work co-operatively with a range of agencies, including local authorities, voluntary and special interest groups, to identify routes of enhancing eligibility, promoting take-up of benefits, and sharing good practice. These policy developments provide a response to calls for integrated social policies to address the diverse needs of an ageing population (Bernard and Phillips, 2000).

However, independence is a complex and amorphous concept, subjectively and objectively variable and linked to a number of interrelated socioeconomic characteristics. For example, older people are both the recipients and providers of various forms of care (looking after grandchildren, partners, etc.), and their support needs and capabilities are hugely variable and related to health, socioeconomic and demographic characteristics. Secker *et al.* (2003) have highlighted the need for further exploration of the meanings of independence for older people. They have argued that the very subjectivity of the concept, encompassing meanings such as self-esteem, purpose in life and personal continuity, make it possible for pensioners simultaneously to experience high levels of dependence and independence. However, independence may also be a painful subject for older people, particularly when it is associated with loss (Audit Commission, 2004, forthcoming); this may be related to the time that has elapsed since these events (such as bereavement or a health crisis).

The forms of support which enable older people to maintain their independence may derive from the statutory and voluntary sectors, drawn from family and friends, privately purchased, or a combination of these, and are likely to be influenced by income, service availability and local social networks. Informed choice in negotiating these is of fundamental importance to older people's perceptions of independence (Boaz *et al.*, 1999). However, the relative significance of these factors has been a subject for ongoing debate; for example, Bowling *et al.* (2002) have assigned social support, health, personality factors and area, relatively high ratings in terms of pensioners' self-perceived quality of life (not necessarily coterminous with independence, though likely to be related), in comparison to income, the results for which were inconsistent. Pensioners' definitions of independence are also likely to vary over time, and research conducted by Means (1996) highlighted maintenance of the home as a priority. However, he also observed that in its absence, independence became increasingly measured in terms of friends, familiar environments, personal security, participation in valued activities, and access to good transport and other social services. This research engages with these issues, exploring how perceptions and experiences of independence are facilitated and improved by a range of service providers and forms of informal support, and the ways in which these patterns may be linked to sociodemographic characteristics.

¹ Joint teams are The Pension Service local service and Local Authority (LA) Financial Assessment and Benefit (FAB) teams, working as joint teams under a single management structure. Joint teams will be targeted at capturing the estimated 20 per cent of vulnerable older people that are not already included in the Pension Service net, and who, typically, tend to contact local authorities' social services departments at times of acute need rather than The Pension Service.

² Pension Credit is a new entitlement for people aged 60 or over (or who have a partner aged 60 or over). At the time of publication, this guaranteed this group an income of at least £102.10 a week if they are single, or £155.80 if they have a partner. It also rewards some of the savings and income of people aged 65 or over. This extra money can be up to £14.79 a week if they are single, or £19.20 a week if they have a partner.

1.1.3 The need for support at key transitions

A number of key transitions will be experienced by many older people, which have the potential to transform their lives. Three of these have been a focus for this research. These are: returning home after in-patient hospital treatment; bereavement; and entry into residential care. By looking at these three relatively common experiences, we have been able to explore the extent to which the predictability or unexpected nature of these transitions affects the ways that people cope, and the potential for supporting particular types of transition.

Hospital discharge services are likely to have been stimulated by the 2000 National Health Service (NHS) Plan, which signalled the Government's concerns over bed-blocking and promoted supported early hospital discharge. However, Grewal *et al.*'s (2003) recent research on disabled people's transitions found that over-bureaucratised communications between healthcare professionals and social services have frustrated both of these providers in managing this transition. The planning, management and quality of hospital discharge care, and the ways in which formal services interact with support from family and friends, is undoubtedly influenced by whether hospital treatment was emergency or scheduled. Furthermore, as Phillips and Waterson (2002) have described, hospital discharge and moving into residential or nursing care may coincide, constituting a 'double transition', with particular issues for inter-disciplinary co-operation. Phillips and Waterson drew attention to a devaluation of the 'social' dimension of hospital social work, which had hitherto been its mainstay, and which was decried by users and carers alike. Heaton (2001), who studied the temporal interface between the hospital and home-based care regimes prompted by hospital discharge, has highlighted important discontinuities and tensions in these services' time frames, and between the less institutionalised time frames of patients and carers.

The loss of a close family member, particularly a partner, in later life can have a particularly strong impact because it occurs at a time when other social networks are shrinking, for example, those associated with the former workplace. Cumulative loss over a relatively short-period of time can have a particularly detrimental effect upon older people's mental and physical health (Stillion *et al.* (1989). While the literature often suggests that women cope better than men with the adjustments involved, there is little empirical evidence of this; the centrality of the marriage relationship to the individual's identity is a more important factor (Van Baarsen *et al.*, 1999). However, Davidson (2001) reports gender differences in attitudes to remarriage amongst those widowed in later life, with women generally enjoying life alone more than men. Correspondingly, Borell and Karlsson (2002) have recently drawn attention to the phenomenon of 'living apart together' (LAT) relationships as a preferred re-partnering choice in later life, providing evidence that women are often the prime agents in steering these arrangements, which appear to provide important advantages over remarriage in later life, including promoting personal autonomy and protecting assets intended to be passed on to extended family.

While entering residential care is often regarded as an option of 'last resort', both by older people themselves and in the literature, a great deal depends on the ways in which services are provided. Oldman and Quilgars (1999) point out that institutionalisation can occur in a domestic setting, and that the quality of life can improve markedly on admission to residential care. Indeed, those with the option to enter residential accommodation on a self-funded basis, rather than being required to satisfy an assessment of needs, frequently do so because of the inadequacy of home-based care services (Netten *et al.*, 2002). In order for such moves to maximise independence, it is important for older people to have sufficient time to adjust to the idea of the move, be able to move to accommodation that meets their criteria for 'feeling like home', and to be offered continuity. Unfortunately, the latter is often unavailable, and many older people experience forced moves when

their health condition changes, as a result of the criteria applying to particular care homes (Reed *et al.*, 2003). Furthermore, movements into residential care may be both temporary, for example, in response to a short-term health crisis, or permanent, in response to a sustained and ongoing deterioration in mobility, transitions that may be experienced rather differently.

1.2 Research objectives

The research reported on here has had three complementary aims:

- to explore concepts of independent living in later life, in particular the circumstances and services which support or inhibit independence;
- to analyse pensioners' service needs and service accessing behaviour;
- to provide refinement of the DWP's customer segmentation model.

Taking these together, the research will test the hypothesis that independence in later life (as defined by sociodemographic characteristics) influences service use and access, and that the ways in which services are provided have consequences for how older people are able to live their lives. It thus provides information on how services can facilitate independence.

1.3 Methodology

An iterative case study approach has been used to address these issues, deepening knowledge of the boundaries between the seven groupings in the CSM (and, thus, the impact of key demographic characteristics upon perceptions of independence), while exploring the effect of local factors upon pensioners' experiences. Case study areas were selected to provide a range of geographical and service delivery circumstances, and were purposefully revisited in three successive phases of fieldwork. Interviews were conducted with 98 pensioner households (118 individuals) in the four different case study areas to examine experiences within and across a range of socioeconomic groupings which proxied for 'customer segments'. A range of sampling techniques were employed to provide access to these distinctive groups, including approaching older people in receipt of various types of benefits, via pension records, and through specialist services. Successive tranches of fieldwork focused upon emerging issues within and across customer segments, and explored patterns of service use and non-use. Complementary topic guides were used in the three phases to investigate different aspects of pensioners' experiences, and these were supplemented in the tranche one fieldwork with social network maps and service use diaries. Strategies employed to address pensioners' differential access needs included interpreted interviews, the use of type-talk facilities, interviews conducted in BSL, and interviews facilitated by carers, disability experts and housing wardens. For a subgroup of households, partners were also interviewed. Wherever possible, these were conducted as simultaneous interviews, with two researchers interviewing both partners at the same time. Additional key informant interviews, which preceded those with pensioners, have augmented local knowledge of the case study areas and enhanced the range of sampling strategies employed. Further details of our methodological process and how it was informed by the ethical issues raised by conducting research with the kinds of vulnerable groups found within the pension age population (for example, in terms of using specialised access and facilitation techniques), can be found in Appendix A.

In order to protect the identities of the people who participated in the research, both individuals and areas are presented in anonymised forms. Areas were assigned a number, and individuals, whose

accounts are embedded in the research, have all been given unique pseudonyms. To ensure that anonymity is ensured within as well as outside the sample (crucial when couples are interviewed, and particularly so in light of the sometimes sensitive and possibly conflictual nature of the topics discussed), pensioners' identities have been disguised where this was necessary to prevent potentially damaging disclosures (Tolich, 2004). In Chapters 3 to 6, where the material from the interviews with pensioners is presented, quotations are used to illustrate points which reflect the perspectives of the groups identified in the text.

1.4 Structure of the report

This report considers the findings of the research with pensioners and key stakeholders in the four case study areas, analysing the three tranches of fieldwork. The report is divided into the following sections, in addition to a number of appendices providing supplementary research information:

- Chapter 2 introduces the four case study areas, and reflects upon the interviews with key informants to consider the particular issues for service delivery in relation to independent living in later life. It also introduces a number of specialised services, whose users were studied in later periods of fieldwork to look at ways in which common transitions can be supported: bereavement, leaving hospital and moving into residential care.
- Chapter 3 starts to present the material from the pensioner interviews by considering what independence means for older people, relating it to key assets, such as health, social support and income. It considers older people's fears about losing their independence, and looks at the kinds of coping strategies that they employed to maintain and prolong various forms of independent living.
- Chapter 4 identifies and explores the kinds of key transitions that are faced in later life, taking these up in terms of the ageing process, leaving work, and changes in health and domestic situations. Three case studies of transitions associated with specialised service use are drawn upon to examine how transitions affect older people's independence, and how they may be supported during these times.
- Chapter 5 develops these issues by looking at older people's support needs, preferences, and the ways in which these are met through a combination of formal services (statutory, private and voluntary) and informal social support (through partners, extended families, friends and neighbours), drawing out differential patterns of support needs among the pensioner population and exploring how older people feel about these, and their implications for negotiating independence in later life.
- Chapter 6 introduces the DWP's Customer Segmentation Model (CSM) in more detail, and presents the research findings in relation to the categories of pensioners identified in the hypothetical model. Particular attention is devoted to identifying common transitions across the pensioner population, which are illustrated through pen portraits. The chapter also provides a discussion of the model's strengths and limitations as a policy and marketing tool.
- Chapter 7 develops the findings presented in the preceding chapters, identifying the main themes emerging from the research, and analysing these in terms of the current policy context, as well as presenting their implications for the CSM.
- Appendices include: a more detailed account of the research methods used in this project; an overview of the characteristics of the research sample; suggested refinements to the CSM; and documentation on key research instruments.

2 The case studies

2.1 The case study methodology

The three tranches of interviews employed in this research were 'nested' within four case study areas, in order to explore the effects of local issues and facilities in shaping pensioners' experiences. In addition to contextualising the research, this approach provided methodological rigour, enabling areas to be revisited to test and explore emerging theories. Areas were selected to be representative of qualitatively distinctive experiences for older people, and consultation with the DWP ensured that a broad range of policy issues were reflected in the service delivery structures operating in each area. Pensioner interviews in each case study area were prefaced by six to eight depth interviews with a range of key stakeholders in each area, in order to develop an overview of local issues and to inform subsequent sampling techniques. These typically included representatives from The Pension Service Local Service, voluntary sector, housing, transport, and specialised housing sectors, but also reflected local service delivery patterns, and included additional providers representing unique or innovative local services that affected pensioners' experiences in the area.

The fieldwork with key informants (and subsequently pensioners) was structured in the following way:

- **Tranche one:** fieldwork in areas one and two, respectively mixed urban and mixed rural locations, which offered a neat comparison of key geographical distinctions that would be reflected across much of the UK.
- **Tranche two:** fieldwork revisiting areas one and two, and introducing areas three and four, which provided two distinctive new sets of local concerns. Tranche two also included a subset of research with pensioners living in contrasting forms of residential care, associated with area one.
- **Tranche three:** fieldwork focusing upon key pensioner transitions – bereavement and hospital discharge, and nested in areas one and three, organised around particular services and their users in these areas.

Census small area statistics were used to identify wards in each area, which included a suitable proportion of pensioner residents, and which covered a range of key characteristics, including ethnicity and score on the English Index of Multiple Deprivation³. Reflecting these differential

³ The Index of Multiple Deprivation offers a measure for deprivation at both the ward and local authority level by combining data on income, employment, health, education, housing and access to services to produce an overall score, providing a ranking and thus comparison of area circumstances.

demographic characteristics, the socioeconomic circumstances of pensioners interviewed was not evenly distributed across the areas, although as far as possible it was attempted to obtain a range across each area. Within each area we also included a number of households in which couples were interviewed separately in order to explore both sides of the account of household circumstances, a technique which provided some illuminating results (see Chapter 3). The distribution of interviews across the case study areas over the course of the research is outlined in tables 2.1 and 2.2 below.

Table 2.1 Household level interviews across the four areas

	Area 1	Area 2	Area 3	Area 4	Total
Tranche 1	18	17	-	-	35
Tranche 2	13	13	10	12	48
Tranche 3	8	-	7	-	15
Total	39	30	17	12	98

Table 2.2 Individual interviews across the four areas

	Area 1	Area 2	Area 3	Area 4	Total
Tranche 1	19	23	-	-	42
Tranche 2	17	17	13	14	61
Tranche 3	8	-	7	-	15
Total	44	40	20	14	118

The remainder of this chapter introduces the four areas in which fieldwork was conducted, providing an overview of their contrasting demographic and service provision characteristics. Key informant interviews are drawn upon to illustrate the main issues for independent living in later life from providers' points of view. These are taken up in subsequent chapters in the discussions of the pensioner interviews. Following the descriptions of the fieldwork case study areas, a series of pen portraits are presented for the three specialised services studied in tranches two and three to explore pensioners' experiences of receiving this kind of support during critical transitions – a bereavement centre, two distinctive forms of specialised residential care, and a home-from-hospital scheme. Each of these services was nested within a case study area, and was identified for the research on the basis of preceding interviews with key stakeholders. In order to protect the identities of stakeholders, areas are presented in an anonymised format, with statistics approximated to prevent identification.

2.2 The case study areas

The four case study areas in which the research was conducted were purposefully selected to illustrate pensioners' qualitatively different local circumstances. Key characteristics and distinctions of these areas are considered below.

2.2.1 Area one profile

Area one was an urban area encompassing an inner-city core and suburban neighbourhoods. Its population had fallen in recent years, since, reflecting the national scenario, the birth rate has slowed at the same time as people are living longer. The latest census indicated that for the first time the proportion of people in area one aged 60 and over was higher than that of children in the population.

Almost 45,000 people in the area were of pensionable age, with a particularly stark growth in the proportion of elderly pensioners. There was a substantial ethnic minority population in this area, with almost a quarter of residents classifying themselves as being of non-white ethnic origin. The largest ethnic minority group, by some margin, was Indian, followed by the Afro-Caribbean community. While there has been an influx of asylum seekers into the locality, their age profile has tended to be young.

There was considerable variation in ward demographics in area one, and the sampling of pensioners reflected this. Most of the area's pensioners were poor, and were often in receipt of both state and small occupational pensions. While pockets of affluence existed, this concealed pensioners living in fairly highly valued properties but experiencing financial hardship, whose pensions excluded them from qualifying for MIG. Politically the area was Labour, and was regarded as an innovative player in terms of its pensioner provision.

Interviews were conducted with eight key informants in area one, representing: The Pension Service Local Service, the Older People's Strategy Team in social services, Over 50s Forum, two key voluntary sector organisations, representatives from both traditional and new-style specialised residential homes, and a local bereavement centre. Several key informants noted a service shift towards promoting active independence among pensioners. For example, one voluntary sector organisation described how people can now expect to spend as much time in retirement as in paid work, increasing the importance of changing attitudes about how retirement is conceptualised.

The Pension Service Local Service's main initiative has involved outreach to disadvantaged groups in the local community, providing benefits advice and raising awareness of entitlements. Advice surgeries were held in the community at regular times, for example, in libraries, GPs' surgeries, and community centres, and the team was constantly thinking about new outreach strategies. The Pension Service Local Service team was fluent in the first languages of several ethnic groups, recognising the impact of language needs on access to information and services. The team had also produced a directory of local services for pensioners and worked in partnership with other agencies on a range of initiatives. Advice surgeries were a good example of this, with collaboration taking place between the welfare rights department of the city council, the voluntary sector and primary care teams. Collaboration had also taken place with social services on issues of elder abuse and self-neglect. Other examples of partnership working included the development of a bereavement centre, and the growth of joint care resource centres, focusing on pensioner personal development, quality of life, and supporting people in staying in their own homes. There had also been a shift from traditional residential homes to extra-care housing. Social services explained that the demand for ordinary sheltered housing had dropped because people were increasingly staying in their homes until they reached a point when they needed a level of care requiring more support, leading to the development of 'very sheltered' housing. A further development had been local educational institutions collaborating with the voluntary sector to provide educational opportunities for older people.

While joint and new areas of service provision tended to be run in-house in area one, some services had been externalised to 'private' contractors, within the voluntary sector, primary care teams and extra-care housing trusts. This process involved a learning curve, and the need for improved monitoring of contracts for service provision became apparent over time.

Local issues and service gaps

While there was a great deal of service innovation in area one, key informants raised a number of local issues and drew attention to some service gaps in current provision:

Extending take-up. One concern raised by The Pension Service Local Service was that pensioners who did not attend advice surgeries were probably those most in need of help. Some pensioners may have used up their savings to undertake house maintenance, and qualified for MIG, but did not claim it. Making contact with these 'property rich, income poor' pensioners to provide support was a major challenge, and it was difficult to gauge the size of this group. Pensioners in deprived areas were generally more likely to access services as they were more familiar with the system and what was available, having been in the position of using services prior to reaching retirement age.

Personal safety. Area one's deprived sub-regions had a higher crime rate, and pensioners living in these were more concerned about drugs and crime, and some were afraid to go to the bus station. Such fears may also restrict their use of local services. While The Pension Service noted concern from local residents about asylum seekers, it also emphasised that one area's crime rate *fell* when asylum seekers moved in.

User groups. The Over 50s Forum acted as a conduit for some pensioner concerns and was organised into a number of groups reflecting these. For example, its public safety group had explored the need to refurbish public toilets and ongoing problems of vandalism. Its health group worked closely with local hospitals and health departments, and had been instrumental in setting up a bereavement centre, discussed in Section 2.3.1. The forum had also been central in limiting public drinking and introducing a reduced speed limit in the city centre.

Gender issues. Sometimes related to cultural factors, men and women's distinctive patterns of behaviour were described as a big factor in pensioner independence. There were widowed men who lacked knowledge of how to cook and attend to their nutritional needs, while many widowed women encountered difficulties dealing with building maintenance and repairs. One route through which voluntary sector had addressed these issues was the Experience Corps, use of whose volunteers by older people had, to some extent, made possible their deferrals of otherwise early entries into residential care.

Specialist healthcare. Key informants pointed to inadequate specialist care in the area for people with dementia, which was particularly prevalent amongst elderly pensioners. While the local authority was acutely aware of this issue, there was uncertainty over whether it had the resources to commission further dementia care services, and there are ethical and methodological difficulties in consulting people with severe dementia about their needs. Far more people with learning difficulties are surviving into old age, which raises care issues. There were no community-based services for people who have had a stroke in the area, and a general a lack of palliative care services geared towards meeting non-cancer related needs.

2.2.2 Area two profile

Area two was in a rural location, with a population of around 130,000, distributed across a relatively large geographical area. Politically, the area was conservative. One of the UK's less densely populated areas, it consisted of a few towns offering business services, although most people resided in the scattered villages and hamlets. The area had a high proportion of pension age inhabitants (over a quarter of the population) relative to the rest of the country. Ethnic diversity was low, with the vast majority of the population being white.

The area's economy, being rural, was primarily sustained by farming and tourism. Unemployment was similar to the rest of the country; however, due to the high pension age population, the proportion of economic inactivity was relatively high at just over half of all residents. The countryside, along with low house prices and low crime rates, had attracted pensioners to the area from other regions of the UK. Despite this influx, a substantial degree of disadvantage remained, with relatively high rates of pensioners receiving means-tested benefits.

Seven interviews were conducted in area two with representatives from The Pension Service Local Service, social services, residential care and sheltered accommodation services, transport, and voluntary support agencies.

Informants were of mixed opinion on the extent to which collaboration existed among service providers: government representatives generally held a more favourable view than non-governmental agents. As one informant observed, '*There is a developing desire to work collaboratively.*' The local healthcare trust was the main providers' forum for building joint practices. The Pension Service Local Service was regionally based with resources shared among three district offices, area two being one of these.

The bulk of social services were delivered by the private and voluntary sectors. The housing stock and public transport had been privatised, while domiciliary care encompassed a mixture of in-house and contracted-out services. On the whole, service reform was described as '*developing*' and in its '*early days*'. Not surprisingly, due to the ongoing demand for accommodation, housing for older people included innovative solutions alongside a more traditional stock. However, transportation remained a problem because of the widely spread population. In many rural areas, main service providers did not offer a physical presence, and large distances necessitated the use of the telephone to supplement home visits. A number of local pensioner forums were active throughout the area.

Local issues and service gaps

Geography. The physical distance between mainstream service providers and customers, and the distances between rural communities, encouraged communal isolation and reliance upon informal support networks. In some hamlets, this nurtured a pensioner culture that frowned upon the use of public services, which clearly presented a barrier to local providers, and which had created a potential gap in pensioners' stock of support services.

Inadequate transport. Public transport provision was unable to meet the geographically widespread demand for services in area two. Pensioners relied on private transport into old age, particularly their own vehicles. Loss of car access or the ability to drive a car could have adverse consequences, and sometimes led to isolation.

Service access, particularly benefit eligibility information. Outreach to individual pensioners was difficult given the area's geography. Many pensioners in need were unaware of the support services that were available to them. The most frequent request to advice agencies was for help with benefits applications.

Migrants to the area from other parts of the country. There was a growing population of pensioners who had retired early, and moved to the area from other parts of the country. Since they tended to have left their support networks behind, this group was vulnerable and in greater need of formal care than those who had lived in the area for longer.

2.2.3 Area three profile

Area three was an urban population encompassing an inner-city core and suburban neighbourhoods. With a population of close to 200,000, about one in five residents were of pension age, a figure close to the national average. A slightly lower than average proportion of pensioners in the area belonged to an ethnic minority group; the largest groups represented were the Bangladeshi and Chinese communities.

Area three had an economic mix with low-income pensioners concentrated in its densely populated central core. Despite efforts at urban regeneration, pensioners living in the city centre tended to be

more disadvantaged, with higher rates of poor health, lower living standards and a consequent lower life expectancy. However, there were also pockets of affluence, mainly concentrated in suburban areas. Primary local industries in the area were engineering, manufacturing, tourism, retail and leisure. In 2001 the unemployment rate was comparable with the national average.

Interviews took place with six key informants in area three, representing The Pension Service Local Service, social services, a voluntary carers' network and a voluntary befriending scheme. The Pension Service offered two access points in the area. At the time of the research, their remit covered a geographical area that went beyond area three; however, there were plans underway to reorganise so that a team of staff would solely serve the area.

Informants from The Pension Service Local Service reported a good relationship with the local authority. Local government was described as '*proactive*' and taking the lead on pensioner initiatives introduced at the national level. It ran a 'living independently' scheme. A key feature of social services was a designated older people team with a mission to '*reduce isolation and improve quality of life, whilst reducing dependence on mainstream social services.*' The team applied a preventative strategy, covering the primary, secondary and tertiary services. The bulk of this work was concentrated on primary prevention, delivered through a community development approach. The team was active in advising other local authorities on best practices for serving pensioners. The Local Service also led a multidisciplinary preventative network, with representatives from health, housing, transport, voluntary services for older people and elders groups involved. At the user level, the area boasted a strong pensioner forum. This lobbied for local interests, as well as publishing an information magazine.

Social services were contracted out to both private and voluntary sectors, for example: falls prevention, nutrition, home economy, shopping service, local social and ethnic clubs, leisure, learning and intergenerational opportunities. These were advertised at Pension Service surgeries, health centres, in community newspapers, through a pensioner radio station and on the local council web site. Services in highest demand included the meals-on-wheels service, social clubs and help with shopping (both in and out of home). Descriptors like '*partnership*' and '*joint-working*' were often used to describe the organisation of service help and provision.

Local issues and service gaps

The area was described as offering '*more for pensioners than many other areas in the country.*' Nonetheless, there were some recognised gaps:

Access issues: Although the area offered a wide range of provision, there was a gap in awareness. Older people lacked information on what The Pension Service had to offer. This was evident in the low attendance at surgeries, which mainly relied on word-of-mouth promotion. To address this issue, The Pension Service Local Service was broadening its outreach to build a presence at existing community group meetings and special events.

Non take-up of benefits: The Pension Service was committed to making contact with the 'harder to reach' pensioners, who may be eligible but who were not claiming benefits. However, staff were unclear on who exactly these groups were in their area. It was recognised that the Service needed to reach the public by knocking on doors, but that it lacked the resources to do so. One excluded group were pensioners who owned their homes outright and who were living off their savings; since they had some assets, they assumed that they were not entitled to benefit support, when, in fact, some were.

Specific services identified as needing to be made more readily available included education in terms of falls prevention and podiatry care.

2.2.4 Area four profile

Area four covered an inner-city, relatively deprived population, with high levels of poor health and long-term illness, and a high proportion of single households. It had a relatively low proportion of residents over 60, although the area's most elderly population had been increasing at the same time as its overall pensioner population was decreasing. The area was particularly polarised between rich and poor, with fewer people on moderate incomes. One of its most marked features was its ethnic diversity, with approximately two in five residents coming from ethnic minority backgrounds; Muslim, African, Afro-Caribbean and Jewish communities provided a particularly strong presence. This characteristic exerted a strong influence upon service delivery patterns and styles. Reflecting national patterns in the age profile of the UK's ethnic minority communities, this feature of the area was anticipated to have particular consequences for the experiences of older people in the future.

Area four's unemployment rate was significantly higher than the national average. Its labour market relied heavily upon small to medium-sized enterprises, particularly in business and financial services, and in education, health and social work fields. The area also had a low proportion of owner-occupiers, and recent localised property market booms had created an acute housing affordability crisis for residents, particularly as the population continued to expand. There were high levels of local need, with one in five households containing someone with a special need, and one in three having basic skills issues, some of which were ESOL related. Levels of mental illness were significantly above average.

In this area, six interviews were conducted with representatives from The Pension Service Local Service, a community project for older people, a strategic partnership on older people, a voluntary support organisation, the manager of a supported living scheme, and an organisation representing ethnic minority elders.

Area four had a particularly active community and voluntary sector, highly regarded by The Pension Service Local Service, which recognised the need for partnership working to provide an effective service for older people. Stakeholders widely regarded one voluntary sector organisation as the natural leader in terms of providing pensioner services, due to its established credentials and the entrenched community trust it enjoyed. This phenomenon was consistent with the greater trust which Barnard and Pettigrew (2003) observed that voluntary and community sector organisations often enjoy with black and minority ethnic groups, since area four was particularly characterised by its ethnically diverse population. This organisation acted as the key referral agency for many services, and statutory agencies expressed a keenness to learn from the inter-agency working of the voluntary and community sectors. Despite this, some front-line service providers perceived area four's service provision to be fragmented, and partnership forums were not yet fully functioning. It seemed to be generally agreed that inter-agency work was a learning process for all providers in terms of finding out what was locally available.

A large proportion of the local housing stock in area four continued to be in the hands of the council and housing authorities, although the housing benefit service had recently been contracted out. As in many other areas, public transport services had been privatised. Local care services took on some innovative forms, and were strongly influenced by the area's Labourist paternalistic tradition of 'cradle-to-the-grave' provision.

The high level of pensioner need entailed in the area's demographic characteristics were recognised in its Older People's Strategy, which set out the challenges for service providers, drawing attention to the need to ensure that services were provided in a multitude of ways to promote accessibility. Reflecting the area's high levels of poverty and social exclusion, a priority for service providers has been welfare rights publicity, and it was recognised that some degree of organisational change

among statutory services was necessary to enhance pensioners' knowledge about their entitlements, and to increase take-up. There was significant evidence that resources were being redirected to facilitate this joining up process. Health promotion was also seen as critical to the development of preventative work. Several stakeholders stressed that with such a high need client group, it was vital to start working with pensioners at an early stage, before they began moving towards greater vulnerability.

Key stakeholders repeatedly referred to the importance of promoting holistic services for older people, aimed at individual rather than broad-brush needs, and reflecting the area's diverse spectrum of experience. Several services approached needs holistically by assigning pensioners a caseworker, who functioned as an ongoing point of contact on a multitude of issues.

Local services and gaps

Special needs housing: Historical policies in the late 1980s under the Community Care regime, to move away from residential care, left area four with a shortage of residential care facilities. This was being addressed through a re-emphasis upon supported living and the development of extra-care facilities promoting independent living for pensioners with high support needs. These emphasised residents' continued involvement in the community, challenging the traditional self-contained model of supported care: '*We try and sort of maintain the connections that they had in the community and just not break them.*

Ethnicity: The ethnic diversity of the area provided a particular challenge for service providers in ensuring that services were accessible and appropriate to cultural needs. Several stakeholders noted the significance of extended family networks among particular ethnic minority groups, which needed to be taken into account in service provision. Key informants frequently stressed that service accessibility issues for ethnic minority groups would become increasingly important as these populations aged, increasing the demand, for example, for specialised supported living schemes aimed at Turkish and Asian pensioners.

Access issues: As in the other case study areas, there was a strong feeling among providers that services were going to waste because people did not know about them. However, in area four, more emphasis was placed upon multiple access barriers, which included issues around mobility and disability, and pride issues about claiming, particularly for certain BME groups.

Hard-to-reach groups: Stakeholders were concerned about the difficulty of communicating with many of the neediest pensioners in the area. These included the housebound, pensioners who lacked local family and/or community networks, older people with mental health needs, and homeless pensioners. Consequently, local providers placed a strong emphasis upon outreach and consulting with user groups.

Transport and special needs groups: Key informants in area four emphasised that transport was central in service access, but that traditional transport services could be inappropriate for pensioners with acute health needs. One provider explained, '*We're talking about people with severe disabilities, wheelchairs, two crutches, that sort of thing, they can't just come on anything and no, they cannot use public transport. That is out.*' However, the shortage of local community transport services meant that pensioners with the highest support needs were often the most excluded from services.

2.3 Specialised services

As described above, the research included interviews with three sub-samples of specialist service users: pensioners who had made use of a local bereavement centre; people living in specialised residential care; and older people who had used a home-from-hospital scheme. These services are described below to provide an overview of the type of provision offered to pensioners during times of critical change in their lives. Pensioners' experiences of using these types of specialised services are considered in Chapter 4 (Section 4.6).

2.3.1 A bereavement centre

An innovation that had taken place in one of the areas was the development of a bereavement centre. Eight users of this centre were a focus for the tranche three interviews.

Bereavement often involves a period of trauma and transition, during which time the affairs of the deceased have to be settled, requiring an intensification of organisational activity. This involves liaison with a range of agencies, for example, the registrar of deaths, funeral directors, probate, social services, housing and council tax departments, The Pension Service, the Inland Revenue, pension providers and financial institutions. These activities can clearly be difficult to manage at a time of grief. The 'one stop' bereavement centre developed in area one constituted a single point from which next of kin could access most of the services they needed at this time. The centre opened a few years ago and was located in the city centre, in the main offices of the local council. It was funded by the local authority, and had received financial support from a number of sources over the course of its set-up.

The genesis and progress of the bereavement centre has been the result of close and ongoing partnership working with a range of agencies. This began with the area's proactive Over 50s Forum expressing concerns to social services about the lack of support for the bereaved. Social services subsequently invited a number of agencies undertaking work related to bereavement to a fairly open forum to discuss their roles in the bereavement process. This involved collaboration between the Over 50s Forum, and local authority departments, NHS, The Pension Service Local Service, Inland Revenue, probate and court offices, and the voluntary sector. The services available at the resultant centre were wide-ranging, and included death registration, burial, cremation and memorialisation, the provision of a comprehensive benefits service, addressing the affairs of those who were in residential care/nursing homes, and the availability of a housing officer to consult about the termination or succession of tenancies. Other advice and assistance provided by centre staff included a direct link with the Inland Revenue, returning library books, passports, driving licenses and bus passes, and contacting aftercare services for the bereaved. The partner organisations have been a vehicle for publicising the centre's existence and services.

The centre operated on a core of permanent staff, complemented by more intermittent staff, facilitating its responsiveness to service user needs. The former included a number of Pension Service staff, who had remote access to the centre's computer systems. The latter includes social service financial assessment team members, and housing and council tax benefit staff. A probate officer attended the centre on a weekly basis. There has been no charge for use of the centre's services, and it was anticipated that eventually nearly 80 per cent of the people registering a death in the area would go on to use one or more of the services provided at the centre, and pensioners are likely to be a major user group.

2.3.2 Specialised residential care schemes

The most established kind of specialised residential care for older people has consisted of sheltered housing, and accommodation and care in traditional residential care homes. However, very sheltered housing and extra-care housing, together with a range of other terms, are now being used to describe a style of housing that falls somewhere between the more established types (Appleton and Porteus, 2003:2). This research has provided an opportunity to explore the experiences of older people living in both old and new types of specialised residential care.⁴ Area one was the focus for this study, drawing upon information and contacts developed during the initial interviews with key informants, and most of these eight interviews took place in one of its traditional homes and one of its new style homes. Notably, we recognise that despite our efforts to enhance the accessibility of this research to all participants, within the required timeframe we have inevitably interviewed pensioners in residential care with fewer extreme physical and mental restrictions, and this kind of accommodation will include a much wider range of experience than it has been possible to address in a sample of this size.

Over the last few years, area one had been in the process of radically transforming the nature of its specialised residential care. It closed most of its traditional local authority-owned residential homes, and moved towards privately run provision for the remaining stock. In the main, these homes have been replaced with extra care housing schemes that involved older people becoming tenants in self-contained flats or bungalows, with all the accompanying legal rights. This was in contrast to the payment of allowances and habitation of single rooms by residents in traditional homes.

Within the new schemes there were 24-hour care teams so that people who need care and support can get whatever they want, whenever they want it. Many of these were well equipped with café restaurants, social clubs, computer suites, jacuzzis, gyms, pottery kilns, woodwork shops and greenhouses. These facilities symbolised how the schemes not only look after and maximise people's physical functioning, they also sought to find out what mattered to older people. For all residents, whether aged sixty or ninety, this entailed exploring personal development opportunities that may improve their quality of life.

Developments in residential care in area one were still bedding down, and some perceptions of progress that emerged from key informants were contradictory. A key informant in an extra-care home emphasised that the aim of the facility was to provide access to pensioners with health needs, as well as to pensioners who were relatively healthy, and that in this way it aimed to build retirement communities. In this community of people, there was a continuum of care that people could access as their needs changes. The service provider explained:

'I like to think that we can cater for anyone here, we took people in when we opened from the local care homes who had been assessed and labelled by social workers as needing transfer to nursing or transfer to other residential care homes and we actually resisted that, particularly people with dementia, and we said, "No, we think we should be giving these people a chance here." If it doesn't work, it doesn't work, then they can transfer to residential care or move on, but we think that they should be given a chance, we think that there is a chance that they could have a better quality of life if they came to us and I think it's very significant that there isn't one of those people that moved on...because it was unsuitable for them to be here.'

⁴ Note that we have purposefully not included pensioners residing in nursing home care within the scope of this research, since it was felt that the issues were likely to be significantly distinctive for this group, although they are considered together with pensioners living in residential care in the DWP's Customer Segmentation Model (see Chapter 6, Table 6.1).

Another key informant, managing a traditional home, emphasised that there had always been a need for residential care and that this was unlikely to change. He felt that sheltered housing did not fit the needs of people needing total 24-hour care and described how some people were being transferred out of sheltered accommodation into more traditional residential care settings in order to have their needs met.

2.3.3 A home-from-hospital scheme

The home-from-hospital scheme whose users were interviewed was nationally run by a high profile voluntary sector organisation and was offered in many areas throughout the country. The scheme offered a 'settling in' service to community residents who had recently been discharged from hospital. It operated in one of the four case study areas, and the details below reflect this one local service only.

The home-from-hospital scheme had been running in the local area for almost ten years. It was administered by two staff who co-ordinated the services and assessed service needs, and was delivered by a team of field volunteers. The service was contracted by social services to cover a six-week period. No charge for this help was made on users. At the end of six weeks', customers were assessed to determine if longer-term care was needed. At this point, customers might be referred to social services or voluntary agencies; they might be charged for this longer-term support.

Clients were referred to the scheme from social services. In area three, where seven service users were interviewed, the vast majority of the home-from-hospital customers were of pension age. Common reasons for a hospital stay included injuries sustained through a fall, knee and hip replacements, and terminal illness. A volunteer was matched to a customer on pragmatic grounds of geographic location and on the basis of common interests and experiences. Most were pensioners themselves. A volunteer often accompanied a customer from hospital to home. They provided practical help around the house: buying groceries, preparing light meals, washing up, performing light cleaning duties, and attending to bills. Often the customer needed some company. The volunteer was not contracted to provide personal care, except for foot care and help with stockings. Typically, the help involved two visits a week over the six-week period, but visits were adapted to customer needs.

It was perceived that the home-from-hospital scheme gained credibility by being delivered by a respected voluntary sector organisation (seen as 'experts' in the field), as opposed to by local government social services. The scheme received feedback through a monitoring form that customers were asked to fill out at the end of their six-week involvement. To date, the service had been received very positively by the pension age population.

The pensioners interviewed as users of these three specialist services provided particular insight into the kinds of support that is helpful in helping older people to negotiate critical transitions. Their experiences are presented in the following four chapters on independence, transitions, support needs and the customer segmentation model, both together with the broader pensioner population, but also in isolation when this offers a distinctive perspective.

3 Older people and independence

3.1 Introduction

The following three chapters draw on the interviews with older people. This chapter provides a context for this by examining what independence means to older people, and how different aspects of independence are prioritised by pensioners according to their circumstances, and at different times in their lives. Chapter 4 focuses on transitions among older people, looking at the implications which periods of change have for pensioners in a range of circumstances. It explores both the most common transitions associated with old age, and also three case studies of transitions associated with specialised service use. Chapter 5 examines people's help needs in later life, looking at the various packages of help which people draw upon to promote their independence, which include support from their friends and family, statutory and voluntary sector support, and privately purchased support. As stated in Chapter 1, all pensioners' identities are protected in the findings that follow, and none of the pseudonyms used reflect the true names of any of those interviewed.

3.2 The meaning of independence: autonomy and self-reliance

The interviews with pensioners explored older people's perceptions and understandings of independence, how these were affected by factors like health, income and social support, and whether and how the values that pensioners attached to independence changed or became compromised over time. Within the interview structure the issue of older people's independence featured as a subtext to questions about service use, health, finance and mobility. At the same time, interviewees were asked directly what the concept of independence meant to them, and what they regarded as being its most important or valued aspects, which they would find hard to give up. For some, questions about the meaning of independence had a particular resonance and they talked at length about their conception of independence. However, for others it was too abstract a question, the concept was not something they had really thought about and its meaning was not something they could easily articulate. The second question was often easier to relate to, and many were able to think about aspects of their lives that they would find hard to give up.

Notably, older people did not necessarily draw upon a single constant definition of independence; the meaning of independence was malleable, adjusting itself to reflect transformed circumstances, and various aspects of independence were often interdependent. However, two central strands to independence emerged from the interviews. The phrases that came up repeatedly in all areas and across pensioners in a range of circumstances in response to the question: 'what does being independent mean to you?' were '*doing what you want to do*' and '*doing things for yourself*'. These two phrases capture conceptually distinct notions of independence. The first is essentially about personal decision-making, and as such related to the person's sense of control over their lives and autonomy. Interviewees often exemplified this in terms of having the freedom to choose to do things, such as visit a friend, do some gardening, stay in and watch TV, or decide what and when to eat. It also implied having a choice about not having to do certain things. There was a sense that some people felt that later life and retirement was a time when they were able to be less burdened by the responsibility of work and family, and they relished being able to choose to do nothing. Josephine, a widow in her 80s, explained:

'It means you can do what you want to do when you want to do it and you're not beholden to anyone else to ask whether you can do it or not or whether you can go anywhere. That's really being independent. You can do your own thing.'

The second phrase, '*doing things for yourself*' tapped into a view of independence as being a form of self-reliance or self-sufficiency, and this emerged as the most common understanding of the concept amongst the older people interviewed. Crucial to this was the importance of not asking for help. This was manifested in different ways. At one extreme, an interviewee described receiving help as '*charity*'. Eliza, a married woman in her late 70s, was more typical in describing her and her husband as a self sufficient unit, despite the fairly severe health problems they both suffered:

'I like me independence, I don't like people interfering, never have, so we've always, well I don't know if this is the right word, looked after ourselves. We've never had... been lucky maybe we haven't had to ask for help, we worked things out between us.'

There were some subtle differences between those of different class and cultural groups in how they defined self-reliance and who they would or would not accept help from. Charlotte, a married woman in her 80s, linked her expectations about independence to her cohort and place:

'You see we're of a different generation, we've always had to look after ourselves, nobody has ever done anything for us... we're country people who are independent anyway.'

Interviewees' understandings of family and kinship obligations were often important in terms of how they framed independence, in particular, what support it was reasonable to expect children to provide their parents in later life. Ethnicity played a complex role in this. For example, Yvonne, an Afro-Caribbean woman, who suffered from fairly regular dizzy spells and mobility problems, relied upon an extensive support network from her large extended family for day-to day help at home. She was very comfortable with this situation and found the idea of using statutory home care support hilarious. By contrast, Sanjay and Amisha, respectively a Pakistani man and an Indian woman, both had quite severe limiting health conditions, and more ambivalent feelings about relying upon their extended families, although this help was available; their experiences are explored later in the chapter.

The following sections explore how the issues of self-reliance and autonomy, as key features of older people's sense of independence, shape the practical reality of living in their own home, getting around, managing finances, and caring for their own or their partners' health needs. Within this, the importance of maintaining independence in both or just one of these senses is highlighted, in shaping older people's strategies for managing their lives and maintaining a sense of self-respect and dignity.

3.3 Home

When asked about the most valued aspects of their independence, pensioners repeatedly emphasised the importance of continuing to live in their own home. The physical boundaries of the home represented an important part of pensioners' identity, which they went to great lengths to maintain, and which they feared might be subsumed in alternative forms of supported living. Personal autonomy and control were central to conceptions of home. Being able to '*please myself*', '*come and go as I want*', and the freedom to '*do my own thing*' were typical and common refrains. Often discussions about personal autonomy derived from living at home were developed in contrast to perceptions of '*going into a home*', where many pensioners felt responsibility for day-to-day decision-making, and, thus, personal freedom, would be taken away from them. For example, Miriam, a widow in her 90s emphasised the importance of being able to maintain responsibility for her daily routine, something she regarded as incompatible with life in supported accommodation:

'I'd sooner be in my own home than in a home...you know, I can have what I like to eat and all that, you see...I can please myself, I can go out and I can come in, and I can get up when I like.'

At one extreme, one pensioner attached such high value to this aspect of independence that she admitted to planning to commit suicide if she lost her home and her mobility. Although this theme did not emerge more widely in the research, it seems likely that the social taboo of suicide and the desire to protect one's family limits the extent to which older people disclose this kind of information. Recent Home Office research (Davis *et al.*, 2002) on the inquest process in the UK uncovered evidence of elderly people committing suicide when a decline in health compromised their ability to continue to maintain independent households.

Whilst framing independence in terms of living in their own home, many interviewees relied upon other people to do certain things for them around the house (see Chapter 5 for a more detailed exploration of this). Many were paying for services, particularly in the garden or for one-off repair jobs, although some people on a lower income referred to not being able to afford desired services such as decorating, cleaning or gardening. Where an individual needed help it was important that it was provided on their terms and that they were in control of the process; in other words, that their autonomy was maintained. Paying for services was noted by several interviewees as something that could enhance feelings of independence and autonomy. Their relatively high income enabled them to select and pay for suitable care and domestic services, which in turn allowed them to remain at home during a period of vulnerability. These findings reflect Clark *et al.*'s (2004) recent research which reports that older people who received direct payments to buy-in care reported feeling more in control and consequently experienced an improved quality of life as a result of these arrangements.

Sometimes, however, older people had family who lived locally and who were willing to provide support around the house. Again, the way that older people drew upon this support was related to their lifelong expectations about the role of family support. The ways in which interviewees used informal support to promote their independence is explored in greater depth in Chapter 5. For example, Yvonne's family took turns to sleep at her house every night and do her weekly shopping, despite the fact they all had families and young children of their own. Widows appeared to experience less difficulty accepting help from their children, indeed there was a fairly normalised expectation that mothers and daughters would provide emotional and practical support, an assumption heightened by bereavement, which consequently did not compromise older women's feelings about independence. By contrast, Ida, who had been widowed over 20 years ago, when she was in her 40s, had had sufficient time to adapt to self-sufficiency at the household level, and preferred to '*help myself*' rather than looking outside the household for support. She explained, '*I've always had to stick up for myself, you get into a habit.*' Similarly, pensioners who had divorced and lived alone for some time were more

likely to associate autonomy with personal self-sufficiency, and to guard the contours of the household more closely.

Sometimes a self-reliant attitude had been developed through necessity, such as changes in older people's household arrangements and hence in their support networks. For Fergus, a divorced man who appeared to have lost all contact with his family, this was partly a matter of survival, and the interview bore a number of hallmarks of regret, '*Nobody wants to help or know you, you have to survive yourself.*' Sometimes self-sufficiency was not valued, simply a factor of older people's existence. Mete, a Turkish man who lived in Hackney, had lived a very isolated life working in a textile factory, and although self-sufficient, he desperately wanted to get married and become part of a family household.

Not everyone was able to remain in their home and those who were living in sheltered accommodation or with relatives found strategies for maintaining their sense of independence. Phyllis, an elderly widow who lived with her extended family, had severe arthritis that prevented her from performing many routine tasks. Although she was not self-reliant, she negotiated this scenario by placing increased emphasis upon maintaining personal decision-making. Having decided how and when she wanted to do something, she would then ask her daughter or son-in-law for help, and they were happy to assist. She emphasised that had she not been able to achieve this sense of autonomy then, '*I might as well give up and go.*'

The issues of independence and staying in their own home were also linked to 'privacy' by a number of pensioners. The importance of privacy was tied up with maintaining '*dignity*' or '*pride*'. One woman in her 80s who lived alone, although reliant on neighbours to do odd jobs for her, was fiercely independent and explained that she felt that someone offering to do her shopping was an invasion of privacy. Similarly, Esther, a woman in her 70s who relied heavily upon her neighbours for household support, complained of the lack of control she felt this gave her, '*Sometimes I get fed up because I never know who's coming in that door... just don't seem to get a minute to myself.*' In this case it was evidently a struggle to balance privacy with the support that enabled her to remain in her own home.

3.4 Mobility

Many pensioners raised mobility as something that was central to their understandings of independence. This was tied to the issue of autonomy, the ability '*to do what you want when you want to do it.*' Keeping mobile enabled older people to remain self-sufficient, carrying out valued routine daily tasks without asking for help. For many, getting to places that they wanted go, such as the local shop, post office, pharmacy, dental surgery, or taking a stroll – accompanied or unaccompanied – was central to maintaining their sense of self. Maintaining mobility also enabled them to enjoy their retirement more fully, and many spoke fondly of drives to the seaside, holidays abroad, chartered coach trips, pubs and restaurant outings. Couples frequently went out on errands or social outings together. Many of those living alone made a measured effort to leave their homes daily, even if only to pick up a newspaper or a pint of milk.

Most importantly, being mobile brought people social contact. Penelope, who had lost both her husband and her children, reflected on her need to '*pop out*' to see a neighbour from time to time:

'Yes I think I do like the company, I mean I can manage on my own, I'm perfectly alright on my own and I don't mind being in the house on my own at night, but it is nice to have the company now and again... I don't want to get all reclusive and miserable, like a lot of old people do.'

Some factors limited people's mobility. Concerns for personal security and safety tended to stop people from going out at night, especially in urban areas, whether by car or on foot. Understandably, people with mobility problems were most restricted. Those less steady on their feet were concerned about falling, particularly in wintry conditions, so their outings were reduced. Yet despite the many barriers older people faced, they continued to find ways to ways to get out of the house. Remaining active and interested in the world outside '*these four walls*' was critical. For Adeline, whose walking and balance were limited by circulatory problems, this meant relying on her children or friends for assistance. To her, the alternative would be unbearable: '*Well I think if you couldn't get out at all, I don't know how to put it, you're like a prisoner in your own house, aren't you?*' Home might be the preferred location for older people to live, but without mobility it could also be a prison.

Maintaining control over mobility was critical. Some interviewees spoke of their lack of patience and frustration when waiting for someone else's help, and this limited their feelings of independence. As one pensioner put it, '*if you're totally immobile then you've got to depend on other people to carry and fetch stuff to you.*' For instance, Unis and Elliot lived in sheltered housing and were both wheelchair users. They did not have regular contact with their children. Unis had previously suffered a neurological virus that affected her brain and motor functioning. Her condition required carers four times a day to get her up in the morning, wash and feed her, then help her to bed at night. She was put to bed at seven o'clock every evening and was not pleased with the rigidity of the routine. Unable to propel her wheelchair, she relied upon neighbours and friends to wheel her about. She spoke of how little she could get outside of her home because '*who's going to push me when I get out there?*' Consequently, most of her social activities took place in the communal area of the complex. In contrast, Elliot, who had recently traded in his manual wheelchair for an electric model, marvelled at his enhanced mobility:

'Where I used to have to wait and be pushed around to look at things I can now glide round myself and look at what I wanna look at. You know, it's so much easier, so much better.'

Those interviewed used a variety of means for keeping themselves mobile – by foot, bicycle, car, public transport, with the aid of a stick, walking frame, wheelchair, electric scooter and adapted vehicles. Some were aided in the home with elevated seats, stair lifts and bath lifts in order to maximise physical mobility when there were health or disability issues. The importance of car ownership and being able to drive was emphasised by several pensioners who saw this as their greatest mobility asset. More men than women were drivers, and often in couple households, the male partner did the driving. Fairfax, one of the more affluent pensioners, who was physically fit and well, equated his car to his independence: '*So, that, that is my independence, out there on four tyres.*' However, the value of car ownership was not confined to affluent men. Attachment to a vehicle cut across gender, age, locality, and health. Isabelle, was an avid driver into her 80s. She lived in a rural community where problems with her legs and spine made travelling distances more difficult. When asked why her car was so important, she responded:

'Made me feel independent. I love my independence. What I'm going to do when my legs finally give out I don't know, I don't worry about it, but I love my independence. I have to have a taxi on occasions and the fact that I have to wait for him to come to take me out infuriates me because, I think, I could be at the wheel of the car and be home by now. It's the independence, it means so much.'

Compared to other modes of transportation, driving a car was viewed as easier, more convenient, and not restricted by other people's timetables. Some people could not walk distances and found it awkward to board a bus, but they could walk to their car and '*take off*'. Particularly in more remote areas where public transport was limited, the car enabled mobility beyond the local shops and

amenities. It brought people '*much further afield*'. If they did not drive themselves, many pensioners knew a family member, friend or neighbour who could drive them. In the rural area, one key informant reported that it was quite common for pensioners to rely upon one driver to run errands for a number of older people, and it was not uncommon for people to be driving into their 80s and 90s because there was no other means for them to get around.

The more affluent pensioners with fewer health problems tended to have more mobility options. Some were running two cars, while many lower income pensioners were entirely reliant on public transport. For some public transport users, bus passes and tokens were praised as a '*godsend*'. Those who received (mobility) disability benefits, reported using taxis, community transport or motability vehicles, although cost and availability issues were attached to these. Whilst public transport could be integral to some pensioners' daily lives, particularly in urban areas, there were some crucial disadvantages (see Chapter 5).

3.5 Health

Health was viewed as inextricably linked to quality of life and, by extension, impacted heavily upon older people's feelings about independence. Pensioners representing a cross-section of sociodemographic characteristics spontaneously mentioned the importance of maintaining their health in order to preserve their independence. Pensioners drew on the impact of their own past experience of poor health (or on observations of someone else's experience) to relay the impact of poor health on their current lifestyles and those pensioners with a limiting illness reflected on changes to their circumstances before and after the onset of illness. Loss of '*good health*' was often equated with '*losing independence*' or taking away an accustomed and valued lifestyle. For example, Erwin, a man in his late 80s, had had to reconsider his self-definition as independent following a period of hospitalisation which reduced his capacity to run the household and look after his disabled wife single-handedly.

'Well it has taught me that one cannot be one hundred per cent independent. That there are times when you've got to forego independence in return for help.'

Reflecting the importance of maintaining control over particular (sometimes symbolic) aspects of their daily routine, a number of interviewees voiced their concerns about conditions which caused mental degeneration, such as Alzheimer's disease and Parkinson's syndrome, that would ultimately threaten this crucial component of independence.

Interestingly definitions of health and ill-health, and the impact of these upon independence, were highly relative. Pensioners with fewer health problems viewed the onset of ill-health as a threat to their independence, subscribing to the attitude, '*you can't be in poor health and be independent*'. Jeanette was typical when she commented:

'Well I think if you didn't have physical health, and you were sort of not able to do things you want to do, I should think you'd get very frustrated. I would, anyhow.'

However, those experiencing a limiting health condition did not necessarily view themselves as being '*not independent*'. While relatively healthy pensioners tended to regard deteriorating health as a threat to their independence, some less healthy pensioners, perhaps with the knowledge of experience and adaptation, still viewed themselves as independent. This was evidenced in the subjective ratings reported by tranche one interviewees, indicating their level of independence on a scale from one to ten (where one was not independent and ten was very independent). On the whole, ratings by more non disabled pensioners balanced towards the '*very independent*' end of the scale,

but the opposite was not the case for pensioners with a health condition. Clearly an individual's concept of independence could be quite unrelated to objective determinants, like ill-health and disability benefits. For example, Miriam, who was in her 90s, rated her independence a 'ten', despite severe arthritis, deafness and age related deterioration. She equated her independence with being able to remain in her own home (she received Attendance Allowance) and being able to pay someone to take care of the house and grounds. Another interviewee, Alan, suffered from osteoarthritis, asthma, angina, deafness and difficulty walking, but rated his independence '*between seven and nine*'. He received Attendance Allowance, and he and his wife received regular help from a gardener and housekeeper. This, and the use of a car, contributed to his feelings of independence. Again, remaining self-sufficient or autonomous was paramount in creating a feeling of independence. What was important for Alan was being able to make decisions about what support he needed, and to have options:

'And that's how you go through life really. That's how I've always adapted, that's why I've lasted so long I suppose. I've adopted the attitude, a problem comes up: can I do anything about it? Yes. What are my options? Select an option. Do it. No, I can't. Write it off. Forget it. Eliminate it from your mind completely, don't worry about it.'

Still, poor health, lacking energy and consequently having to resort to help from others, introduces a dissonance between the human will and the means for getting things done. Poor health often meant needing others to do what older people had done themselves in the past, and consistent with people's need to feel self-sufficient and self-reliant, many did not want to burden anyone, to rely or depend on other people, '*I hate the idea of being a nuisance to people*'. Sanjay, a widower in his 70s who lived alone, stated this sentiment clearly. He had lived with Parkinson's disease for five years but was determined to stay on his own and in his own house for as long as possible. His closest family lived outside the area and he did not want to involve his children with his care in the immediate future:

'No, nobody helps me. I do everything for myself. I like to be that way, I don't want help. I know that they try, but at the moment I can do for myself and cope... Maybe if it gets worse I will need help, but at the moment I am ok. I like to be by myself and do for myself. Sometimes the people say that I should move into my children's home, but I do not want to be a burden to them or anyone else. I like also my freedom in the house.'

For some, however, their ill health had had a strongly negative effect on their sense of independence and, through that, their self-worth. Amisha expressed her unhappiness about her situation. She had severe epilepsy with complications following a stroke. She and her husband lived with their son's family, and their daughter-in-law attended to her care needs. She rated herself a 'two' on the independence scale, and explained:

'I don't do anything. I have to rest everyday. My daughter-in-law does everything. She does the cooking and cleaning, all the work. I cannot get up or do anything... I am not independent, I have the help for everything. I am very dependent. But my family are ok, they do not mind.'

The privacy issue that came up in relation to older people remaining in their own homes, was also talked about by a number of informants in terms of the importance of maintaining privacy in personal hygiene tasks, such as cleansing, dressing and toilet (Twigg, 1997). These encompassed the last aspect of independence that many people could tolerate losing and some older people who suffered from a limiting disability or ill-health, and who lived alone or in supported living, spoke of being independent because they had managed to maintain this element of their privacy. Two severely disabled women, one in residential accommodation and another who lived with her daughter who provided all her care needs, were determined to provide as much of their own personal care as they

could manage in order to maintain their privacy and dignity, and through this their sense of independence.

The issue of severe ill-health and disability also raises the issue of caring and the impact this has on perceptions of independence. In terms of the caring that goes on between couples living in their own homes, deteriorating health can influence the dynamics of couples' feelings about independence. Interestingly, the group who were most open about defining themselves as dependent or admitting that their independence had been compromised in some way, were those who were carers and taking on the bulk of care for an incapacitated partner, which could be particularly problematic when their own health was deteriorating. They acknowledged their lack of freedom in a way that the 'cared for' often did not. Elliot, who had given up work to care for his wife when a virus damaged her central nervous system, explained:

'I mean I suppose in a way because I wasn't able to go out at all. Not that I used to... I mean we used to do everything together anyway, mostly you know. So I suppose where it would have affected a lot of men's independence, it didn't affect mine to that extent really I suppose.'

Feelings about providing care, however, were complex, and tended to be counterbalanced by the strong sense of responsibility that carers felt for their spouse (Parker, 1992), and their tendency to subjugate their own needs to maximise their partner's quality of life. This was intertwined with the potential emotional pain of separation for partners whose sense of independence had become interdependent over the years. For example, Erwin spoke of his worry that his wife had been taken into residential care when he was taken to hospital for emergency treatment, and he discharged himself earlier than he might otherwise have done in order to ensure that the two of them could be reunited in the family home. Discussions on the restrictions of caring were often extremely emotional as husbands and wives reflected on the changes in their relationship. It was always emphasised that interviewers were happy to terminate the interviews in such circumstances; however, most often carers insisted that these were issues which they wanted to discuss and share with a third party, rarely having the chance to do so. Indeed, there was scant evidence of carers having access to respite care and support groups. This kind of insistence upon being the person to provide care in the face of physical limitations, is interlinked with the recognition that autonomy becomes increasingly central to independence when health is poor. Carers tended to emphasise their unique position of knowing how their partner liked their routine to be arranged, and that they wanted to take on their work in order to promote their partner's independence.

3.6 Income and assets

Independence with respect to household finances was one of the key themes explored in the study. Household income is commonly accepted as a proxy for living standards (DWP, 2003). It would be reasonable to assume, therefore, that if independence is related in part to quality of life – as highlighted in the previous sections – then level of income can colour views on independence in later life. Furthermore, changes in level of income upon retirement from paid work could also impose on feelings about independence. The pensioners interviewed represented the range of income anticipated among the pensioner population.⁵

⁵ Pensioners were asked income information in the screening questionnaire, which was further probed in the interviews, which enabled them to be classified as 'high', 'moderate' or 'low-income' (see appendix for more detail).

Although income may appear central to issues of independence, only a few interviewees spontaneously associated having sufficient finances with being independent. However, they did tend to be those on the lowest incomes, who experienced most restrictions on the range of options available to them.

For some of those on a low income, having to claim benefits was at odds with their values and self-concept, and could damage feelings of independence, as Andrew explained:

'That's difficult because we feel that we're independent now and yet we're not independent because the state is, independence to me means being able to look everybody in the eye and being satisfied that I've provided for my family and myself... We're not truly independent when the state is, our whole life is totally dependent on the state, so that extent you could say not independent. On the other hand we're independent to spend the money that the state gives us and we've got a house to live in on our own. It's awfully difficult.'

Those on the higher levels of income were well able to afford holidays, trips out, and often ran cars. The level of income they enjoyed made it possible for them to prioritise activities which enhanced their sense of autonomy in later life. They were also confident of being able to replace major household appliances without having to borrow money or rely on help from family members. Home ownership was also important, since ownership of this asset made it possible for people to move to another area, or to free up capital, and helped people feel more secure in planning ahead for their future. At the same time, for home owners on moderate income, the responsibility for repairs could create additional anxieties about finances, as Harry explained:

'I have to be careful because I just can't go spending willy nilly sort of thing, you know, and I've got to watch it as well with the house, because it's my own house and if there's any repairs then, oh God, I'm in trouble, I've got to watch it you know.'

Ivy, another pensioner with a moderate income, had a precarious sense of financial stability, and the couple had already been forced to dig into their savings in order to meet monthly bills.

A number of older people commented that their normative expectations had changed as they had grown older, or in response to health constraints, and that this could make it easier to cope with managing on a limited income. Sanjay was one of these, saying, *'At my age there is not so much to do, I can afford [it] on the pension'*, and these comments were echoed by Alan:

'Our needs now are much simpler. We don't go abroad for holidays anymore, it's too much hassle at the airport and I can't get about as easily and [wife] can't walk at all at the moment, only upstairs and stagger along... So, you know, as you get older your needs sort of get narrower, you haven't got such a broad spectrum to spend money on.'

For a proportion of those interviewed, coping on a low income was not a new phenomenon, but something that had also characterised earlier phases of their lives and their expectations were shaped by their experiences. Some people had developed strategies for coping and were quite resigned to living on a low income. Ruth, a low-income pensioner with health problems, said of her finances *'we get by without too many worries.'* Others expressed more frustration and felt restricted by the level of income on which they were surviving. Mete said *'You could spend this amount on a dog, if you had a dog'*. Similarly Fraser, who had had to stop work on his wife's death, as they had a young child in the household, commented of his life on MIG:

'Well if you can manage on chips and egg and don't go out, don't put the lights on, don't put the heating on, walk everywhere and buy all second-hand stuff, then you'll just about get through.'

People who had lived on a low income for long periods were used to budgeting tightly and some took pride in their ability to manage. Lynne, who had been widowed for over 20 years, explained that:

'all my life, I've loved to be able to survive on whatever I've got and I always like to know I can make ends meet. I've had to do that all my life, and I think to myself that's an achievement, to make your money do what you want it to do.'

Many interviewees, particularly women, also displayed a considerable degree of resourcefulness and described skills, such as carrying out household repairs, doing their own decorating, preparing meals using cheaper cuts of meat, and making their own clothes, which helped them to manage on a limited income, and reinforced their feelings of self-sufficiency.

However, there are some ways in which money is essential to help people maintain their independence. For those with savings, although a number expressed concern at the rate at which these were declining, this meant that they were able to spend money according to their own priorities, reflecting their own concepts of autonomy, rather than having to rely on being assessed as eligible to receive a service. For instance, Elliot had been able to purchase an electric wheelchair which meant he could go out unaided:

'I've got arthritis and I can't use a manual one. They'd let me have an ordinary chair, not a manual one, but one for somebody to push me. But they won't let me have a powered chair, they say I'm not bad enough and yet I've got to get around in it.'

Few of those on limited incomes or who were in receipt of MIG were able to afford cars, holidays, or to pay for people to do odd jobs in the house and garden, which the previous sections revealed to be crucial ways in which people felt able to maintain their independence. Many of those on low incomes expressed frustration at not being able to implement simple changes to their house to improve their daily routines and help them with mobility problems. For example, although throughout the interview Yvonne stressed that she '*managed fine*' through a strategy of careful budgeting, it was clear that she could not afford to fit the downstairs toilet that she needed, since she was finding the stairs in her house more and more difficult to manage. She spoke of the likelihood that she would spend her '*funeral money*' on this, and it seemed likely that her supportive extended family might supplement this. For this group, tapping into savings in their retirement to enable them in these kinds of ways, was a limited or non-existent option, as very few had earned enough to save money. Ida explained that she had no savings because, '*My husband never earned a lot, so we couldn't really put anything by, you know.*'

Older people were more likely to describe their independence as compromised when they experienced a sudden decrease in income. This situation was harder to adjust to than when a decrease had occurred more gradually. Several of those who found it particularly hard to manage had experienced a major life transition, which had led directly to a drop in income. Andrew and his wife had fled Zimbabwe, where they had been very wealthy, with nothing. While they described themselves as '*grateful*' to be safe and able to claim benefits, they were finding it difficult to adjust to a level of income which made it hard to afford even simple activities, such as joining a local choir or going to the hairdresser. This undermined Andrew's concept of himself as family provider:

'I'm still unhappy in my own mind that all my working life I thought I'd made adequate provision for [name of wife] now I find that at the back end of life when she should be enjoying the fruits of her labour because it's been a partnership, now I've got to say "You can't get your hair done. "'

Although Jennifer had been divorced for a number of years, her expectations were based upon her previous income and lifestyle, and she found MIG restrictive as it did not allow her to participate in the

social activities, such as holidays, that she had formerly enjoyed, saying '*By the time you've paid all your bills and everything, you just sort of exist*'. She also felt uncomfortable about being dependent on MIG, commenting, '*I think it's demeaning, after working hard so long and then through no fault of my own I come down to relying on the state, which you shouldn't have to do*'. Laurie and Meredith, both recently bereaved, had also experienced a large drop in income at the time of their husbands' deaths. Although one was classified as having a high/moderate income and the other a low income, both were struggling to adjust to their changed living standards. Meredith was worried about being able to maintain a car, which was key to her independence and mobility:

'I don't know how much longer it will last, we've had it now fourteen years, and we bought it from new and it's still going but how much longer I don't know because I won't be able to replace it.'

Some had overcome the drop in income that happened on retirement by simply going back to work. Nancy, a widow who owned her home and received the basic single person state pension, returned to work nine months after retiring. She reported having no savings and said she needed the extra cash in order to make ends meet:

'To be quite honest with you, by the time you've paid your gas, your electric, your phone, your food, your water rates, which my water rates are £30 a month, I mean you haven't got hardly anything to live on... I needed the money. Oh, yeah, I mean I think it's absolutely ridiculous what they expect you to live on. Oh and the television licence I have to see to.'

Not everyone reported this kind of drop in income. A small proportion of pensioners had received MIG/tax credit or mobility allowance assessments and found their weekly and monthly earnings had increased. Adeline noticed a considerable improvement in her living standards after her recent MIG claim, and was able to start saving up for a much-needed holiday, mostly because of the additional 'passported' benefits she became entitled to:

'They gave me thirty-six pence a week. Well, people thought that was funny. But that thirty-six pence a week for me, opened up a lot of doors... It meant that I didn't pay rent... I didn't pay council tax. I've had false teeth... And I get help now with my glasses.'

While interviewees did not spontaneously associate increases in their income with an increase in independence, this was implicit in their descriptions of the activities and services which they were able to access as a result. Those claiming disability benefits reported using them to pay for general living expenses, disability related expenditure such as medicines and labour-saving devices, and services such as help in the home and gardening, which enhanced their feelings of control over their lives.

3.7 Conclusions on independence

The chapter has illustrated how autonomy and self-sufficiency intersect in older people's understandings of their independence. These aspects form a dialectical relationship with one another, the balance between which may shift as pensioners' circumstances change. Independence is neither a static nor an abstract concept, but a multi-dimensional, fluid entity, that was understood by individuals in relation to their particular social context. Key aspects of it explored here include self-reliance, personal autonomy, and the importance of the home, mobility, health and income. Those who were still fairly fit and mobile mentioned ill-health and loss of mobility as events that could compromise their independence, while those with limiting health conditions had often come to terms with these constraints, and defined independence in different terms.

Where individuals' or couples' ability to do things by themselves unassisted had been compromised, they could maintain their sense of independence if they still felt some autonomy over how and when that help was received. Independence was interconnected to finding a way through transitions that worked for older people, a theme explored in the following chapter. Those who felt that their independence had been most compromised were those who had least say in the shape of their daily lives and routines. This has policy implications, providing a re-endorsement of the need for flexible services that meet older people's widely varying needs, providing mechanisms for pensioner voices to be heard. The importance of the quality of support is taken up in more detail in Chapter 5.

The relativity of people's understandings of their independence lends an additional dimension to these understandings. There were subtle class, cultural and gender differences in how people understood their dependence or independence and the strategies they implemented to manage their situations. In particular, income in later life informed the choices people were able to make, and the resources they were able to employ to enhance their sense of autonomy.

As people grow older, whilst many regard independence in much the same terms as always, others found the ways they thought about and experienced independence changed. Among those we interviewed, the dominant pattern was that older people associated the same things with independence in later life as they had done throughout the life course, relating it to personal priorities. However, a sizeable proportion of pensioners explained that meanings they attached to independence had changed as they got older, that they both saw things, and acted, differently, in a range of subtle and more obvious ways.

These shifting perspectives on independence were not particularly age-related. However, a distinction was observed between those with long-term health conditions and disabilities, and those with fewer health problems. Whilst non-disabled pensioners were more likely to report there being no difference in what independence meant to them in later life, pensioners with long-term health conditions and disabilities explained that their views and experiences of independence changed as they got older. The effect of these changes ranged from severely restricted lifestyles and constrained personal freedom, to more subtle reprioritisations of day-to-day activities to reflect diminished levels of energy.

A second distinguishing feature regarding changing notions of independence related to household stability. Pensioners whose feelings about independence remained fairly constant were more likely to be married, and, if they lived alone, they tended to have been divorced or widowed some time ago, and thus to have experienced fairly stable household arrangements in later life. By contrast, older people whose understandings of independence had changed as they got older were more likely to live on their own, and particularly, to have been bereaved in the last five years. Thus bereavement had more noticeable recent impacts upon this group in terms of their social networks and expectations about mutual support. Additionally, the group who felt that their concept of independence had changed relatively little as they got older was more markedly female, a finding which may be the consequence of women's traditionally less standardised relationship with the labour market (OECD, 1995; Bottero, 2000), such that retirement has less dramatic impacts upon their experiences.

Again, significant events and changes in the life course, such as bereavement or an acute health condition, had an important impact on older people's sense of self and the way they viewed their independence. These are taken up in the following chapter.

4 Lifestyle transitions and independence

4.1 Introduction

Old age may be associated with periods of great change, which involve adapting to both anticipated and unexpected circumstances. This section outlines commonly encountered transitions in relation to the broad spectrum of pensioner experience, specifically changes associated with the ageing process, retirement, health and the domestic sphere. Taken together, these provide a context to older people's experiences of independence in later life.

The chapter concludes with an analysis of three specific transitions, illustrated by reference to the subgroups of interviewees whose experiences have been informed by their use of particular services (see Chapters 1 and 2 for a full description): people moving into residential care and other forms of supported living; those coping with bereavement who had used a local one-stop bereavement service; and older people who were leaving hospital and returning to their homes with the support of a voluntary sector service. These explorations of change and adaptation provide a context for understanding the differential motivations and needs of pensioners as they negotiate key life transformations.

While to some extent, many of these transitions can be anticipated, it is less true that it is possible to prepare emotionally for the change, and sometimes trauma, which they can bring. In addition, transitions may occur alone, or may be interconnected and/or simultaneous, intensifying pressures upon older people. While the transitions discussed below are commonly associated with old age, their effect upon individuals is varied and mediated by a variety of socioeconomic, demographic and personal factors. This section examines the ways in which transitions influence pensioners' perceptions of independence over time, and may intensify their support needs, which are in turn explored in more detail in Chapter 5.

4.2 The ageing process

The ageing process, which may be linked to changes in health, is an under-recognised aspect of pensioners' experience, not least because this transition may be relatively subtle and indistinguishable in its effects. Ageing encompasses both intrinsic (feeling more tired, having less energy) and extrinsic dimensions (the kinds of attitudes society displays towards older people, perceptions that older

people may receive a poorer quality service and may not be regarded as a priority), which may in turn be assimilated by older people in terms of their normative expectations. Getting older, then, is likely to have a significant influence upon pensioners' physical capabilities and social networks, availability of assets, and the ways in which older people are perceived and treated by broader society.

Dale, a man in his late 70s, explained that he had outlived most of his close friends, and this had qualitatively changed the character of his social networks, an experience which may have repercussions for the expectations placed upon marital relationships and prompt feelings of loneliness at the end of the lifecycle. A number of interviewees also talked about the trauma of multiple bereavement, an experience that is likely to become more common in old age. Charlotte, who was in her 80s, explained how her social circle had been transformed by loss in a very short space of time:

'Since we moved here, we have lost...twelve friends ... close friends. And numerous .. [acquaintances]...In fact I was saying to [husband] the other day, I said "Do you realise, in the last five weeks we've lost nine people we know?"'

The complex relationship between health and ageing is illustrated by Eliza, a woman in her late 70s who suffered from quite severe long-term limiting health conditions, as did her husband. She had enacted several changes in her day-to-day routine which related to coming to terms with ageing and developing practical responses, as this exchange illustrates:

Eliza: *'I really am slower. At one time you could maybe, like you do a lot in a day, or I used to do a lot in a day. What I used to do in a week, well a day, it takes me a week to do that now.'*

Interviewer: *'Is that because of your health?'*

Eliza: *'No, I think it's age. I think it's an age problem. I think up to being seventy I was quite agile, you know, sort of having a day doing the housework say, but now I don't. I have one day upstairs and there's only two bedrooms, and I'm tired out, so I think it's just age really.'*

Often the way people presented themselves in relation to their age cohort was telling. A number of interviewers commented that particular older people had emphasised that they did not regard themselves as elderly, and made efforts not to be associated with stereotypes about older people or particularly to socialise with a similar age group, and appeared to be a good deal younger than their years.

By contrast, the way in which attitudes to ageing affect people was more clearly conceptualised by key informants, service providers who reflected that older people often received a poor deal. For example in area four, a service provider explained some of these discrepancies:

'One of the complaints from older people is about being kind of dumped and ditched when they reach a certain point in their lives and aren't working and visible in the community, and cease to exist or be seen as a functioning active...those sorts of issues come up quite a lot and people think it affects a lot of things, like service provision, for them, the way they're looked at. I hear a lot of suspicion about the Health Service, that you reach a certain age and it's not worth doing things for you any more, and you have to accept this anyway...so people [feel] that they're discriminated against and not valued when they kind of reach retirement age or they're approaching it.'

The ageing process, however, also provided a context for the range of transitions which pensioners went through during this period of their lives, which to some extent enabled them to normalise

transformations which might otherwise be viewed as traumatic and untenable, such as losing a partner or leaving a much-loved job.

4.3 Retirement transitions

A critical transition, and one which commonly has distinguishable boundaries and relatively standardised expectations, being associated with State Pension age (currently 60 for women and 65 for men in the UK), is retirement, the point at which people leave paid work. However, retirement is not a single event, but a process, and the pathways into retirement are diverse and often complicated. Retirement ages across Europe have become increasingly destandardised (Kohli *et al.*, 1991). It has been suggested that because retirement is no longer a predictable life event that occurs at a definite age, it has lost much of its capacity to provide a recognised social transition (Taramarcaz, 1998); instead individuals are increasingly constructing individualised roles and identities to make sense of these changes.

Retirement, of course, can mean different things for men and women, particularly for this cohort, whose labour market expectations have been gendered in critical ways, including differential State Pension ages (Slevin and Wingrove, 1995). Indeed, recent research by the authors (Barnes and Parry, 2004) has suggested that the adoption of particular gendered roles and identities ranks alongside financial resources and social capital in terms of achieving satisfying retirement transitions. Leaving paid work can be a welcomed or a dreaded change, but more commonly retirees' emotions are complicated. Leaving employment and negotiating a lifestyle outside this kind of institutional framework may provide a new set of opportunities or restrictions, and can coincide with other changes, such as health transitions. Accompanying the practical changes bought on by retirement, this period of life was often also associated with emotional adjustment and re-evaluation of priorities. Eliza, whose retirement had coincided with the onset of her own and her husband's health problems, explained:

'I think retirement brings a lot of these thoughts on, how you're coping and how you're gonna cope.'

One dual transition, exhibited by a number of the more affluent couples interviewed, was to coincide leaving work, with moving to a 'retirement' home or location, which might be more attractive in terms of facilities, closer to social networks, and/or a more desirable environment within which to embark on this period in their lives. For example, Margaret, a widow in her late 70s, explained that she and her husband had moved to area three from the Home Counties because they thought that this area was a pleasant place in which to retire:

'Well my husband rather liked the sea so that's why we came down here really, we looked at various places on the south coast but Eastbourne was full of old people [laughs], so we ended up here.'

However, older people's social networks could also be constrained by this type of retirement move in later life, particularly if they moved to an area with which they had no prior connections and left behind a more established social network, or if they had moved to be nearer family who might themselves then move.

A number of the pensioners interviewed had left paid employment sooner than anticipated because of the onset or intensification of health problems or redundancy, and they had thus embarked on the retirement transition at a relatively young age. This often had important effects upon their financial security in later life, restricting their ability to accumulate pension entitlements, and limiting the

choices they could make in retirement. Earlier than anticipated exits from paid work were also sometimes prompted by declines in partners' health, and the necessity to take on caring duties.

For example, Jack had been a skilled craftsman until the progressive arthritis in his hands had forced him to stop working. In addition to the financial hardship which unanticipated early retirement brought, thirty years later, he continued to find his situation frustrating, as the following exchange illustrates:

Interviewer: *'How did you feel about it, having to retire?'*

Jack: *'Well, [starts to shout] I'm not. I don't, for the simple reason that I am doing nothing, just some messing around the house.'*

Similarly, retirement was problematic for Horace, a twice-divorced man in his 60s, who had finally come to regard himself as retired after reaching State Pension age, following ten years' of unemployment: *'Believe me there's nothing worse than being sat and looking at four walls.'*

Partners' retirement also had an impact upon pensioners' experiences, and the kind of independence they were able to negotiate in later life, as couples' plans tended to be intertwined. A partner's retirement could therefore have practical and emotional consequences. For example, Gwyneth, a woman in her 60s who had left work early due to health complications, described how her husband's redundancy threw the household into financial crisis:

'my husband was made redundant so it was very difficult for a bit, well it still is now, but we manage, but that's it isn't it, you have to, don't you? You've got no choice.'

People who had been strongly occupationally identified, mainly, but not exclusively men, often talked about the difficulty of leaving paid work in terms of their social networks being curtailed. Dale, a skilled craftsman who had worked for the same employer his whole life, explained, *'it was a big shock from going to work, then having to stay home.'*

Dorothy, a divorced woman who had worked as a PA all her life, explained:

'Yes I did miss it, I missed it enormously, I missed the status that it gave me, and I missed the class of people that I mixed with professionally who were educated, sophisticated people, and yes I missed the company of nice people.'

As previous studies (Barnes *et al.*, 2002; Kim and Feldman, 2000) have shown, the retirement transition was undoubtedly the smoothest for people who were able to negotiate a gradual withdrawal from work, although this was associated with particular forms of employment. Emily, who had worked as a secretary for her husband, and who was able to reduce her hours around State Pension age, explained:

'That wasn't such a bad thing, was it? I'm not sure I remember the difference, you know, 'being retired'.'

As pensioners got older, they tended to talk less about how retirement had affected their lives; relatively few worked after State Pension age, and their normative expectations increasingly coincided with their circumstances.

4.4 Health transitions

Perhaps the most visible, and to some extent predictable, transition that pensioners will confront is in terms of changes in health; that is, that their health will become less robust, and that acute and long-term ill-health and disability may set in or intensify. In part, this is linked to the ageing process, although deteriorations in health rarely correspond neatly with pensionable age. A sizeable proportion of those interviewed had some sort of long-term health problem, although not all of these were entitled to disability benefits.⁶ These were broad-ranging, but included: conditions typically associated with old age, such as diabetes, heart disease, cataracts and arthritis; longer-term conditions and disabilities, such as deafness, epilepsy and learning difficulties; mental illness, such as hypertension and depression; and acute conditions and degenerative disorders, including cancer, strokes, osteoporosis and diseases of the central nervous system.

Health transitions can be experienced in terms of an extended and gradual process, or at the opposite extreme, as an unexpected and acute decline in health, and medical conditions may occur singly or in combination with others. These changes are characterised by a range of trajectories, frequently interlinked with partners' experiences and health, and which may incorporate improvements and recovery as well as decline and restriction. Health transitions are likely to involve contact with a range of services, among them doctors, hospitals, social services and private carers, or may be dealt with more individually and informally, or using some combination of these, depending on a variety of factors (see Chapter 5).

Pensioners with more acute medical conditions, characterised by a sudden onset, tended to adopt a narrative which identified a defining moment when they had realised that they could no longer rely on their health, a realisation which could be particularly upsetting or disturbing. For example, Noreen's cancer diagnosis had initially been devastating to her self-concept, but she had since moved to frame this experience in more progressive terms, and talked about re-evaluating life and developing a heightened appreciation for the here and now:

'I cried and cried and cried then... I cried when I first found out I'd got cancer, but... I've got to thinking to myself, right girl, get on with it, you've got to get on with it, you know, this is life and you've only got... you might have a short space of time, get on with it. Make life as you can.'

By contrast, Frank was interviewed at a time when he was in the middle of a health crisis. He was as yet undiagnosed, and was suffering from episodes when his thinking became severely compromised, an experience he self-evidently found extremely frightening. The unpredictability of his situation was reflected in his narrative, which veered from lucid to confused, and it was clear that his formerly relatively stable status of living at home by himself, was under threat. He had recently gone to stay in a care home for a week after one attack, and it seemed unclear whether this would need to happen again in the future:

'Up to then I was quite with myself, you know. I was in good health. But one day something clicked one night, and I wasn't... I couldn't remember when I woke up. I couldn't talk. I don't know how I'm talking I couldn't understand myself, I couldn't understand what I were talking about. And my daughter, my daughter took over and she, she does the thingy now. I don't know...'

⁶ This was partly an issue of the eligibility criteria associated with disability benefits, in particular qualifying periods before disability benefits can be claimed, and age limits for claiming DLA mobility component.

These kind of acute health crises often required hospitalisation, and consequently prompted or overlapped with a more specialised transition, that of leaving hospital to return to the home (sometimes interspersed with residence in some form of respite care or supported accommodation), which is explored in more detail in Section 4.6.3.

A particularly common response to a health crisis was to talk in terms of a '*loss of confidence*', and the discussion of these trajectories often formed a sensitive moment in the interview, when it was clear that people had lacked (or might still lack) emotional or practical support. Fergus, a divorced man in his late 60s, elaborated on this experience, in terms of the discovery that he had cancer:

'It was really bad because I have been fine before and for the first time I started to feel very ill and like an invalid. I felt very lonely and isolated. I think for the first time I felt that I was alone and sick. It's a horrible feeling to have something like that and then not know if you are going to live or die.'

A critical factor in pensioners' responses to health crises was the time that had elapsed since the events which marked out the start of their health transitions (although these could also be more gradual and less easy to delineate). Pensioners adopted a range of techniques to 'cope' with declining health, to some extent informed by their medical conditions. For example, Joy, a woman in her 80s who had suffered from arthritis and a crumbling spine for over 30 years, appeared to normalise her almost constant pain as something which was to be expected at her age. She painted a relatively positive picture of her health that was in tension with the objective reality of her situation. For a significant group of pensioners, relatively early health crises had prompted their retirement, occasionally some years before they had intended leaving work, illustrating one way in which transitions commonly coincide. Interestingly, discussion of health matters tended to be a less emotionally sensitive topic for these people, presumably because they had had longer to come to terms with limiting health conditions, and longer to develop adaptive strategies.

Changes in partners' health usually heralded something of a transition for both members of a couple, although this varied in intensity. These ranged from a demand to provide care and the accompanying change in personal priorities which this necessitated, to restrictions upon the kind of lifestyle that couples had previously enjoyed. For example, Eliza explained how over the course of two decades her husband's Parkinson's disease had an increasingly limiting effect on the couple:

'We used to go away a lot and it first showed up when we were in Greece. He fell backwards for no reason whatsoever in the bedroom and knocked himself out, and from there he just seemed to go downhill, and of course with Parkinson's it takes a lot of diagnosis, so I packed in work to keep us until, and I never went back.'

For pensioners who relied heavily upon their partners for their care, even small changes in their spouses' health could have significant and sometimes dramatic impacts upon their own circumstances, possibly propelling them into supported forms of accommodation.

Notably, most of the pensioners who described health transitions were those already claiming disability benefits (exceptions to this are explored in Chapter 6). While some of the others had experienced health crises, these were more treatable in the short-term, or else they were at the start of health transitions. One common response to anticipated or actual health transitions was to rethink housing arrangements to meet changing physical needs.

4.5 Domestic transitions

Changes at the household level, whether in terms of moving to more desirable or suitable forms of housing, such as retirement homes or other forms of supported accommodation, or changes in household structures, in terms of bereavement, relationship breakdown, or moving to live closer to or with extended family, are all transitions which may characterise older age and these can involve both negative and positive transformations. Downsizing, or moving to a smaller house, could reflect smaller households in later life, and there was also evidence of this kind of strategy being used to release equity. For example, following Noreen's husband's redundancy in his 50s and their recognition that he was unlikely to find alternative work, they decided to pursue a domestic move in order to protect their financial security in later life:

'So we decided then to sell the big property that we'd got, make some money out of it, and buy this and not have a mortgage round us neck, because at the time I think, mortgage rate were about twelve percent. And so we decided to clear the mortgage off, buy this and then we'd have a bit of cash in the bank to retire. But, funds were getting very low because he'd got no job.'

A number of people in later life also returned to an area where they had lived earlier, where they felt safe and had some established networks, and this seemed to be particularly the case with area two.

People who had left their longer-standing family homes and moved into specialised residential care's feelings about independence are explored in Section 4.6.1. Domestic transitions in later life, of course, were not always as dramatic as a movement into supported accommodation, and sometimes simply involved adapting current housing using various mobility aids. Particularly for couples, moving to more convenient housing, such as a bungalow, or housing in a desirable or well-serviced area, was a suitable alternative in terms of promoting a more manageable lifestyle. Income, as well as assets, could affect the ease with which such transitions were effected.

However, domestic transitions were not necessarily coterminous for couples, and some of those interviewed had remained in the family home while their partner moved into residential care, or alternatively adopted such arrangements as a short-term solution to accommodate intensified care needs following hospital treatment. Emily, who had latterly been unhappy in her marriage, explained how her husband's movement into residential care had actually provided a release for her in both a practical and an emotional sense:

'Because before he wanted to know where I was going every time I went out. I went out with friends, I went everywhere [in the interim period after her husband moved out but before her own health took a downturn].'

Interestingly, Emily's husband was much older than her, and this kind of phenomenon, or the assumption of a care giving relationship, might be expected to be more common in partnerships with large age differentials. Conversely, separation could also be painful for couples and was anticipated with some dread (see Section 3.5).

The effect that bereavement, particularly but not exclusively in terms of older people's partners, has upon later life (see Section 4.6.2) cuts across socioeconomic boundaries, in that one member of a couple can usually expect to outlive the other, and thus to experience this period of intensive transition. Linked to health, bereavement had a range of short and long-term effects upon widows and widowers, depending on the extent to which partners had died suddenly or following an extended period of illness. The extended emotional process of grief has been much researched by both sociologists and practitioners (Hockey *et al.*, 2001; Currer, 2001), and likewise the practical

implications of bereavement may extend over a prolonged period and resonate long after the initial shock of a loved one's death.

Even more so than health, bereavement transitions offered an identifiable 'beginning' – the moment when a loved one died, although the emotional preparation for this journey often began sooner, particularly if a partner had been diagnosed with a terminal illness and/or if ill-health had been protracted. The process of bereavement was also clearly shaped by the quality and character of couples' relationships. For example, the loss of a loved one, after an extended and painful illness, may in some senses provide their carer and partner with an enhanced sense of independence. Most commonly, however, older people talked about bereavement in terms of emotional devastation and the necessity to reassess expectations and practices that had been based upon a shared assumption of interdependency. Eleanor, whose husband had died six years' ago, explained, '*he was my rock, and I depended on him.*' Pensioners frequently emphasised the length of their marriages, illustrating that the majority of their adult life had been spent as a couple, and that this was not a transition that they had given any thought or emotional preparation to. Particularly if they had been bereaved at a relatively young age, bereavement contradicted people's normative expectations about shared retirements. Iris described the shock of the realisation that she could no longer rely upon her lifelong taken-for-granted assumptions about the couple's life together, and her process of coming to terms with this:

'I lived and worked with my husband for forty years, worked together. And then I was without, the panic and the shock at the thought of being alone was tremendously scary... It took me one year to cope, I went just a bit mental, erm, we lived up in Scotland... in a very remote kind of place.'

Domestic transitions were sometimes also prompted by relationship breakdown, and divorce settlements and the division of assets, provided the material impetus to set up a different home. On an emotional level, divorce could prompt feelings of abandonment, loneliness and a loss of trust in others, sensations that were often quite long-lasting, or conversely, feelings of relief and freedom to escape from an unhappy marriage. Notably, amongst our sample, divorce had some quite gendered effects, in that while it tended to push women into greater poverty in later life, men were more likely to see their social networks curtailed as a result, and in particular to lose touch with their children. The mixed effect of divorce upon her transitions in later life are illustrated by Jennifer, who used her divorce settlement to purchase her own home, and who felt both that she had become more independent as a consequence, but also poorer financially and in terms of emotional contact:

'I used to rely on, well my ex-husband I should say, he was a man who could do everything and I relied on him, now I have to do it all myself... when I married, my husband was coming up to sixty, had a fantastic job, going to have a lovely retirement, and then it was just all taken away from me through no fault of mine... I'm afraid I can't take things for granted now, I've just got to get up each day and take each day as it comes.'

Notably, most of the divorcees we interviewed had been divorced for some time, and consequently had had time to develop coping strategies. The distance from critical transitions, such as divorce and bereavement, had an important influence upon interviewees' perceptions of independence, with those furthest removed from these transitions more likely to regard themselves as single sustainable households.

These domestic transitions are likely to influence the density and quality of social networks in important ways.

4.6 Transition case studies

Beyond our broader fieldwork, which looked at older people's experiences of independence in later life in terms of the kinds of service use which supported this, we conducted a subset of interviews with three distinctive groups of pensioners who used specialised services to support their experiences of moving to residential care, coping with bereavement, or leaving hospital, although these transitions themselves also overlapped. These are presented here as case studies of how transitions affect older people's independence. These case studies provide a lead into the consideration of pensioners' support needs presented in Chapter 5, by reflecting upon very specialised sets of help needs. Necessarily, particular attention is devoted to specialised residential care, since this offers a holistic set of support services supporting a long-term lifestyle. By contrast, the bereavement centre and home-from-hospital service, focus on providing support at the beginning of particular transitions, with the intention that this help will promote pensioners' subsequent independence in their own homes.

4.6.1 Older people in specialised residential care

Discussions about moving into supported forms of accommodation were often highly emotive, and a significant number of the pensioners we interviewed gave the impression that they would guard against moving out of their homes for as long as possible. Adeline insisted, '*I would never go in a home*', and Joy explained, '*I want my independence, I don't want to go in a home and be treated like a cabbage.*' However, supported living was not always viewed so negatively, indeed some pensioners regarded it as a move that would actively promote their independence in a way that remaining in a self-sufficient individual home would not. The people who felt like this were not necessarily, as one might expect, those with more severe health problems, but included younger and more fit and active pensioners. Several older people were in the process of contemplating or organising such a move at the time when they were interviewed. Eleanor, a woman in her late 80s who lived alone, had manageable health problems, and was in the process of moving to a sheltered housing complex, an environment in which she felt more secure, since it was more geared up towards supporting her through any future downturns in her mobility. One attractive element of supported living accommodation was felt to be the social environment, which could counter the constriction of social networks following bereavement, limited mobility and general ageing. Esther, a widow in her early 70s, who appeared to be giving renewed thought to her living arrangements following a recent hospital stay, explained how sheltered housing offered her a compromise option, reflecting the health transition which she felt she was likely to experience:

'Well that's why I've got my name down for a warden controlled flat, and they'll be people my own age there, so it will be all right.'

As a subset of the fieldwork, nine interviews were conducted with pensioners living in specialised residential care. These interviewees lived mainly in area one, which was undergoing a shift in character from traditional residential to extra-care housing, a trend that was reflected in several of the case study areas. Five of these pensioners lived in traditional residential homes, and ranged in age from 69 to 92, while four resided in a new style home and were aged from 75 to 87. Five men and four women were interviewed, including one couple. Two of the interviews took place in tranche one, and the remainder were conducted during tranche two, when the decision was taken to focus on area one because of an interest in evolving innovations in these kinds of specialised residential care. Most interviewees were widows or widowers, and one was separated from his wife.

This section explores the reasons underpinning this group's life course transitions into specialised residential care, and traces the contours of independence of those living in a residential care setting. In so doing, it explores their experiences and perceptions of what it is like to live in residential care,

drawing out similarities and differences between pensioners in traditional and new style residential homes.

Life style transitions: the decision to move into 'a home'

Poor health was a critical factor in the decision to move into specialised residential care, for both those in traditional and new style arrangements. Several interviewees' deteriorating health had interacted with a range of other factors to trigger a move. These factors included bereavement, separation, financial considerations, loss of informal carer support, and the desire to be nearer family and friends.

For most of the pensioners interviewed, the encouragement and support of a family member, or the intervention of a statutory organisation was a critical factor in making this transition. Marion's health problems included severe arthritis and incontinence. While her husband was alive, they had been finding it increasingly difficult to manage in the council house where they had lived for 50 years; together they had explored the possibility of moving into a new style complex. An attraction of this complex was that it offered self-contained bungalows for couples, as well as flats for people living on their own. After her husband's death, Marion, with a lot of help and encouragement from her daughter, felt that it was even more important that she moved into extra-care housing. She had relied heavily on her husband for support and was not sure that she would have moved into the home if he had not passed away:

'I wouldn't have had to come in here if he'd still been alive. He did lots of things, he was able, he was two years older than me, but I mean he did everything, you know, I wanted doing or any shopping doing, he'd got a car and he was running us about. Oh, I was in such a terrible state. And I was in the flat, which was very old. We'd lived there thirty-two years and it was built for, I think it was built for tall people because everything was high up!'

Anthony moved into a traditional home after the onset of ill-health, which had triggered his separation from his wife. His step-daughter was the driving force behind this move. Lillian and her daughter jointly made the decision for her to move into a home, when her daughter was no longer able to help with household tasks on a daily basis, although it seemed likely that the availability of better services might have enabled her to stay in her home. Other pensioners described how social services had intervened in terms of an assessment that they could no longer cope in their own homes. Helena had had carers coming in to do her cleaning, but had reached a point where this level of support no longer met her needs. While she was happy to stay in her own home, she was in agreement with social services that she could not manage, and after a short-term trial stay in a home she became a permanent resident.

Most people moved to a home in their local area, and the proximity of family could be critical in moderating anxieties about a potential loss of independence. Marion did not worry about losing her independence when she moved to a residential home, although she did think about it. The home was local and her family was very reassuring about her new situation:

'cause I knew from the family, when we knew what was happening, they all came, they were all surging forward and that, "Now just don't worry about a thing, don't think about anything, there's nothing you've got, if there's anything you want, or you want doing, or you want to see somebody, you've got the phone there, all you've got to do is phone us, we'll be over." What more could I ask? I mean, you've got nothing to worry about have you really? I didn't, I didn't worry about it. I thought about it, I thought about it before I came in, I thought, 'Oh, what am I going to do? How am I going to manage? What's going to happen?' I did, I thought seriously about it.'

Most of these pensioners had viewed few, if any, homes before moving into the residential care setting. An exception was Elizabeth, who was relatively new to the area. She had moved to live closer to her son, and then came to the area when she moved into the traditional residential home. Elizabeth had seen many homes before making this move. She had visited her sister, brother-in-law and friends in different homes and thought '*I'm never going in one of those*', and that they were '*horrible*'. However, her views changed in later years. She had found it increasingly difficult to cope with the practicalities of living on her own, and her living arrangements were proving expensive. A friend gave her a leaflet about a traditional residential home, which she had visited and liked enough to decide to move in. After some hesitation thinking about the upheaval which the move would involve, and concerns about whether she could afford to live there, with encouragement from her friends and relations, she sold many of her possessions and moved in, feeling it was the best move for her condition. Elizabeth had been in the home for eight years when interviewed, and, following a stroke eighteen months ago, her health had further deteriorated.

Housing arrangements and independence: having your own space

In the new style home, there were self-contained flats and bungalows for couples, located within an extra-care housing complex. As well as having their own personal space, residents had access to communal dining and lounge areas, and to a range of other in-home facilities. Those in the traditional homes also had access to communal and dining and washing areas, but the range of additional in-home facilities was more limited, and personal space confined to a bedroom with a wash basin. Neither of the traditional homes featured in this report made provision for couples to live together, which tends to be the case more generally in residential care settings.

Whether large or small, personal space is important to people, and its configuration can influence the ways in which they live their lives, interacting with their personality and personal circumstances. Marion, who lived in a new style home, and Elizabeth, who lived in a traditional one, illustrate this. Marion's flat was self-contained with her own front door. On first viewing, she had not been impressed with its décor, but she had brought her furniture with her and decorated it to her own taste. Her flat included a furnished kitchen with washing-machine, bathroom, lounge and bedroom. She also had access to the communal eating and leisure areas of the extra-care housing complex. It was very important to Marion that she could lock her front door and maintain her own space, keeping control over who entered it. Her daughters visited regularly, her sister occasionally, and from time to time she entertained her friends at the home. Emphasising her control over her space, Marion was adamant that living in this kind of residential care did not affect her independence in any way:

'I mean you're in, this is your own place, you can lock the door and nobody need come in. You can be quiet, you can make a noise, you can have your telly, you can do any immortal thing you like. You can have the whole building in if you want to!'

Elizabeth also had her own room in her more traditional residential home, and access to communal dining and lounge areas. She valued choice over whether she remained alone or mixed with other people, and felt it was important to have control over who entered her room. She made a rule of not inviting anyone into her room, fearing that if she started doing this, people would come and go as they pleased. Consequently she met and talked to other people in the lounge or dining room areas of the home.

'Because I can be private in my room, I can walk to any other room I wish and have a chat to anybody. I tend not to ask people in here because I feel that if somebody comes in and they just come in any old time, that leaves me rather, well, susceptible to people coming in when I don't really want any visitors, so I never invite anyone here, if I want to talk I go wherever they are, sitting in the lounge or at the dinner table.'

The importance of life continuity

Several interviewees, in both traditional and new style homes emphasised the importance of maintaining some continuity with the lives they had led before the transition in their living arrangements. In spite of recognising that there were things that they could no longer do, being able to do things for themselves was integrally linked to this sense of life course continuity and, implicitly, these activities helped shape their identity and sense of independence.

Alan, who lived in a traditional home, felt that he had a nice room and people to talk to. He had been feeling isolated in his own home and had not been able to keep it as clean as he wanted; in these respects, moving into residential care had been a positive change. Being able to live in the location of his choice, in his longstanding local community, was very important to him and he described the home as being '*handy for visitors*'. His concerns about losing independence centred on the likelihood of being obliged to leave the home and his community if his care needs changed, a relatively common scenario in the UK (Reed *et al.*, 2003).

Elizabeth made it clear that if there was anything that she could change it would be having her good health back, and, thus, being able to stay in her own home. However, she emphasised that in her current circumstances a home was the best option for her, and provided an environment that enabled her to feel independent:

'There are certain things I can't do of course but if I can do something then I'm allowed to do it if you understand what I mean. I've always been very independent and I do prefer to keep it that way if I can and I'm allowed to do that here.'

Caroline emphasised that living in a new style home did not compromise her independence. She expressed this in terms of her two friends and niece regularly visiting her, and her practice of undertaking as many household tasks as possible herself, as she had done in her own home. It was through the things that she was no longer able to do that her view of independence had changed. She missed having a car and taking holidays. Marion's sense of lifecourse continuity was linked to her self-contained living arrangements and being able to maintain links with her family.

Autonomy and self-reliance in everyday life

Neither those living in new style nor traditional homes reported any formal or informal rules that made them feel that they had restrictions on their movements in and out of the home, times at which they went to bed, when they received visitors, or pressure to participate in organised activities. Nevertheless, there were tangible differences between the opportunities that people had to be autonomous and self-reliant in the two types of residential care. In the self-contained living arrangements of the new style home, people had facilities to cook for themselves and to do their own laundry should they want and feel able to. They could also have their own telephones. Interviewees confirmed that they were able to exercise choice over these aspects of their everyday lives. Martin's perception of his freedom of discretion in these areas was typical:

'[There are] no restrictions at all. It's like being in your own home almost... Totally independent... I can do what I like.'

Martin emphasised an advantage of this new style home was that help was available if you needed it. For example, if he did not feel up to going out for a pint of milk, a friend or one of the carers would get it for him. This theme of help being there if you were in need of it was a recurring one.

This type of new style housing tries to maximise pensioner choice in their everyday life, including over the degree to which social participation is centred on the home or in the external community, though recognising that higher care needs might constrain choices. Having the ability to do what she wanted

was important to Caroline. She worried about losing her independence, but did not feel that it had been compromised by living in a new style home. Caroline stated that she had complete choice over her daily activities, apart from in terms of her husband's demands on her time.

The exercise of choices about social participation tended to be linked to social network patterns. Marion had a family-centred social network pattern, facilitated by the close proximity of her family to her home. Most of her activities outside of the home involved her daughters and daughter-in-law: visiting her husband's grave, going shopping, and going on outings. Indeed, her family provided the catalyst for her interaction with the local community beyond the home. However, she was also integrated into other networks; she interacted with other residents at the home and was encouraged to do so by her family.

Interviewees who felt that they had lost their independence all came from the traditional home sample. Anthony explicitly said that he felt he had lost his independence, and expressed particular resentment of this in terms of his financial circumstances. Several traditional home interviewees did not venture outside the home. Health was sometimes a factor in this, but not always. Helena said that she did not have many visitors or go out of the home, in her words, she '*didn't bother going out*'. She was a widow without children and did not mention any family or friends. Elizabeth was reluctant to leave her residential home because of her poor health and fears about having an accident. While she described herself as a loner, she had been more socially active before her stroke. She participated in fewer group leisure activities these days, since she became tired in the afternoons and found going outside the home overwhelming. Although she maintained contact with her son and daughter, they both lived some distance away. This explained, at least in part, why her social network patterns were centred on the residential home rather than her family.

4.6.2 Older people and bereavement

As discussed in Section 4.5, losing a loved one has a range of effects on the bereaved over a period of time, and may have distinctive effects at different periods in people's lives. For Laurie, a relatively young widow in her early 60s, bereavement marked a period of her life that was distinctive from any that had gone before, since previously her life had been characterised by looking after others – her children, her mother, and latterly her husband. Despite the close relationships she maintained with her daughters, she felt unsettled by the solitude that she now experienced at home:

Daughter: '*She doesn't like the quiet, the quiet in the house at all.*'

Laurie: '*I don't, wherever I've lived it's never been quiet like here, and with the living room at the back here all you're doing is looking at your garden, do you know what I mean?*'

Given women's greater life expectancies and tendency to marry older men, bereavement in later life is a fairly predictable transition for women. In practical terms, the most obvious effect of bereavement was to reconstitute pensioners' household arrangements in terms of single occupancy. Amongst those we interviewed, this was generally anticipated as being the way they would continue to live, although sometimes health limitations prompted them to move in with extended families, or into supported forms of living. Particularly for those who had been bereaved at a relatively young age, repartnering was an option.

Despite the process of grief that pensioners often emphasised, the depth interviews often provided a sense in which pensioners bought into a popular discourse of 'coming to terms' with bereavement, which influenced the responses they gave, but that loss remained ever-present and could never be completely absorbed and accepted.

Bereavement sometimes also pre-empted or coincided with health crises, with depression being a relatively common response. In later life bereavement may have an intensified effect, occurring at a time when other social networks are shrinking, and the emotional loss of losing a loved one may thus be combined with the loneliness of social isolation (Baarsen *et al.*, 1999)

Depending on a bereavement centre

Eight interviews were conducted with users of a bereavement centre in area one. These ranged in age from 64 to 84. Four men and four women were interviewed. Their circumstances covered a range of health conditions and included pensioners with high, moderate and low incomes. Seven of these older people had been widowed in the past year; the eighth had used the centre after losing her mother. Five lived alone, two lived with extended families, and the woman who had lost her mother was married.

Those who had used the bereavement centre were unanimous in praising the service, received at a time of emotional trauma when they needed to depend upon others to get through it. The centre provided access to a range of services and raised pensioners' awareness of their rights. Interviewees described the centre as '*out of this world*', '*marvellous*', '*fantastic*', and '*a first class development*'. Even those who had criticisms were reluctant to voice these, given their high overall degree of satisfaction with the service. The 'one-stop shop' aspect of the service was particularly valued; those with previous experience of registering a death valued the ease with which they were able to deal with the various documents and procedures, which '*saves a lot of running around*'. Harry said:

'I mean I'm going back years when you had to go and register a death at a different place altogether and it was solely for that, and all they were interested in was registering the death and nothing else, but this bereavement centre is really brilliant I think.'

Interviewees had found out about the centre from a variety of sources, including family members, undertakers, or simply when attending the civic centre to register the death. Some were aware that it was an innovative service, and expressed the hope that it would be extended to neighbouring areas. The central location of the building, good disability access, closeness to public transport, and good parking facilities were all noted by interviewees. There was felt to be an appropriate degree of privacy, and individual interview rooms were available, so that not all matters needed to be discussed at an open counter. Laurie noted that this was an improvement on her previous experience, when she had registered her mother's death.

Interviewees expressed their relief at not having to deal with numerous agencies in order to return benefit books, wheelchairs and so on, at a time when they felt shaken and vulnerable. For example, Deirdre described herself as being in shock and hardly able to speak upon the sudden death of her husband. In this context not being self-reliant, and depending on the centre, was empowering, facilitating access to support and services. Arnold said '*I didn't have to do a thing*', while Roger saw the centre as '*taking over your life for a day when you're not capable of thinking straight*'. Interviewees were provided with a list of people and organisations that they needed to inform about the death. Deirdre reported:

'I found the list to be invaluable in that it provided me with a check-list. It also contained organisations I would never have thought of.'

Services offered included collection of keys to local authority properties, and dealing with practicalities, such as the disposal of unwanted furniture and prevention of problems that can arise from non-notification of death. The latter included accessing pension and benefits advice, clarifying entitlements and preventing overpayments. Two people had received help to organise a memorial tree or bench, and had been very happy with the way the centre dealt with these arrangements.

The staff at the bereavement centre were generally perceived as knowledgeable and helpful. Fraser commented:

'They told me what to do with the wife's disability books, the, her driving licence, passport and everything involved, and how to get the Family Allowance book changed into my name, and how many death certificates I needed, where to go, where to go for the funeral and all that lot, not where to go, but how to go about it, not where to go. So the information I asked for they gave me, and they also gave me information which I wouldn't have thought about, so I really, from my point of view, I've got nothing but thanks, they also told me about the, what was it, because I have £2000 bereavement grant which I didn't know anything about.'

Harry also welcomed the authoritative financial advice he had received, saying '*they put me right as far as all that was concerned, and put my mind at rest*'. At the same time, there were instances where the service provided had been less than optimal. The centre had failed to advise Roger about the £2000 death grant to which he was entitled (although he did go on to claim this after he remembered seeing an article in the national press), and he was anxious that others should not miss out on this.

The manner in which staff dealt with centre users was also much valued. Two pensioners described them as '*really understanding, really nice*' and '*considerate and kind*'. Fraser particularly appreciated the professional detachment of staff, and felt that this had helped him at a difficult time:

'Well at the bereavement stage you can go over the top and make things worse or you can be too mean and make things miserable. I found the place itself was alright, it was clean, it was tidy, there was enough there, they didn't keep you waiting no longer than necessary, and I found the staff very formal, very pleasant, very much to the point and asked the questions they'd got to ask.'

Most of those interviewed had simply used the centre on a single occasion, although they appreciated the fact that they were told that they could get back in touch at any time. Meredith, who had telephoned for advice on several occasions said:

Meredith: '*Well if I need any[thing], I ring them, I ring them and say, you know, "Can you help me with this?" If I've needed anything I've rung them.*'

Interviewer: '*So you feel able to ring them whenever you need?*'

Meredith: '*Yes, yes, no problem at all, well like I said that fellow said, "Come back anytime, just come in and ask to see me," he says. I suppose you have to wait your turn, you know, but I haven't needed to.*'

This kind of open-door, light-touch approach seems to have been particularly appropriate for working with a group of pensioners who are vulnerable emotionally.

Most of those interviewed had close and supportive family relationships, and had not taken up the centre's offer of bereavement counselling.

Unmet support needs in everyday life and independence

There did seem to be some unmet need for ongoing emotional support following bereavement. Arnold described continuing feelings of loneliness following his wife's death, which he felt unable to confide in his family about, and had only discussed with his doctor. Deirdre, the only person in the sample to have been referred for bereavement counselling, had also been very unsatisfied with the counsellor allocated to her, and this was why she had not continued with this:

'her attitude, her general attitude and I didn't feel, I only had about an hour with her, but I didn't feel she'd done me any good at all, and I know you've got to establish a relationship but I thought 'I'll get through this myself,' and oddly enough the lady that you speak to when you get through to [the centre], I felt I got on better with her than I did with this lady, so I just rang her and said "I think I'll be alright," so I think it's a pity that.'

However, she had not expected to be feeling so grief stricken one year after her husband's death. At the time of interview she was taking medication to help her sleep. A bereavement centre might usefully meet this kind of support need, perhaps by contacting people several months after bereavement to see whether they are in need of further support.

The bereavement centre has a focus on short-term needs. However, interviewees also reflected on the impact that their loss had on their everyday lives. A theme emerging here was the re-evaluation of independence that could follow bereavement. Deirdre had not thought about independence until her husband's death. She described her fears that she would be treated differently now that she lived alone, in particular because she now had responsibility for the household maintenance tasks that had been taken care of by her husband. Deirdre was living in fear of being exploited by workmen, which appeared to be intensified by her feeling that independence meant not having to rely on anyone else (implying that as she trusted her husband she did not feel dependent on him). She seemed unaware that the Experience Corps operated in the area, or that a local voluntary sector organisation had compiled a list of reputable maintenance workers. The voluntary sector and the Experience Corps might usefully work in partnership with the bereavement centre here, to compile an information sheet on reputable workpeople, making it available to bereavement centre users.

Others saw bereavement as a challenge to be more independent. For example, Arnold described how he wanted to do more things for himself and not rely on others. Nevertheless he did get lonely, and information about networks that can promote companionship might also be circulated by bereavement centres.

Not everyone felt that the centre was being publicised as effectively as it might be. Meredith suggested that it would benefit from being advertised more widely. The majority, however, felt that it was well known in the local area, and that people were in any case signposted to the range of services on offer by the registrar when registering the death. It was also pointed out that this is, by its nature, one of those services which people only think about when the need arises, which may limit the effectiveness of blanket publicity.

4.6.3 Older people leaving hospital

Seven interviews were carried out with older people who received help from a local home-from-hospital scheme operating in area three. Most of this help had been received in the past few months. Scheduled joint replacement surgery was the reason for a hospital stay in all but one of the cases, the exception being an emergency hospital admission due to a heart attack. Interviewees were predominantly female and ranged in age from 62 to 89 years. All but one person lived alone, and in this case their partner was also interviewed. The study focused on interviewees' adjustment after leaving hospital, asking people to reflect on the role various forms of help played in their recovery.

The transition between being hospitalised and '*getting back on your feet*' inevitably has an impact on feelings of identity and personal independence. This transition is tied to a change in physical and often emotional health. In this case, recovery may entail a return to a former state of independence. However, it may also correspond to adjustment in having to accept a changed state of independence, as the transition may not result in a full return to physical fitness. During recovery, people must come to terms with relying upon others to do things which they normally do for themselves, which may

contrast sharply with the perception they have of themselves as self-sufficient. Dorothy described the feelings of vulnerability this created:

'Well you suddenly become, you feel you suddenly become dependent whereas you were independent and although you know it isn't going to last long it's quite, it's quite a knock if you are an independent person to think you can't do anything, that you need help with everything.'

The need for assistance during this transition phase was particularly acute for older people who were living alone. Dorothy had lived alone following her divorce over a decade ago. She described the emotional element of her adjustment:

'I guess you just worry that you're not completely in control of your life because you've just had a big operation and now all you've got to do is sit around and get better... I felt very vulnerable being on my own at home with nobody there and me being disabled, I felt a bit, it was a bit scary really, I mean nothing went wrong but you just felt vulnerable basically.'

As described in Chapter 2, the home-from-hospital scheme was designed to help older people settle back into their own homes, with in-home support offered over a maximum of six weeks. In the case of this sample, the majority of help supplied by the scheme consisted of changing pressure stockings and washing feet. This was a medically necessary task welcomed by interviewees because, at the time, they were not physically flexible enough to perform the care themselves and it required a specialised knack. As one person worded it, *'there's no way to take off those rotten beastly things.'* Interviewees were very grateful for this regular help which usually occurred as two visits a week, describing the service as *'very nice'* and *'absolutely marvellous'*.

For those who had experienced a recent spell in hospital, having good health and retaining mobility were at the forefront of factors important to feelings of independence. The experience triggered awareness of their vulnerability to their physiology and the dramatic debilitating effects of coping with pain and immobility. Lesley was in her 70s and considered herself to be in good health before her hip replacement surgery, describing her old self as someone who was *'out all the time, I hardly stopped moving.'* Unfortunately her condition was followed by complications and the need for extended care. Her recent health transition caused her to reassess her identity in terms of her level of independence, *'cause you can't do a great deal for yourself if this experience is anything to go by.'*

Erwin, on the other hand, was more accepting of a spell of vulnerability. He was in his 80s and had been in hospital following a heart attack. The value he placed on health was tempered by his acceptance that his body was not getting stronger with age. Still, he looked upon his recent experience as a temporary decline to his accustomed level of independence:

'Well, when one's health is not at its best, as it has been recently, you've got to rely on other people, but we just do it with thankfulness... the independence will come back.'

The home from hospital service contributed to feelings of independence because it assisted pensioners with recovery while they remained in their own homes. This enabled continuity of independence, when independence is defined as staying in home as opposed to being in residential or extended hospital care. All interviewees felt they were ready to leave hospital when they did. Like many pensioners in this study, Joy equated her independence with being able to remain in her own home, and she linked the service that made this possible to independence:

'And the only way I can keep my independence is either manage to do the jobs that at the moment I can't do, or there'd have to be a service, or even somebody that I could pay, for them to come and do the jobs that I would like done.'

Yet during their transition, several people chose to spend time in a convalescent care facility after leaving hospital and prior to coming home. All viewed the experience very positively as contributing to their recovery. Using this facility also contributed to feelings of independence because it allowed people to manage an intensive period of care without relying on informal social support networks. Margaret was grateful for her stay in a respite facility and echoed the reluctance of others (see Chapter 5) who did not want to call on family and friends because they '*had their own lives*'. From the perspective of older people living alone, a convalescence facility offered an environment that was conducive to recovery. Interviewees talked about certain expectations attached to being mobile and participating in social activities. For Dorothy, '*It took a load off my mind and I didn't have to feed myself, I didn't have to, I just didn't have to be alone, it was company.*' Margaret greatly valued the effect of her stay in rebuilding her confidence:

'it's just that little bit, I mean there were people in there who were far worse off than me and it gave them confidence to get out of bed, to get walking because they had to get dressed to go out to a dining room to eat, and it gave them the confidence to do it... I think it was quite important. I wish there were more places like that.'

Apart from the valuable service supplied by the home-from-hospital scheme, interviewees mentioned a host of strategies and supports they appreciated. Those with joint replacement surgery received specialised equipment to aid their mobility in the home, such as a trolley, crutches, hand rails, raised toilet seat, and elevated bed rest. Assessment for these devices was usually mediated by social services while the patient was still in hospital, and the devices were made available when or shortly after the people returned to their homes.

Adapting to changes after a serious illness or medical intervention entails preparation and anticipation of needs. In all but one of the cases the surgery was a scheduled transition, and interviewees took up the opportunity to plan for their after home care. Help was drawn from both formal and informal sources, and often a combination of the two. Some had made arrangements for daily meals to be delivered and for domestic cleaning services. An informal social support network was also of key importance. All interviewees had family and friends to help during their recovery period. For example, Lesley arranged for her daughter to pick up her weekly pension cheque, a friend to do some cooking and cleaning, and her neighbour to do her shopping.

Past experience and anticipation of what to expect following the scheduled surgery seemed to make a difference to recovery and feelings of independence. For instance, Margaret, having had two previous joint replacement surgeries, felt this knowledge helped her recover from her most recent operation, '*I'd had some experience of what to expect and what I could expect to do, and I also knew what and how to organise things here for help which I did before I went in.*' In contrast, Lesley, despite organising a strong network of family and friends to help out, had no experience of surgery to draw from and felt unprepared for the changes involved:

'No, I didn't know I was going to feel like I did, did I? I've never had a major operation before in my life. So I had no... I mean if I'd had someone here like a husband or someone living in, it wouldn't have been quite so bad.'

Erwin's experience was unique because he was the only male in the sample, he lived with a partner, Rosemary, and his hospital stay followed a medical emergency. Erwin was also the carer in his relationship, because Rosemary was a wheelchair user and had severe mobility limitations. After Erwin's heart attack, support services had to be put into place immediately because Rosemary needed to stay in a nursing home during the week Erwin was in hospital. After his discharge and during his recovery, extra help was brought into the couple's household so that they could remain together in

their own home. The home-from-hospital scheme was part of this strategy, as was a charitable agency that supplied domestic care, and local friends. Reflecting on the experience, Erwin commented that, *'Well it has taught me that one cannot be 100 per cent independent. That there are times when you've got to forego independence in return for help.'* This example illustrates the complexities of help systems, both formal and informal, needed for older people to maintain their independence through an emergency health transition.

The timing of information seemed to be a critical factor influencing the take-up of formal help, and this ultimately influenced the kind of support packages interviewees had in place after leaving hospital. None of the pensioners who used the home-from-hospital scheme had been aware of the service prior to entering hospital. Most were told of the service and asked if they would like to participate during their stay in hospital. By this time, however, support systems had been anticipated and were already in place, as might be expected with scheduled surgery. Most of these prior arrangements were informal in nature. For example, Lesley had arranged for help through a wide network of friends and family when she returned from hospital, although she would have appreciated knowing what help was available beforehand:

'So social services did step in. But nobody tells you about it in advance. I could have known, I could have done with knowing about these things longer than last week or the week before. Do you know what I mean?... The services are there but nobody tells you about it.'

As pensioners' circumstances varied, so too their responses to change and adaptation differed. While some recovered quickly and stopped using the home from hospital service before the six weeks' were up, in other instances healing was slower, and pensioners would benefit from a degree of flexibility in the way that services are provided. However, beyond the contracted period of the scheme, interviewees were typically assessed for additional help needs, which were then referred to social services. There may be continuity of care issues here. Furthermore, feelings about receiving help (as explored in Section 5.4), were rarely sector-neutral. In terms of the home-from-hospital scheme studied here, the fact that it was provided by a voluntary sector agency, rather than through the statutory sector, made a difference to a number of interviewees in how comfortable they felt accepting help. Erwin clearly found it problematic to have to rely on outside help for the first time in his life. Yet he was able to address this difficulty by making a donation to the charity, which enabled him to conceptualise himself as having purchased the service, and he felt measurably more independent for having done so.

4.7 Conclusions on transitions

This chapter has identified common transitions in older people's lives, and has discussed the ways in which these affect independence, giving particular attention to how three specialised services can help people to manage during periods of acute adjustment.

Key transitions, distinguishable in terms of the ageing process, retirement, changes in health and domestic circumstances, can occur alone, simultaneously or consecutively. They may also be anticipated and gradual, such as a slow decline in health or moving into sheltered accommodation, or unpredictable and acute, such as bereavement or emergency hospitalisation. The context of these transitions will inform pensioners' service needs and how they respond to these changed expectations. Their effect upon older people is also mediated by socioeconomic, demographic and personality factors.

Given the difficulty of planning for many of the transitions associated with later life, it is vital that services are targeted to meet pensioners' needs at key crisis points, and that services are accessible, easy to navigate, and effective. Critically, transitions have important effects upon older people's perceptions of independence. As this chapter has shown, these vary over time, depending on their distance from transitions, and the intensity of pensioners' support needs are likely to reflect this.

The following chapter looks more broadly at help needs in later life, and how these are met by a combination of formalised services and informal social support to maintain independence. The chapter looks at service use patterns among the pensioner population and discusses older people's unmet needs for services, exploring the ways in which these relate to their personal circumstances, their values and motivations, and the particular transitions which they are involved in negotiating.

5 Pensioners' help needs

5.1 Introduction

This chapter examines the range of support needs across the pensioner population, looking at how these are met (or fail to be met) through a combination of formal services and informal sources of support – an individualised ‘package’ of help, which in most cases is determined by the recipient. The idea of ‘help’ is extended here from the more conventional sense of domestic and personal care to cover a range of support and activities, but also looks at the often unacknowledged help that older people provide to others.

These issues were explored in the interviews by asking pensioners about their use of informal sources of help as well as formalised services. The kinds of services probed on broadly covered health, practical, social and community, leisure and privatised services. This line of questioning was supported in the first tranche of fieldwork by the completion of activity diaries and social network maps (see Appendix D). The activity diaries charted pensioners’ typical use of formal services over the period of a month. This provided a useful *‘aide memoire’* to pensioners as service use was discussed during the interview. Also employed in tranche one interviews, were social network maps. This method drew out the ways in which formal and informal forms of support were prioritised by pensioners, and enabled us to unpick why particular types of support were preferable in different circumstances, and to identify access issues associated with various types of support (for example, in response to financial, practical or emotional needs).

This chapter begins with an overview of the main types of support used by the pensioners interviewed and the factors that influenced their patterns of use. Complementing this, the chapter then examines people’s complex feelings about asking for and receiving different types of help at particular points in their lives, and looks at the types of services that help older people maintain their independence in later life. This is balanced by a consideration of how particular gaps in provision may compromise pensioners’ ability to maintain independent lifestyles. Finally, the chapter provides an overview of the kind of unpaid work that older people are involved in, examining what it means for them to be able to offer, as well as to receive, support, and in particular, how the kinds of help they give to others is influenced by a range of capabilities and resources.

5.2 Patterns of service use

While patterns of service use differed according to older people's personal circumstances, support needs and cultural practices, the services identified by pensioners as most important for older people were:

- health-related services, including local doctors, hospitals and related healthcare professionals;
- transport services, including public transport, community transport and personal transport;
- home-based care services, including domestic and personal care, occupational therapy and food delivery services, which were provided by a range of statutory, voluntary and private agencies;
- informal support networks that provided ad hoc or regular domestic help, do-it-yourself, gardening, transport, and emotional and social support.

5.2.1 Health services

Most pensioners mentioned accessing some type of health service, although frequency of access varied dramatically, with those with long-term health conditions or disabilities, and those who had recently suffered from acute illness, being the heaviest users. Non-disabled pensioners tended to use health services for periodic maintenance, such as prescription renewal and monitoring blood pressure. In order of priority, pensioners regarded GPs' surgeries, district and practice nurses, hospitals, physiotherapists, occupational therapists and psychologists as the most important elements in their day-to-day healthcare management programmes.

While generally not critical of their GPs and hospitals, a significant group of interviewees described interactions with health professionals in which they had received insufficient information, or in which their problems or needs had been misunderstood in some way. This could have repercussions in terms of increasing interviewees' health problems, general unhappiness and perceptions that they had not been listened to, and had a knock-on effect upon their future use of services. While major health problems tended to be resolved through the NHS, some respondents felt compelled to buy in private services in relation to what they defined as their health needs, which included a pain relief machine, a wheelchair, a lift and nursing care. Although statutory service boundaries between health and social care define who is responsible for these different elements of support, few pensioners made these kinds of distinctions when they talked about their needs. The strategy of buying in services encroached upon pensioners' savings and subsequently made them poorer and more vulnerable; at least one woman had moved into a lower income group as a result of such a strategy. Less frequently used, but also important, health services included opticians, chiropodists and dentists. There was little evidence of alternative therapies being used, and due perhaps to their separation in most areas from the NHS, it was those in higher income groups who had done so.

5.2.2 Transport services

Mobility, or getting about, was a key need among interviewees. However, the reliability of transport services varied from area to area. Public transport, although noted as being '*fantastic*' in one area, came in for criticism in other areas in terms of services covering only daylight hours, which limited pensioners' movements. In the rural area it was noted that visiting a local hospital using public transport entailed a very early start. A lack of weekend services in rural areas also limited the ability of pensioners without cars to get out and about and to visit friends. As noted in Chapter 2, community transport services were felt to be under-resourced in area four, an issue that was critical in terms of its pensioner population. Additionally, public transport came in for particular and detailed criticism in this

area, a finding that is perhaps contrary to the expectation that transport provision will be most comprehensive in inner-city regions. Lynne pointed out that certain bus drivers were particularly helpful in stopping at her request outside designated stops, an issue which is important to older people with mobility issues, although the freedom of drivers to do this may be curtailed by efficiency drives. Transport providers appeared to have standardised procedures in some areas, restricting drivers' ability to meet customers' (in particular, older people's) requests, the context for such decisions presumably being the potential for litigation which might be opened up through responding to a more diverse array of needs.

In order to avoid the limitations of particular forms of public transport (see Section 5.6), pensioners without access to cars tended to combine their use of buses, trains and community transport with taxis, although their use of this option was limited by financial constraints, and there were access issues for pensioners with mobility difficulties. In area three, a system of using tokens to facilitate the use of taxis was particularly established, and made use of by most of the pensioners interviewed. This appeared to offer an important element of choice in the way that pensioners planned their journeys.

In Chapter 3 it was shown that pensioners often saw having a car as making an important contribution to independence. Those who maintained a vehicle tended to fall into the high income category. However, a number of pensioners with more moderate or low incomes explained how the importance of personal transport led them to prioritise a car over other expenditures, since it offered particular advantages over statutory services.

Shopmobility and local community transport schemes provided an important aspect of disabled pensioners' mobility strategies. Shopping was a valued aspect of independence (see Section 3.4) and services that enabled pensioners to do this on their own were appreciated. The use of these community transport services were sometimes combined with receiving lifts through friends and family and taxis. This was a strategy for dealing with the lack of accessibility of other transport options for disabled people (see Section 5.6). Disabled pensioners were often less confident negotiating physical space on their own, and having access to this kind of variety of support services was particularly vital for them. Hospital appointments were often met through pre-booked ambulances, reflecting the transport needs of pensioners receiving ongoing treatment.

5.2.3 Home-based care services

Experiences in accessing home-based care services varied, particularly in terms of social services. What mattered to pensioners was how they felt an assessment of their needs had gone. Those assessed as low-need had to wait a long time for work to be done. There was evidence of health problems intensifying dramatically, but of pensioners being unaware of how to request increased levels of support, as the eligibility process was not transparent. A number of pensioners noted that they did not feel they had made a good case for themselves at their assessment, and it seemed likely that they would have benefited from an advocate to channel the communication process. The family of one interviewee, who had recently experienced a major deterioration in his health, was struggling to access help from social services because his needs had changed.

Correspondingly, many interviewees who might have been expected to make the most use of home-based domestic services (those with high level mobility impairments and low incomes) were receiving little in the way of statutory support with day-to-day activities around the house. Difficulties experienced gaining access to desired services often had adverse long-term effects, with pensioners developing negative views about particular services, who they subsequently avoided, presumably, thus, missing out on additional relevant services. Such perceptions are important, and at least one man noted that he had been put off finding out more about home helps because he had heard bad reports on them from friends.

A number of pensioners were currently using food delivery services, or had used them in the past, and these types of services were felt to be particularly useful in helping older people manage health transitions (such as leaving hospital when they lived alone), and hence maintain their independence.

Reflecting the health transitions made by many of those interviewed, which were often characterised by a period (sometimes sustained) of impaired mobility, various mobility aids, obtained through occupational therapists, social services or purchased privately, were an important aspect of older people's coping strategies, and enabled them to regain or maintain independence within their homes. Rachel, a widow in her late 80s with spinal problems, had used an insurance policy to get a lift put into her house, which she described as '*wonderful*'. This enabled her to stay in her home. Patience explained how she had been housebound and had taken to sleeping downstairs, but managed to obtain a hospital bed, a hoist, a ramp and a stair lift from social services. These adjustments had revolutionised her quality of life. Where these kinds of aids were obtained through the statutory sector, there was some evidence that they were in scarce supply, since they were '*reclaimed*' relatively quickly. Several pensioners reported difficulties accessing relevant mobility aids at the time when they most needed them. For example, Bridget,, who had had to wait eight months to receive a gripper commented, '*What do they do, wait until they die?*'; this was not an isolated incident.

For the most housebound, services like personal alarms were particularly valued and provided considerable peace of mind, although charging for these applied across income groups. These gave additional reassurance to people who were fearful of, or who had been the victims of, crime. Sheltered homes tended to be equipped with comprehensive panic button systems, connected to a warden who lived on-site. Several people referred to their concern about not wanting to be '*a bother*', and stressed that they would only use the alarm if it was absolutely necessary. Others said that they would use the telephone in a medical emergency and felt no need to have a personal alarm. In both types of residential homes case studied, staff were informed when someone was leaving the home and when they were expected back, a practice that did not appear to be resented by interviewees. Rather, reassurance was derived from knowing that there was carer support to hand if someone's health took a turn for the worse. Martin expressed this in terms of there being '*security in everything...really good*'. Residents also had easy access to call systems should they need to alert staff to their need for help.

5.2.4 Other forms and sources of support

In addition to formal services provided by statutory bodies, voluntary organisations and community projects, many older people relied on informal support provided by spouses, extended family, neighbours, and friends. These provided support that ranged from domestic help for transport, decorating, shopping and gardening, to emotional and social care.

Emotional support, which family and friends were often well placed to meet, was important to pensioners' well being. Extensive care was frequently provided by family members who acted as carers. This included care for a spouse, and, where a partner was severely disabled this could carry a particularly heavy burden. Charlotte and Henry, a couple in their 80s, had been married for over sixty years. Henry had mobility problems and Charlotte attended to all his dressing and bathing needs. They received Attendance Allowance to cover the extra costs associated with his health restrictions. Henry was prone to falls, which limited the couple's outdoor activities. However, despite these limitations, Charlotte had no regrets about their situation.

Caring could also be taken on by sons, daughters and other members of the family. Yvonne, an Afro-Caribbean women living alone in her own home in her 80s, used a stick to get around and had been suffering from dizzy spells. Her extended family provided a comprehensive web of support, which

involved one of them sleeping at her house every night, making sure her shopping was done, and at least one of her grandchildren popping in to see her after school. She had never used social services and laughed off the idea of receiving a food delivery service, as her daughter cooked Sunday lunch at her house every week, which provided food for her for several days.

Informal help also came from non-family members, often friends, but also neighbours and others in the community. In addition to the help with cleaning and shopping that Gilbert, an unmarried deaf man in his 70s, received from a voluntary sector organisation, a friend and neighbour helped him a good deal with his day-to-day communication needs, such as dealing with housing benefit and council tax offices. Without these different kinds of support, he commented that he would not have been able to manage everyday life. Lynne was in her 80s and very frail, although still able to get about with a stick. She had a network of neighbours who looked out for her. One couple who lived close by invited her to their home every Saturday to watch the lottery, and another neighbour would give her lifts when she needed them. In an emergency she explained she could contact the garden centre next door to her home, as she knew the staff and they were really helpful.

Although distinct from traditional understandings of social support, a strong sub-theme to emerge from the interviews was the importance of pets. Attachment to pets, in particular to dogs, was particularly intense for people who lived on their own. For the relatively housebound, interaction with a pet provided an important relationship, as well as making them feel more secure in their home. Isabelle, a woman in her 80s, explained, '*I feel much better about being on my own now I've got another dog... dogs always give me a great sense of confidence... it's company.*' Conversely, for the more mobile, walking their dog, provided a useful impetus for them to maintain exercise, and some people spoke of the social networks that developed around dog walking. Rachel's dog connected her to her voluntary work (see Section 5.7), and was vital in giving her a sense of purpose, '*she is the reason why I keep going. She is the one that makes me live from day to day.*' Pets also sometimes provided more practical help to the disabled: Rachel's dog would fetch her slippers and newspapers, and open and close doors, tasks which were useful in the light of her mobility impairment, and Lucy had been assisted by a series of guide dogs.

5.3 Factors influencing use of support and services

Across the pensioner sample there was huge variety in the way pensioners used the different types of services and support outlined above. Factors ranging from geographical and temporal circumstances, through to socioeconomic situation, health needs, and gender and cultural characteristics, all intersect in different ways to shape the ways that older people engage with and access support and services.

Circumstantial temporal factors such as the length of time elapsed since a critical transition (for example, a health crisis or losing a partner) or the length of time a pensioner had been living in an area, had implications for their ability to access formal services and informal social networks. Those furthest from transitions in temporal terms, tended to have the most comprehensive and satisfactory service use strategies. This is fairly intuitive, in that people learn what services they are entitled to and work out a pattern of use that suits them. However, it also suggests that those most in need of services (in particular, those undergoing a crisis) are in a disadvantaged position in terms of obtaining them, highlighting the importance of specialised services (such as leaving hospital or bereavement services) that focus on heightened periods of need. The length of time a person had lived in an area influenced their knowledge about what was available and some of those who were relatively new to an area had, for instance, not registered with a dentist, or had little contact with local voluntary organisations or neighbours.

As would be expected, pensioners with long-standing health conditions or disabilities were likely to make the heaviest use of formal healthcare and in-home support services (both statutory and voluntary). The extent to which this was the case varied according to the relatively acute or chronic nature of older people's conditions, and how long these had been maintained. Those in poorer health were also more likely to move into supported forms of living (see Section 4.6.1), although people living in their own homes and others in specialised residential care often had comparable health problems. Where people had high support needs and lacked informal social support, they tended to rely more heavily upon the statutory sector. Fergus, a divorced man who had lost contact with his family, noted his vulnerability when he was unexpectedly diagnosed with cancer. Although he had a few close friends, he was reluctant to bother them, and found himself necessarily dependent upon statutory services. While these met his basic needs, having to rely on them had a damaging effect upon his self-confidence, as seen in Chapter 4.

Those in poor health were less likely to access personal development services, like the arts or training courses, compared to non-disabled pensioners. Comparatively, healthier pensioners were more likely to report using leisure services like social clubs, fitness activities, travel and outings, although access to these was mediated by level of income. Conversely, those with more health problems (and those with lower incomes) were more likely to focus on home-based leisure pursuits, such as watching television, needlecraft, doing crosswords and reading. Provided there were no health limitations, both couples and pensioners living on their own tended to live active lives, although the range and type of activities engaged in and the services used varied by income and preference. However, some pensioners in new style specialised residential care were participating in exercise classes. For example, Simon, who had dementia, was using the on-site gym.

Where people had comprehensive informal support systems, their demands upon statutory services were often reduced, for example, in terms of home-based care and transport services. However, access to informal support varied considerably. Living as part of a couple did not guarantee that an older person would have access to informal support. Some couples became particularly insular and dependent upon one another, which cut them off from wider social networks from which they might have benefited. A number of pensioners who lived with a partner completely lacked support themselves, since their husband or wife was too incapacitated to provide this. Conversely, pensioners who lived alone sometimes enjoyed comprehensive support systems involving their extended families or local neighbours.

Support from families was informed to a large degree by whether older people had children, where these lived, and the closeness of the relationship. Familial support was commonly offered and received between siblings (particularly sisters) as well as spouses. There was also a gender bias in the way family support was offered, with women being more likely to receive day-to-day support from their children, in particular from their daughters, which ranged from telephone conversations to practical help with all aspects of personal care. A number of pensioners lacked physically or emotionally close relationships with their families, being sometimes estranged from them. People were somewhat more likely to live further away from their extended families in areas two and four, the rural and the inner-city areas. Leo and Sandra, a couple in their 60s living in sheltered council housing on a low income in area four, were both severely disabled and limited by their dependence on public transport. Their four children did not live close by and rarely visited. As Sandra said '*they are busy, they all work*'. The couple were entirely dependent on social services and the health services for their care and support.

5.4 Feelings about receiving help

The ways in which older people responded to receiving help was complex, and in part was related to their individual support needs and past experience of receiving help. These feelings were also linked to their understandings of independence (see Section 3.2). A crucial aspect of this was *asking* for help and the discomfort this could cause, which often provided a major barrier to receiving help. Feelings about receiving help also related to the source of support, and the same types of help, provided by the state, family, private services or neighbours, were not perceived in neutral terms. Additionally those with fewer resources, and more disabled generally, reported more problematic feelings about receiving help, in large part because they had less choice about the forms in which these were provided.

Glennis's experience provides insight into the complexity of these relationships. She clearly had mixed feelings about receiving help from her friends, and this related to the way in which help had been offered. She described how one friend, '*really has been a great friend since [husband] died*', providing the kind of thoughtful responsive help that had been just what she had needed during her bereavement. She contrasted this with another friend, who had offered support, but only on an asked-for basis, which made her feel uncomfortable and unlikely to approach her:

'she never asks me to go anywhere. But she was saying to me, "If you want to go anywhere just ask me," well, I couldn't. If she wanted me to go somewhere with her she will ask me, won't she?'

Generally interviewees' feelings about receiving help were much more positive if it was provided by a family member to whom they were emotionally close. Marriages in particular provided a comfortable way of receiving help for many pensioners, since partnerships offered a taken-for-granted assumption of mutual support (Parker, 1992), and couples' expectations had often been based upon an expectation of interdependency. As Leo explained, '*Well, obviously we help one another, you've got to help one another, else you don't survive.*' Riana's response illustrated a normative expectation regarding the nature of support between husband and wife, '*because he's my husband and I love him.*' Similarly, transfers of support between daughters and their older mothers, more often than cross-gender familial relationships, were described in terms of an environment in which interviewees felt comfortable receiving support.

However, an important issue for many pensioners was their worry about being '*a nuisance*' or '*a burden*' upon their loved ones by asking for help. Patience, who was a wheelchair user and who had recently suffered a stroke, was being cared for by her son and felt guilty about '*depriving him of his life*'. She asked that someone come and take her out for a day as a '*wheelchair pusher*' to give him a break. Paradoxically, while support relationships which offered an emotional closeness (that is, largely, family and friendship-based ones), were valued precisely on account of those aspects, the fact that these relationships were imbued with layers of meaning could also complicate older people's feelings about becoming overly reliant upon informal forms of support. There could also be an issue of uncertainty relating to the boundaries of informal social support, in that older people sometimes felt that because family or friends were helping them on a goodwill basis, rather than because they were '*entitled*' to this support, as with statutory services, they felt uncomfortable asking them to do things which they would like to have done for them. Isabelle, a woman in her 80s, who relied upon a mixture of family, neighbours and paid help for support, explained how she felt about asking for help from her brother, '*other times I think no, is he just saying it, or this, you know, am I being a nuisance?...I don't want to feel that I'm pushing my luck.*' Others commented that relying on themselves for as long as possible was a matter of pride, an attitude that seemed to be little linked to their capabilities. Ruth, a divorced woman in her 60s with mobility problems, explained:

'Independence means everything to me, because if I have to ask someone to do something for me, I don't know how I will feel. I don't want to ask anyone to do anything for me.'

As described in Chapter 3, some older people noted that they preferred to pay for support, such as domestic help and carers, because commodifying these relationships made them less problematic and diminished their sense of being dependent upon others. Ruth explained, '*I can pay them, and they're not doing me any favours. It's terrible isn't it?*' Isabelle reiterated that she felt a shift from informal to more formal forms of support would have important psychological benefits, '*I would love to be able to pay, that would make me feel even more independent.*' Such a strategy, of course, was only available to those with sufficient funds to pay for private support. In particular, private services seemed to provide a continuity of care that could not be guaranteed through social service provision. Indeed, Ungerson (2003) has drawn attention to the significance of 'hot' and 'cold' forms of care services. However, older people often found that informal social support offered the most comfortable environment for receiving support, and enabled them to maintain a quality of independence that would not be possible otherwise. For example, Brenda and Bernice, long-term widows, both lived with their children, and explained that the level of support they received from their families was vital in enabling them to continue to think of themselves as independent people. Indeed, without this support, both felt that they would be forced to move into residential care.

The most entrenched care needs were often met by statutory care, perhaps because pensioners lacked alternative forms of support, and older people felt very differently about this relationship. Esther welcomed statutory services as something she felt entitled to and in control of, preferring this form of delivery to relying upon friends, to whom she felt she '*owed*' something. For her, statutory provision promoted her sense of independence. However, problems were also experienced with statutory services, particularly those subcontracted to and delivered through private agencies, through which pensioners sometimes received care from a number of different people. This could lead to instability in older people's care and a lack of specialist knowledge of their care needs and preferences, which inevitably compromised their sense of independence. Unis described the inconvenience caused to her daily routine by a care assistant who insisted on working to her own timetable and ignoring Unis's own established routines:

'But she was just too quick. She wanted to get out you see. I mean I understand, I used to have to go to bed at seven, I'd get up at seven ... it's a bit off, isn't it, going to bed at seven, get up at seven every morning... When I get as old as what I am, you want to [have a] little rest don't you?'

In this way, Unis's sense of autonomy over the care process was compromised. Miriam, a widow in her 90s, commented on the statutory care she had received, '*the thing is, you never knew which day they were coming, and who was coming and all that.*' She had subsequently invested a substantial part of her income in paying for two private carers, an arrangement which worked much better for her, having developed a personal relationship and sense of trust with them. Others, such as Lynne, did not feel that they would be entitled to statutory support and so did not apply for it, or like Leo, had bad experiences of using particular services in the past, and so avoided contact with external agencies as much as they could.

The way interviewees felt about receiving help often displayed a degree of relativity. Several pensioners commented that while they were comfortable receiving family or statutory support with domestic tasks, that they were more uneasy about the prospect of the same person helping them with personal care. For example, Patience lived with her son, and relied heavily upon him for cooking, shopping, and sometimes also, financial support. However, the emotional closeness of their relationship and their gender difference made relying upon him for intimate tasks more problematic,

and a series of carers came in every day to help her with washing and toilet needs. Others, like Noreen, ordered things differently; she explained that, '*It's when you get strangers in your house, I think, that I'd feel awkward*', and that while she would happily ask friends for practical help, she felt that she would be unable to concede control of personal care herself, '*probably [a] psychological thing, I don't know. Probably me.*'

Similarly, some people displayed a sliding scale of willingness to ask for or accept help, depending on the situation. These differences were particularly highlighted in relation to questions asked in the second tranche of fieldwork, when interviewees were asked who they would go to for help in the event of a fall, if their transport had broken down, and if they found themselves faced with an unexpected bill. In particular, it emerged that older people were less willing to approach friends and family about a financial crisis, seeing it as something they should be capable of dealing with alone, the implication being that such a situation was shameful. This was often related to lifelong attitudes to finances and '*coping*'. Conversely, people were far more willing to accept that they would need to approach someone to help them after an accident, the overall sense being that health is relatively uncontrollable and that it is normatively acceptable to require support in circumstances of compromised health.

5.5 Services that help maintain independence

As the preceding chapters have shown, the degree to which pensioners considered themselves 'independent' and felt happy with their quality of life, was more complicated than simply whether they were non-disabled and able to remain in a self-sufficient household unit. So the question then, is whether independence is related to the quality of support that pensioners have been able to negotiate.

Broadly, the services flagged as the ones that maintained independence were the same ones that pensioners had identified as their priorities (health, transport and home-based services), a rational assessment based on experience. The explanations that people gave for these related back to the core components of independence, their autonomy and self-sufficiency (examined in Chapter 3), and were related again to personal circumstances. For example, transport services, which were identified most often as key to independence, focused upon community transport, and tended to be raised by people with quite severe limiting health conditions or disabilities, such as Parkinson's disease, blindness, or being unable to walk. For these individuals, community transport made a dramatic difference to their lives, enabling them to continue to get out and about, maintain a community involvement, use a variety of services, and generally orchestrate a degree of control and convenience over their lives. Ruth, who was regularly attending hospital for cancer treatment, explained how a pre-booked transport system to hospital reduced her sense of dependency on her husband:

'I think it's a godsend. Because normally [husband] takes me to the hospital where I have to go, but this way now, I'm quite relieved in the knowledge that I've got about being able to phone the doctor and he can arrange that for me.'

Other service priorities for maintaining independence included mobility aids, medical treatment and personal care, all services which promoted and supported the capabilities of older people with health problems or who were disabled.

Older people also emphasised their relief at not having to organise a battery of services themselves (particularly in situations which might already be quite stressful), providing support for a simple approach to access. It was also vital that older people met with a positive response when they first approached a service, since interviewees tended to rely upon tried-and-tested routes of access, and

were often put off pursuing a service if the response they received was negative, ambiguous or confusing. This points to the need for flexible service access, in which a range of services can be made available through multiple and cross-sectoral entry points. One example of the kind of joined-up service provision that was most appreciated by interviewees was the '*rapid response team*' that Elliot explained had stepped in after his wife's fall. This had both responded to their immediate needs and flagged the availability of relevant supplementary services. This took a great deal of stress out of a crisis point in their lives. Elliot explained how it worked:

'That was a team of nurses, an occupational therapist, a physical therapist, the doctor and all sorts, you know, and they all came out, one after the other to look after us. And then...after a few weeks they go over to the caring side and you get a carer, carers coming in and you get an occupational therapist allotted to you.'

Notably, this kind of joined-up provision was atypical of the services that most interviewees had received during health transitions.

The well-timed targeting of services, in particular during the period following a crisis and phase of increased need, played an important role in maintaining independence in later life, enabling interviewees to feel more confident that they could cope with an unfamiliar set of circumstances, and as far as possible, maintain valued aspects of their lifestyle. For example, Erwin felt that his hospitalisation for an angina attack had made him more aware of his vulnerability, and this had caused a dip in his self-esteem. However, the support he had received at this stage, both from his healthcare team and from the voluntary sector and social services, in terms of providing domestic support and respite care for his wife, enabled him to negotiate this crisis and to view the downturn in his health as, '*only a temporary loss of independence. The independence will come back.*'

A key informant in area four, who worked in a cross-sector role with older people, noted that a key aspect of promoting independence among older people was concerned with providing services that emphasised their value and enhanced their sense of being able to cope. In this, she highlighted the importance of continuity of care, but explained that it was the seeds of confidence that were built in people which would enable them to cope with the sometimes unpredictable course of future events:

'One of the things we're aware of is that if someone is in hospital or receiving a lot of care at home that lasts for a particular period of time, so individually they feel loved, cared for, the experts or the important people are looking after me, you know, the consultant said this. And you get cheered by that.'

Charles, who had been living with Parkinson's disease for fifteen years, continued to live an active and fulfilling life, and emphasised that he was able to do this because of the health management strategy that his doctor had negotiated with him, in particular, a well-regulated course of medication. He contrasted this with the experience of many others with Parkinson's, who had been less fortunate, '*I've seen people do with this worse than I am now.*'

Confidence was a reiterated theme in terms of the services that promoted independence; loss of health and becoming disabled having a heavy impact upon people's self-concept, as seen in Chapter 4 (see Section 4.4). Well-targeted packages of support could counter this and enable older people to re-imagine themselves as capable of coping with life's changes.

A recurring theme from interviewees living in new style homes was the degree of choice they enjoyed about whether to draw upon support services or to do things for themselves. A couple of people commented that they would dislike being in homes in which everything was done for them. In their current context, they had the choice about whether to cook for themselves, and sometimes did so. If

they preferred to do their own laundry they had their own washing machine. A hairdresser's was available on-site, but it was up to them whether they used it. When asked what services helped independence, there was a tendency to refer to the general set-up in the new style home:

'I've got no worries. I've got a nice big flat... I'm comfortable. I've got good companions around me. That's a big thing... I go in and out as if I was in my own flat here. This is my castle, this is.'

(Martin)

Sometimes pensioners could get withdrawn in residential homes and benefited from being encouraged to engage in a range of activities. Marion noted that she appreciated her daughter's encouragement to make use of her home's facilities, because '*you can get stale.*' A key informant in area four also emphasised that new style supported living schemes aimed to actually turn around people's concept of themselves as dependent, and that this was done by a package of individualised support services:

'I have seen them from when they've come in here, and I see the changes then that sort of come about within the next six months after the tenants have come here, in that they could move back out of here now, they've regained a lot of their independence from having the support they receive here.'

These kinds of services regarded independence as a fluid concept, which could be significantly influenced by a package of support.

The services that made most difference to pensioners' sense of independence were those that were targeted at pensioners after their health had been compromised in some way, which enabled them to manage their mobility and maintain a sense of stability and control over their lives.

5.6 Service gaps and services that make people feel less independent

As noted in the previous chapter (Section 4.6.2), comments from the bereavement centre users interviewed in area one were indicative of how these kinds of services might also usefully facilitate medium- to long-term support for pensioners. The examples given were of a need for longer-term counselling needs, companionship and help accessing reputable providers of household maintenance services. However, most areas lacked these sorts of facilities.

More generally, pensioners were asked in the interviews if they felt there were services they would like to receive, or which they felt would enable them to feel more independent. Their responses revealed how many older people made few demands of services and, indeed, had very low expectations.

Some older people were relatively happy with their lives and did not feel that there were services that would make things better for them. One need that emerged strongly was relatively simple. Pensioners, particularly wheelchair users, but also some non-disabled pensioners, wanted to be taken out, spending less time at home. Others, who could clearly benefit from additional support, were not knowledgeable about the services on offer, and this tended to be a result of the way they had always tried to maintain their independence through being self-sufficient. The issue of not wanting to ask for help was raised again when people were asked what sort of help they would like. For others, not accessing services was a result of previous experience of not being listened to, or of being promised services that were not delivered. There were many stories of carers and social workers not turning up to appointments, or of waiting years for mobility aids to be fitted. One woman was told to prepare a

shopping list by one carer, but no-one ever came to pick it up. While a minority had fought successfully against what they felt was unfair treatment, contacting local MPs, the press and going to tribunals, others were resigned to the situation. One man with severe arthritis dismissed a suggestion that there might be extra help he could receive saying, '*you're too old. You're just a number*'.

There were several other issues that came up repeatedly in relation to services that older people wanted. One was the possibility of being provided with some support for household domestic chores, someone to come in once a week to dust, or clean the windows, or do the hoovering. This was particularly important for those who had remained in their own home and wanted to be able to maintain it in the way they always had. Several were aware that cleaning services could not be provided by social services or voluntary agencies, but thought that these would make a huge difference to their lives. Patience, who was a wheelchair user and being cared for by her son and husband, felt that if someone had been made available to do the housework, her husband would not have had a heart attack. However, Madeleine, who had got a cleaner, pointed out that they were not allowed to do the very things she needed doing:

'change your curtains, clean your windows, they mustn't lift any furniture, all that they are not allowed to do, and yet they are the things that you yourself can't really do.'

This unmet need for help in the home also extended to larger household tasks, and several pensioners wondered if there was a possibility of finding someone to come and help them with painting or gardening. Decorating was expensive and few felt they could afford commercial rates. Although some voluntary organisations for older people collate a database of professionals who offered these kinds of services at a cheap rate, few of the pensioners interviewed were aware of this.

The other main issue, in terms of gaps in services for pensioners, was the lack of availability of professional carers. Some interviewees were not sure how to access caring services, but many had tried and either found that social services were unable to provide them with a carer, or that the local voluntary organisation had a three-month waiting list. Those who had carers often found that the care they received was not appropriate for their needs. Several noted difficulties securing care at weekends, and found that they had to rely upon spouses or family, who were not always available, or who were themselves disabled and only able to provide limited help. Others found care services restrictive or unreliable.

Transport was mentioned in two contexts. The first reflected poor local coverage. A couple of older people noted a need for bus services, or some form of public transport, to serve the local hospital. The second context was indicative of a lack of disability awareness training amongst transport providers, and poor access for disabled people. Lynne drew attention to the difference between '*good*' and '*bad*' drivers who stopped more or less near the kerb, which made a huge difference to her ease of use of public transport. This point about the helpfulness (or not) of particular drivers was echoed by a number of bus-using pensioners. Coincidentally, two of the older people on low incomes interviewed in the inner city location had been thrown over on buses when drivers had suddenly pulled up, causing broken bones and periods spent in hospital. Several pensioners mentioned that community transport services were limited and inflexible, and in some locations were also rather unreliable so there was little opportunity to use them. Where a disabled taxi service was in operation, few of the taxis were actually able to cope with a wheelchair. It was felt that much transport provision for disabled people existed in name only.

Transport access issues are illustrated by the difficulties Elliot experienced negotiating the local transport infrastructure, as a wheelchair user:

'You see, for instance, they have disabled taxis, which we can use with our mobility allowance and we also get old age pension cheques that you can use. But you get a disabled taxi, and half of them, I won't say all of them, but a lot of them, don't know how to handle a wheelchair, they're not experienced in even putting the ramps up into their taxi. Some of them, they send them out and they don't know what they're doing half the time. Then you have the [request-based community transport service], which would be a good service if it was more of it. But I think there's only one minibus with a lift, and one voluntary driver, and we tried to get it to go shopping with our carers, which would have given us a treat. But because we could only have our shopping on a Thursday, the [community transport service] couldn't provide it on a Thursday.'

Changes in the way services were organised could make a huge difference to older people. For example, Lucy described an unpleasant experience of using community transport, which unsurprisingly had led her to conclude that it was not suitable for her future needs (she was blind).

'I did use the [community transport service] and they took me into [supermarket]...it was agreed that if they took me in their [bus], [the supermarket] would find someone to take me round to do me shopping and then I'd wait for them, and this is one thing I complain about is [community transport service]. Years ago they used to take you in the building, wherever you wanted to go to and fetch you out...now they won't do that. Well it happened the next day I'd got to go to hospital...he took me to [the supermarket] and he said, 'Is there someone to meet you?' and I said, 'Oh no, if you don't mind just taking me into the shopping, people there will take me round.' Oh he went at me like a bull at a gate, 'That's not our job, this is door-to-door now.'...Anyway he went on to me and he kept me waiting a hell of a lot, I think I was about two-and-a-half, three hours out.'

5.7 Help given to others

Recent research by the authors (Barnes, Parry and Lakey, 2002) has drawn attention to the wealth of informal forms of voluntary work that older people are involved in, which are not picked up by national surveys (Davis Smith, 1997), which focus more on formalised types of voluntary work (which has a class bias).

This research was conducted with a larger and older cohort, and reiterated this finding. It emphasised the imaginative range of ways in which both disabled and non-disabled older people continue to help others. Amongst those interviewed, these activities included baby-sitting grandchildren, helping friends and neighbours with errands and transport, participating in church and other voluntary forms of help, and providing full-time guardianship for a grandchild. Often help given to others included an element of mutuality, which reflected the different capacities and skills of the two parties, and which made intuitive sense to older people.

For the most part, people liked helping others because doing so played a role in making them feel valued. It was variously commented that it made older people feel good about themselves, '*useful*', or gave them '*a buzz*'. One pensioner noted that, '*there's always somebody worse off than you*'. A number of people explained that they felt it was important to contribute in any small way that they could. Ivy was restricted by her mobility problems, but helped out by baking treats for her friends. She explained that this helped ease her mind about receiving kindnesses from others, '*it was nice to give back, you know. Because I can't give back in any other way...I suppose in a way it's payment for what they've done for you*'.

For Rachel, voluntary work fulfilled a number of roles, which were linked to her sense of independence in important ways. She had a long-standing involvement in a pet therapy scheme, taking her dog into local hospitals to visit patients. Since her own mobility had become more impaired, she had been forced to scale down this activity, and no longer visited hospitals, but continued to take her dog to visit disabled people in their homes nearby. She clearly took immense delight in sharing her dog with the patients, and doing so gave her a real sense of purpose, '*otherwise you just stagnate*.' Crucially, this work also enhanced her social networks, since through it she had made lasting friendships with some of the patients. An additional beneficial aspect of the activity was that it forced her to maintain physical exercise at a time in her life when she hinted that her declining health had been pushing her towards depression, and she might easily have otherwise become housebound.

The extent to which the informal help given to others extends across the spectrum of pensioner experience is illustrated by interviewees living in residential homes, who commonly reported doing some form of unpaid work inside these homes. Martin took visitors to the home on guided tours, in addition to keeping an eye on his elderly neighbour, with whom he had become good friends. Marion set the table for other residents in the home's dining area twice a week, while Peter delivered newspapers to his neighbours.

Couples often took for granted the support they provided to one another, and did not consider it in terms of help given to others. Unis provided a great deal of support to her partner, including dressing him every day, since his mobility had been curtailed by his severe arthritis. In this exchange with the interviewer, she had to be prompted to recognise this support:

Interviewer: '*Do you provide any support or help for people at the moment?*'

Unis: '*No. No, I don't think so.*'

Interviewer: '*I suppose you help and support your husband, don't you?*'

Unis: '*I help my husband, yeah, we help each other. We do everything together, you know, if we got something, we'll halve it and have the half each. You know, we've always been like that.*'

However, the expectation that couples would provide support to one another in later life was not always so unproblematic. For example, at least two women remained in unhappy marriages, and expressed resentment at the heavy caring duties they felt obliged to take on when their husbands' health declined.

Mutual support often also extended among friends and neighbours. This was frequently related to older people's integration into local communities, a phenomenon which tended to be associated with length of residence. Eleanor had lived in her terraced block for close to thirty years, and spoke of close-knit community and neighbourhood ties, in terms of people who she could rely upon for support, and who in turn, she was happy to help:

'I know the people round me, we're all elderly round this part. The gentleman next door, if I'm in a mess, I can just tap on the wall or he'll come round to me and see what's up.'

Jeanette felt social networks were very important to remaining independent, though she felt that helping out was a skill that was gendered:

'I think women are much better at it than men are. You know, there's a very high proportion of widows, you know, and as I say, they do help each other. In more ways than they realise sometimes, you know.'

Adeline was the designated driver among her group of friends in her rural community. She regularly took them out shopping or to social events. She explained that she enjoyed taking on this responsibility while she was still capable, and that, *'we do this to help each other...we really do.'* Another key informant more explicitly linked a self-help ethos to the geography of the area:

'They care for their own, very much so. A lot of the villages, and certainly some of the smaller hamlets, you maybe don't go through maybe more than once a year or something, and there are no transport links or whatever, so they do rely on each other. If somebody needs to go to hospital, someone within the village will probably have a car and they run people around.'

Caregivers provided a special case, embodying an intensified form of the expectations associated with marital support. Care for a loved one, especially a partner, was often overlooked in respect to helping others. This care was often seen as a labour of love, accepted and rarely questioned. Eliza explained how she felt about taking on this role, and (to her) its inherent non-negotiability:

'I couldn't do without him and I always look at him, I always think of Charles, I think it's a one way of combating what is wrong. I always think of him as the same as when I met him, but he was in a different wrapping, like a Christmas parcel you know.'

However, caring for a partner with intensive health needs was undoubtedly demanding, and sometimes took its toll upon carers. Sachin's wife required round-the-clock care, and his weeks were filled with visits to health professionals. He expressed his despair:

'It gets me down...she takes many drugs for epilepsy and other kinds of drugs, and many times she falls down. All the time someone will have to be with her at home, all the while. Even when she sits down, she can lean forward and fall down. Honestly, this gets me down. When she goes to the toilet, every time she stumbles, my heart goes like this – boom, boom...Every day.'

More affluent pensioners were able to offer financial support to their families, a form of support that enabled interviewees to help out when distance or health impairments limited the amount of practical support they could provide.

5.8 Conclusions

The older people interviewed drew upon a range of support packages. Amongst those interviewed, service use was generally not mediated through representatives (where it was, these tended to be family). There was clearly scope for increased use of advocates and intermediaries, particularly given the negative experiences which some pensioners described and the effect that this had upon their confidence accessing services. This general lack and inaccessibility of advocates increased the pressure placed on an already vulnerable group of pensioners. As Section 5.4 has shown, there was an issue about asking for help among many pensioners, a sense that while they would like to receive particular services, they felt uncomfortable, unconfident, or simply not entitled to receive them. High quality informal social support was considered to be a particularly important aspect of older people's support mechanisms in later life.

Finding out about services took on a variety of means, including through libraries, local newspapers and adverts in magazines, doctors' surgeries, hospital waiting rooms, leaflets, on the Internet, at post offices and council offices, phoning around, and through word-of-mouth recommendations (or criticism). There was a desire for services to be publicised more broadly through local radio stations and press, and one key informant noted that language issues could provide a critical barrier to ethnic minority groups finding out about local services. There was a need for services to publicise their existence in a range of languages. Pensioners' service use patterns were influenced by their health and social support networks and changed over time. Priority services, which were felt to help maintain independence in later life, included transport, health and home based services. These supported older people through health transitions and were important in rebuilding their confidence. However, older people also valued being able to help out friends, family and partners where they could, and this played an important role in maintaining their sense of independence.

There was evidence of people not knowing how to go about accessing particular services, and of confusion in terms of who provided certain services. To some extent, this was related to lifelong patterns of service use, which may disadvantage people, for example, those whose health declines in later life. Isabelle noted that diagnosis of her diabetes could usefully have acted as a trigger for an assessment of her service and benefit entitlement, and that this would ideally have been provided by her GP, although she had to find out what support was available for herself. For elderly people, for whom difficulties reading and hearing could complicate communications, for those who were housebound, and who may have lacked confidence about how to go about accessing services, problems finding out about services could reduce the likelihood of their being used. By contrast, a number of informants noted that their social worker had acted as a key intermediary in putting them in touch with relevant services, and that this arrangement had worked extremely well for them.

Once people found one way of obtaining information when they had a problem, they tended to use this route repeatedly whatever the nature of their problem. This might involve contacting social services, but more often it was to go to a family member, one of the voluntary sector organisations for older people, or to a local social club or community organisation, particularly one where older people were allocated a case worker. What was important for them was being able to access an organisation or person they could trust, and who would find the information they needed, or direct them to someone who could deal with a specific problem. In other words, although services were often fragmented and rarely able to treat older people in a holistic way, it was important that older people's first port of call could direct them through the maze of service provision on offer.

These findings demonstrate that there is a need for service access points to be recognised and supported. This is not simply a case of setting up one-stop shops for older people. Those we interviewed varied enormously in terms of the services they used and the organisations they trusted. Some had a distrust of anything related to social services, but were happy communicating with their local GP, or with a worker at their local social club. Some had never heard of their local older people's voluntary organisation, while others dropped in regularly with questions. Some tapped into knowledge provided by friends and neighbours, whilst others were socially isolated and were not able to access services until they attended a GP for a health complaint or found themselves in hospital. There is a strong argument for moving away from a model of customer interface that is based upon a single entry point for accessing particular services, and to recognise and support the plethora of contact points already utilised and trusted by older people, reflecting the diverse needs of the pensioner population.

Our research found that most older people wanted to be able to access a variety of services through an easily-identifiable access point, rather than taking on the onus of chasing up a number of different

service providers themselves. This was particularly true during times of transition when they were likely to be under some pressure. One-stop-shops, such as the bereavement centre, were based on this kind of approach, and were popular, but their success relies upon people knowing about these kinds of services, and factors such as being happy with their location and being able to access them. It will also invariably take some time for providers to become well known and trusted. Alongside this, some older people (particularly pensioners with special needs, such as disabilities and ethnic minority groups) have preferred to rely upon tried-and-tested access points (such as through respected local community organisations), which they have found to meet their specialist needs, and which might remain their first port of call even where other services are well known. In light of these strongly held preferences, the challenge for service providers is to give recognition to both of these approaches and to ensure that a multitude of resources can provide access to other services directly. This might occur through outreach, direct referral and partnership models, rather than simply signposting people, who might otherwise become 'lost' in the system, ultimately reducing the take-up of services by pensioners who are most in need.

Older people's forums provided an important mechanism for mobilising pensioners' voices and drawing attention to service needs and gaps. A forum in area one had played a pivotal role in the formation of the bereavement centre (see Chapter 2). However, there is a broader issue of how to encourage and enable greater number of older people to make use of forums that are well networked with service providers.

6 Modelling customer segments for today's pensioners

6.1 Introduction

One of the aims of this research study was to test the robustness and validity of the DWP's proposed pensioner Customer Segmentation Model (CSM). The research was to:

- inform the model with rich case data;
- test the assumptions underpinning the model;
- revise and enhance understanding of the proposed CSM for the pension age population.

This chapter introduces the CSM for the pension age population, as it was originally proposed. It then provides feedback on the model based on the research results, considering the separate and interactive roles of customer health, income and social support as they contribute to customer service access behaviours. Additional factors that seemed to influence help access patterns are also identified. A final section presents a more dynamic understanding of pensioners' support needs by mapping possible changes in segmentation that are associated with common types of transitions in later life. Based on this empirical evidence, a proposed revised model for segmenting pensioner customers is presented in Appendix C.

6.2 Background

The concept of customer segmentation derives from a marketing approach to understanding and predicting potential consumer behaviours. Customer groups are often distinguished on key demographic and economic criteria. The underlying assumption is that a correlation exists between the external characteristics of customers and their potential market needs and service accessing behaviour. For example, in the retail banking sector, customer segmentation may be defined through client criteria such as age, profession, income and assets. Take-up of particular products and services can be associated with variations in these characteristics.

The DWP and The Pension Service have recently embarked on segmenting their services through a consumer-focused strategy. Pensioners are identified as a distinct client group connected to certain services and the means in which these services are delivered. The Department is committed to improving pensioners' lives through enhanced provision, information and access to relevant services. As stated in the recent internal Departmental Report, the government aims:

to further improve and modernise services for today's and future pensioners, tailoring services to meet customer needs, improving efficiency and matching the best service standards achieved by comparable organisations in the public and private sectors. (DWP 2003b)

The creation of The Pension Service in 2002, the *Life Begins at 50* consultations, and the *Better Government for Older People* pilots also attest to this commitment.

A tailored service entails aligning support systems and services with pensioners' needs and preferences. In the report, *Customer Service Strategic Framework* (DSS 2000) the department outlines a generic strategy for understanding its customers:

- define the client group;
- differentiate where appropriate within the client group between different types of clients;
- identify the particular service requirements of each customer segment within the client group, noting what is already known about customer preferences for different levels of service and channels for service delivery.

6.3 Proposed Customer Segmentation Model

The CSM for today's pensioners was first introduced in 2001, deriving from secondary analysis of the Family Resources Survey (FRS). The model comprises seven distinct customer segments defined on three key sociodemographic dimensions, which are attributed differential significance:

- 1 **Level of health.** Health categories are derived from the FRS health section, defining health as either i) being fit and well or having a non-limiting condition, or ii) having a limiting disability or long-term health condition. Those in the latter group also tended to be in receipt of Attendance Allowance and Disability Living Allowance and these benefits were used as proxies in the sampling.
- 2 **Level of informal support.** A pensioner is considered informally supported if they live as a couple or in some other form of household arrangement. If living alone, a pensioner may receive informal support from outside the home. Support may be considered as practical (transport, meal preparation) or emotional (a listening ear) help. Informal support is usually not paid for in monetary terms, but may be recompensed in kind. The proxy for informal support used in the model is the pensioner's marital status (i.e. single or couple). The research extended this definition to identify reliable informal help that was received from extended family, friends and neighbours, noting whether this took place at a household or non-household level, and the quality of the support.⁷

⁷ Deriving from the FRS, the scope of the CSM dimensions was somewhat limited by the use of proxy variables for social support (couple or single household) and self-reports for identifying a limiting health condition or disability. The current study was able to refine these dimensions with details collected through a screening questionnaire and in the interviews themselves, portraying a more accurate description of pensioners' circumstances.

3 Level of income. Income is defined on the basis of the benefit unit (combined income if living as a couple) and is based on amounts coming into the household after housing costs (rent and mortgage interest) have been deducted. Low, moderate and high income bands were defined relative to contemporary pensioner incomes reported in the FRS and updated for 2003. These were replicated in the research. More detailed proxies for income developed through the research included reported level of income, level of savings, receipt of occupational pension, Minimum Income Guarantee, and other means-tested benefits.

The model segments pensioners into seven groups defined according to variations in levels of health, informal support and incomes. Segment seven customers are distinct in that membership is defined by reference to the person's place of residence as opposed to variation in socioeconomic characteristics.⁸ Characteristics of pensioner segments are defined in Tables 6.1 and 6.2, and a decision framework is presented in Figure 6.1, all of which have been developed and provided by the DWP.

According to the current model, just over half (55 per cent) of the pensioner population is classified as *independent* or '*generally fit and able to access services with little assistance*' (segments one, two and three). The remaining 45 per cent are classified with a '*limiting health condition or disability*'. This latter group is subdivided into those who need *assistance* (32 per cent – segments four and five) and those with *special needs* (13 per cent – segments six and seven). The proportion allocated to each of these categories may change in the future if the model is revised.

The *independent* group claims the youngest pensioners and a higher proportion of males. The prime distinguishing dimension for segments in this group is level of income. The more affluent pensioners (segment one) possess certain material advantages over the other two segments. They are most likely to receive an occupational pension, and home ownership (90 per cent) and access to a motor vehicle (82 per cent) are relatively high.

Segment three pensioners generally have a lower income than those belonging to segment two, and far more of their income is contributed by means-tested benefits. Aside from range of income, there are only subtle differences between the characteristics of segments two and three. Rates of home ownership and motor vehicle access are very similar.

Pensioners with a '*limiting health condition or disability*' are anticipated on average to be older. Those in the *assisted* category are distinguished on level of income and informal support. Segment four pensioners have a high income, they live alone and, by definition, assistance comes from outside the home. Compared to segment five pensioners, they are older, and the majority are female. Segment five pensioners are more likely to receive support inside their home, usually from their partner. It is the presence of informal support, and not the income range, that is the key distinguishing factor for this segment.

Segment six pensioners are similar to segment four pensioners in that they live alone; however, they have a lower income (low-moderate range), which may affect the amount of outside help they can afford to buy in. Segment six pensioners are also estimated to be older on average.

⁸ The uniqueness of segment seven customers was acknowledged in the study with additional interview questions and a slightly different sampling methodology. Refer to Chapters 1 and 2, and to Appendix A, for further details.

Table 6.1 Customer Segmentation Model characteristics

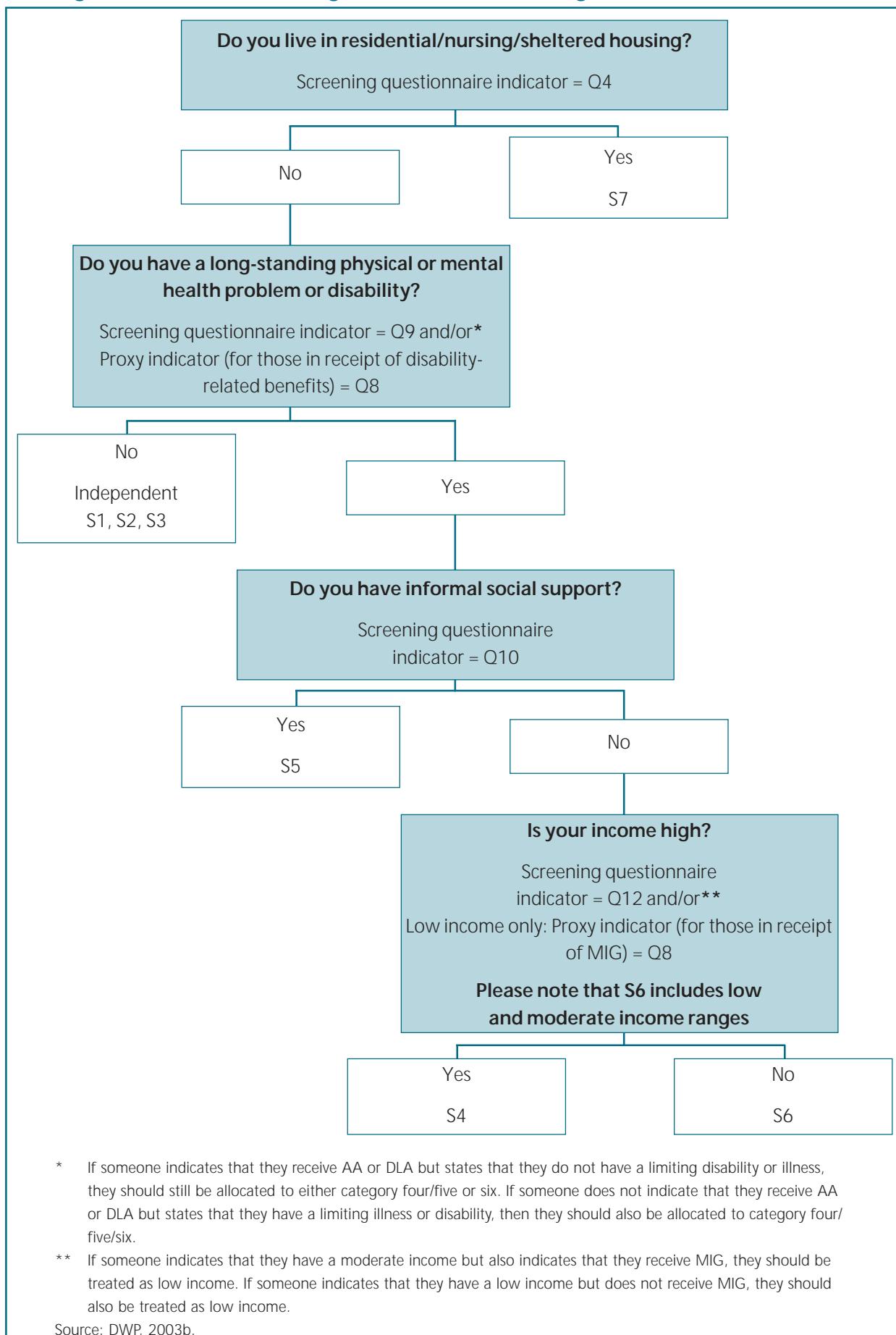
Segment	Independent			Assisted			Special needs
	\$1	\$2	\$3	\$4	\$5	\$6	
Definition	No limiting health problem or disability	No limiting health problem or disability	No limiting health problem or disability	Long-standing physical or mental health problem or disability	Long-standing physical or mental health problem or disability	Long-standing physical or mental health problem or disability	Residing in a residential/nursing home
Health indicators	Reports no limiting illness/disability or related benefits	Reports no limiting illness/disability or related benefits	Reports no limiting illness/disability or related benefits	Reports a limiting illness/disability AA/DLA	Reports a limiting illness/disability AA/DLA	Reports a limiting illness/disability AA/DLA	Long-standing physical or mental health problem or disability
Support indicators	Support not a distinguishing factor	Support not a distinguishing factor	Support not a distinguishing factor	Lives alone and has no informal help network	Lives with partner/other who supplies help in the home	Lives alone and has no informal help network	Long-standing physical or mental health problem or disability
Income indicators	Single: >£140 Couple: >£205 RP	Single: >£105 & <£140 Couple: >£160 & <£205 RP	Single: <£105 Couple: <£160 RP & MIG	Single: >£140 RP	All incomes	Single: <£140 RP & possibly MIG & SDP	Income not a distinguishing factor

Table 6.1 Continued

Segment	Independent			Assisted			Special needs	
	S1	S2	S3	S4	S5	S6	S7	
Definition	No limiting health problem or disability	No limiting health problem or disability	No limiting health problem or disability	Long-standing physical or mental health problem or disability	Long-standing physical or mental health problem or disability	Long-standing physical or mental health problem or disability	Residing in a residential/nursing home	Residing in a residential/nursing home
				No social support	Social support	No social support	Long-standing physical or mental health problem or disability	Long-standing physical or mental health problem or disability
High income	Moderate income	Low income	High income	All income ranges	All income ranges	Moderate/low income		
Age	60-80 90% under 80	60-80 80% under 80	60-80 79% under 80	70-90 68% 70 to 90	70-90 53% 70 to 90	70-90+ 75% over 70	70-90+ majority over 70	70-90+ majority over 70
Gender (ratio female: male)	1.4:1	1.9:1	2.3:1	3:1	1:1	3:1	Majority female	
Housing	90% own home	59% own home	57% own home	62% own home 24% rent from council	76% own home 14% rent from council	41% own home 36% rent from council	33% nursing/ residential	
Housing Benefit	4%	31%	24%	30%	14%	42%	N/A	
Transportation								
Percentage with access to a motor vehicle	82%	43%	46%	40%	72%	16%	Negligible	
Internet access	27%	5%	7%	11%	17%	2%	Negligible	
Telephone access	100%	98%	98%	98%	100%	96%	Most	

Source: DWP, 2003b.

Figure 6.1 Customer Segmentation Model – organisational chart



The CSM contains little information on segment seven customers, who reside in sheltered (66 per cent) and nursing/residential (33 per cent) accommodation. Being older, the vast majority of these customers are females living alone. Their help needs are considered to be mediated through their living arrangements and many customers have agents representing them on their behalf. However, early in the lifespan of the project, the position of pensioners living in sheltered or warded accommodation was reconsidered as distinctive from those living in residential or nursing care, and the DWP recognised that the former should be redistributed across the CSM according to key health, social support and income characteristics.

A primary objective of the research was to enhance the understanding of what 'independence' means for pension age people and, in terms of the CSM, to describe how the understandings of 'independence' differ for pensioners with varied levels of health, support and income, and to assess the relative significance of these factors. These indicators are anticipated to impact in various ways on pensioners' help needs and access behaviour, particularly in respect of more formal support and services. In building up an understanding of independence in later life it is important to explore the ways support and services can enable pensioners to feel independent and the research begs a number of questions. For example, what are the implications of a pensioner with a limiting illness who receives practical help from social services reporting a similar perspective on independence as a non-disabled pensioner who does not receive such help? To give a different example, if a pensioner who receives the help they need reports a greater feeling of independence compared to a pensioner who does not receive the support they need, then it may be concluded that the help is effective in enhancing independence.

The model is based on the assumption that pensioners' need for supports and services, and their corresponding accessing behaviours, are mediated by their levels of health, informal support and income. Thus, it may be expected that a pensioner who has no limiting illness (segments one, two and three) would be in less need of help than a pensioner with a limiting illness (segments four through seven). Likewise, a segment four pensioner may be more likely to have the financial means to buy in needed services than a segment five pensioner may receive through a more informal arrangement.

Quantitative analysis of the FRS can provide only a limited understanding of customer support needs and access of services. The CSM has been derived from a combination of proxies for describing levels of health, informal support and income. The current qualitative inquiry is intended to enrich the model with detail about how levels of health, support and income interact with help needs and support access. Furthermore, these dynamics can play a role in perceptions of independence among pensioners. Correspondingly, our topic guides included detailed probes and exploration of all key demographic criteria.

6.4 Study feedback

The focus of the chapter now turns to consider the implications of the study for the CSM, drawing on the experiences and circumstances of older people in the sample. This analysis considers how the model fits the data, how it can account for different types of pensioner needs and the different means by which these are likely to be met.

Overall, the model identified credible groups and sub-groups of pensioners. There was a core group of non-disabled pensioners with fewer health problems who did not need support and, consequently, did not seek help; these were concentrated in segments one through three. By the same token, an older person with higher help needs and greater use of supports and services sourced from outside the home was likely to have health priorities and to be living alone (as portrayed in segments four and six). At this level, the model is useful for identifying groups on which to target interventions.

Yet these are generalisations and the study identified exceptions to the rules and cases which tested the boundaries of the model. Pensioner circumstances did not lend themselves so easily to aggregation and there were interactions amongst the three key dimensions of health, support and income that are not accounted for in the model. Furthermore, the model depicts only a static picture of help needs, based on current patterns of service and support use. To build a more accurate picture, the model needs to be more dynamic, recognising the connection between changed circumstances brought about by life events and help needs. Independence in later life means having needs met through a seamless flow of supports. The implication for the model is that services need to be responsive to events over the whole course of later life.

The section begins with a brief appraisal of the model by key informants who were interviewed in the four case study areas. It goes on to assay pensioners' behaviours in accessing help, looking separately at the role of health, income and levels of informal support. The analysis then examines how seeking help is a function of the interaction between help needs and pensioners' life circumstances. In this we identify additional mediating circumstances for help access behaviours and trends in the data where generalisations in the model do not necessarily hold.

6.4.1 Key informants

The CSM had face validity with key informants who delivered services to the pension population. In the study key informants were largely in agreement with the model, categorising pensioners according to their levels of health, support and income. Most felt it was a logical way of describing types of pensioners who may use their services, but only one reported actively using a classification model when considering the organisation's client base. Several felt it might oversimplify the issue of independence and gave examples such as dementia and gender issues as factors which were likely to complicate the basic categories. The model triggered comments contrasting different types of customers:

'I mean it's because of the lack of one or more of these things that they come to see us really. The people up here with high income, they might come and see us, but it wouldn't be about things that are specific to older people. It might be because they're having an argument with the neighbour over the fence, you know, or the washing machine doesn't work, and what consumer rights have they got, that sort of thing. But nothing specific I would say. Whereas when you get down here [pointing to segments four, five, and six], not only do they need more support and help, but they probably need more support in terms of things like form filling because they're less able than up here [pointing to segments one through three], you know, they're less confident, all those sorts of things.'

(Area one key informant)

A small number of key informants pointed out that, in terms of their own work, it was really only the low income segments or those with high levels of health needs that their services had contact with:

'...the bulk of our clients are always, always struggling for money, always at the lower end and have invariably got a health issue.'

(Area two key informant)

6.4.2 Health, income and support

The study sample design provided coverage on pensioners in a range of later life circumstances, allowing for variation in health, income and household composition within levels of health and income groups. Here we examine the influence of each of these key dimensions on pensioners' needs and use of support.

Levels of health

As previous chapters have highlighted, pensioners' levels of health were key in delineating the kinds of services and supports that were used. Pensioners who were relatively more fit and mobile (segments one, two, and three) were less likely to access health services on a regular basis and they tended not to call on in-home support services for personal care. Rather, their activities and service use concentrated on non-health related facilities. Hilary and Jarvis, a segment two couple, were typical of this set. Both in their 70s, their activities were focused outside the home. They were both active in local archaeological and history societies; they mentioned their travels abroad; Jarvis attended art classes while Hilary was active in charity work. They did not see their GP more often than was needed for occasional prescription renewal and monitoring of Hilary's arthritis. On the other hand, Erwin and Rosemary, a segment five couple, both in their 80s, experienced a more limited world and needed more day-to-day help, in part due to their limiting health conditions. Erwin suffered from angina and a recent heart attack. Rosemary had osteoarthritis and was a wheelchair user. Both had experienced recent periods in hospital. The couple used travel tokens for intermittent taxi outings, including visits to the doctor. An agency attended to their grocery shopping and housekeeping.

However, whilst there were cases where there was a straightforward association between a pensioner's level of health and their help access behaviour, the research also highlighted some issues with the health dimension. For example, some pensioners downplayed their health problems, equating health decline with ageing, or, in couple households, one partner might place more emphasis on the other partner's health issues in lieu of their own. This calls into question the accuracy of self-reports on health. These issues highlight the need for using different indicators for health in order to increase reliability of the model.

A second issue regarding the health dimension is that the model depicts health as a static variable. However, health becomes less stable in later life. On average, older people's health deteriorates over time. In terms of the model, there is a good chance that pensioners categorised in segments one through three will transfer into segments four through seven. However, not all people will remain with higher health needs. While manageable health conditions can quickly become exacerbated, acute ones can become more manageable, moving people across segments and back again. For example, Noreen, a segment two woman in her 60s, was in good health at the time of her interview, but had recently recovered from cancer which had necessitated support from her husband and neighbours with housework and shopping. Yvonne, a segment three woman, was currently able to get around unaided with just a walking stick, and had recovered from a fall which led to a long period in hospital and the use of a wheelchair for several months. The model needs to account for the dynamics of health more effectively than at present.

Levels of income

The use of supports and services, particularly leisure services, varied according to household income levels, being particularly distinctive in terms of pensioners classified into the higher and lower income bands. As discussed in Chapter 5, lower income pensioners were generally more restricted in their activities; they were less likely to run a car because of the expense, and consequently needed to rely on public or other sources of transport. The research also supports the depiction of income as a

mediating factor for the types of help sought by older people with a limiting illness or disability. There were stark contrasts between segment four higher income pensioners and segment six low-moderate income pensioners in the ways in which they tended to their needs. Eleanor, a segment four pensioner, was deaf and limited by arthritis. Well into her 80s, she was able to remain at home with hired help for housekeeping, shopping and gardening. Low-income pensioners were less likely to buy-in household help and care, or to purchase specialised mobility aids and adaptations. Those who needed extra help in the home beyond statutory provision, relied on informal help; for instance, decorating and gardening help might be supplied by a relative or friend. Esther, a segment six pensioner living in sheltered council housing who had recently suffered a stroke and consequently had very limited mobility, received daily visits from social services, and regular physiotherapy. In addition to this, several neighbours kept an eye on her, bringing her the daily paper, taking her shopping and fixing things for her in the flat.

A theoretical discrepancy was picked up by the research regarding the application of income levels in the model. Income bands were derived separately for single and couple pensioners according to the benefit unit definition. This is straightforward for single pensioners living alone. However, because the model operates at the individual case level, members of a couple can be assigned to different CSM segments, usually due to different levels of health.

Additionally, the model assumes an equal distribution of resources within households. Household income can be misleading in terms of categorising women, particularly where their partners control the household budgets and they have little financial autonomy. For instance, Prudence was classified into segment one, based on her and her husband's income. Yet she reported she had no precise knowledge of her husband's earnings from a full-time job and they held separate bank accounts. Her spending patterns were restricted to the state pension she received as a married dependent. At the other extreme, the model does not account for extra income flows within multi-generational households where a pensioner is sharing resources with children and grandchildren. Issues relating to the distribution of income within a household go beyond the study focus; however, given that income can mediate the kinds of supports that are used, it might be necessary to consider individual levels of income when separately modelling pension age members of a household. The advantages of classifying pensioners individually on the basis of distinctive health and financial circumstances should be balanced against the value of treating couples as a unit, considering their potentially similar social support patterns, life experiences and expectations.

Levels of informal support

According to the model, informal support was defined in reference to the household unit – practical and emotional support within the household, that is, a live-in partner or other person. In fact, living with a partner or being married was taken as a proxy for the existence of informal support. It was the case that many of the couples who were interviewed tended to lean on each other for various degrees of support, and in many instances they relied on each other first, before looking outside the household for help. This was described in Chapter 5 as mutual support and inter-dependence. However, there are two very obvious problems with using marital status as a proxy for informal support. Firstly, the fact of living with a partner or being married does not guarantee that the partner is able to provide support. In cases where both partners in a couple are severely physically and/or mentally disabled and as a unit the couple are low income (segment fives), it is unlikely that they will be able to fully support each other. In these cases the assumption that couples have reliable social support (from each other) is hard to sustain. There would be a strong argument here for reclassifying them as segment six pensioners.

There is a second issue that impacts on the social support category. As the previous chapters have documented, substantial amounts of informal support were provided outside the household by extended family, neighbours and friends. Informal support not only existed at the household level, but for some was constituted by a web of social and/or familial relations and informal support networks. These types of help were not acknowledged by the CSM. The model therefore fails to take into account the way such support networks enable single pensioners to continue to live in their own homes. Pensioners living alone often had their help needs attended to by extended family, friends and neighbours. In some instances these single occupancy pensioners appeared to receive a greater level of informal support than pensioners who lived as a couple, particularly when both partners had health issues.

Whatever the definition of social support, this is not a category that facilitates generalisations about access behaviour in the straightforward way that the dimensions of health and income do. The boundaries around social networks are more fluid, and consequently less predictable. The quality of informal social support, whether at the household or external level, might be excellent, consistent and able to adapt to change, but it might also be superficial and ad hoc, and may come and go. In this sense, it seems unwise to make assumptions about informal support of any kind, particularly in terms of the role it plays in enabling independence.

Likewise, a theoretical distinction needs to be made in order to recognise pensioners who live alone but who draw on informal social support at a non-household level, and those who do not. Some pensioners living alone and needing help in the home had their needs met through an active network of friends and family. Others living alone needed outside intervention. For example, Lucy, a woman in her 70s who lived alone in the inner-city area, suffered from a range of health problems, which restricted her mobility, including it seemed likely, mental illness. She was estranged from her family, and relied upon a combination of statutory support and buying in additional domestic services. Conversely, living alone and receiving disability benefits did not necessarily imply the need for informal help. Living alone incorporated a more diverse range of circumstances – from people with no reliable informal support networks, to those who enjoyed close and regular support from their extended families, who were nearby or who lived some distance away. Other people's support networks might be more focused around their neighbours and friends. Whether pensioners were divorced, widowed or single also seemed to make a difference to their coping strategies and the quality of their social networks.

The CSM does not currently distinguish non-disabled pensioners (segments one, two, and three) according to their level of informal social support. In couple households, one partner often assumed responsibility for routine tasks, such as driving the car, banking, cooking and cleaning. Sometimes these were gender defined roles. In the event of a health transition, or the sudden death of a partner, this routine would be severely disrupted, leaving the remaining partner to cope. For example, as shown in Chapter 4, Deirdre had relied on her husband to organise household maintenance tasks, and when he died she admitted to finding this new responsibility quite daunting.

Segment three pensioners with no live-in social support might very well have more difficulty accessing help, compared to segment one pensioners with no live-in social support but who have the financial resources to spend on formal support. The CSM could usefully differentiate social support for these healthier pensioners to better predict future transitions.

These various examples of problems and anomalies indicate that imagining a spectrum of experience along a continuum of independence is problematic. Rather, the three factors, health, income and social support, interact in different ways, creating various scenarios of independence. Segment four and segment six are conceptually closer than the model implies, and segment five is differentiated

only in as much as living in a couple can help to increase independence. The distinction between segment five and segments four/six, in terms of whether pensioners have access to informal social support mechanisms, potentially groups a large proportion of pensioners into segment five, when what would seem to be the more important issue is whether support is sustained and reliable (often, though not exclusively, contained at the household level). There is certainly value in trying to make the model more two-dimensional to reflect these kinds of issues.

6.4.3 Pensioners in supported living

The segment seven sub-group of pensioners is distinguished from the rest of the population by virtue that their accommodation represents a distinct context for help. The model depicts pensioners who reside in residential or similar extra care facilities as having high help needs, which are mostly attended to by staff in the facility. In addition, access to support services outside the person's residence is often channelled through the same staff or a third person, such as a family member.

It is clear from this research that the CSM does not adequately reflect contemporary developments in housing and related philosophies around independence for older people. This change in ideology was observed in the area one case study, which depicted a trend away from traditional homes towards an extra-care provision⁹. While the model implies that membership of segment seven is distinctive, defined by reference to place of residence and imposing a medical model of disability, the development of new housing initiatives calls this into question. The new style housing appears to be underpinned by a dual model of disability:

'...in which personal/medical factors determine the extent and severity of people's impairments; but social and economic forces determine the extent of their disadvantage...'

(Berthoud *et al.*, 1993)

Taking a dual model of disability perspective, being 'fully supported' means being in an environment that promotes one's *self-defined* notion of independence. As seen in the specialised residential care case study presented in Section 4.6.1, at least some people in this facility wanted to do things for themselves, both within and beyond the residential home, and they were 'fully supported' in doing so. While support is not a distinguishing factor for segment seven pensioners, in order to recognise the innovative developments in extra care facilities, perhaps the model should recognise the role of a variety of supports and the demand for these, in residential style homes. Although many pensioners have agents representing them, these are varied and some pensioners represent themselves. To rely on representation by an agent raises the question of the quality of information at the agent's disposal, which is beyond the scope of this study, albeit pertinent to service delivery. What can be said is that the number of people representing themselves is likely to grow with the spread of new style homes, and consequently the profile of pensioners living in these facilities will change. As the ideological push to extra-care housing continues, the model for segment seven pensioners, as it stands, will increasingly become distant from the day-to-day realities of a diverse specialised residential care population.

⁹ See also the study of a retirement community reported in the recent JRF report on Hartrigg Oaks; the first example in the UK of a continuing care retirement community run by the Joseph Rowntree Housing Trust (Croucher *et al.*, 2003).

6.5 Other pensioner circumstances

Drawing upon the interviews, this section considers how pensioners' life circumstances interacted with their help needs, resulting in different kinds of support and service use. Though older people outwardly displayed similar needs, due to intervening circumstances, their needs were met in different ways.

When considering the role of support in enhancing older people's independence, the study identified a myriad of circumstantial factors that appeared to mediate help seeking behaviours. Some of these circumstances resulted from interactions between the key drivers in the model – health, income and social support – which were discussed in Section 6.4.2. Other circumstances were identified in preceding chapters when examining the link between independence and help. Additional circumstances with implications for support needs include:

6.5.1 Personality characteristics

Some people considered it a personal weakness to rely on somebody else, or equated help with accepting '*charity*'. A resistance to seeking help was observed at both ends of the health spectrum and served to contradict the intensity of care anticipated in the model by some pensioners who were living alone and experiencing poor health.

6.5.2 Temporal factors

Time elapsed since the onset of a health condition or a key life transition, such as the loss of a partner, was key to determining help needs. Time essentially makes a difference between stability and a state of flux. More acute needs surround the onset of a dramatic change in circumstances. The model needs to identify triggers for life course events when more intense help is needed (see Section 6.6 below). The role of time in adaptation also helps to explain why some pensioners in receipt of disability benefits lived an active life while others did not.

Related to the previous point, help that is provided through informal means is likely to diminish over time and even end before needs are fully met. This is particularly pertinent to circumstances where pensioners prefer to draw on help from friends and family, such as, following a stay in hospital or comfort after a bereavement. Therefore, even when informal supports are in place, it should not be assumed these will adequately persist. This has implications for the monitoring of needs by formal help agencies.

Time residing in the immediate area had strong implications for the size and intensity of social networks, leaving pensioners new to an area at a deficit in regards to informal support. It was not uncommon for pensioners to sell up and move house to enjoy a higher standard of living in a new community. However, these older people may be more vulnerable in a time of need, and could be flagged up in the CSM.

Timing of information received about a service was critical for determining the use of informal versus formal support. In the case of planned transitions like a hospital stay, informal arrangements were often made prior to entering hospital, which implies that this would be an optimal time to receive information about formal sources of help.

6.5.3 Household circumstances

Since the CSM segments individuals, some circumstances surrounding couples were awkward to rationalise:

- Partners who were carers were difficult to place in the model. Carers are recognised as agents or 'customer representatives'. According to the model, a pensioner with special care needs who has a partner is assigned to segment five. However, the non-disabled partner is assigned to a separate segment (one through three). It follows then, that the help seeking behaviours of the carer do not fit the profile of a typical segment one, two or three. It seems that pensioner carers warrant a separate segment in the model. This would recognise that these people are also customers and have their own needs, although these are often deferred in the interests of being a good carer. Carers themselves may also have declining health, threatening to shift the position of both partners in the CSM.
- Pensioners in a couple relationship where both partners had a limiting health condition or disability were also difficult to place in the model. By virtue of being a couple, both partners are currently assigned to segment five. However, in this circumstance neither partner may be capable of practically supporting the other person. The model does not currently account for this situation, it seems important to be able to identify this group.

6.5.4 Ethnic minorities

This sub-group of pensioners present issues attached to language and cultural mores that will influence the take-up of services: communication, trust, family expectations and gender issues. There is a projected increase for ethnic membership in the pensioner population (Atkin, 1998) which highlights the need to flag the special needs of this subgroup in the model. Although the CSM does not currently reflect the separate needs of BME elders, these are a growing concern for policies promoting social inclusion. Recent DWP-funded research has taken up these issues (Barnard and Pettigrew, 2003).

6.5.5 Availability of services

There were notable differences between the four case study areas about what formal services were on offer to pensioners. This inevitably impacts on the choices older people have for fulfilling their help needs and accounts for regional variation in patterns of reliance upon formal and informal means of support.

The balance of help described in the above situations was critical for maintaining older people's independence. The DWP's 'Customer Value Propositions' document¹⁰ identifies subgroups of pensioners whose needs cut across the CSM, but who warrant extra attention due to their special circumstances. These additional subgroups in the pensioner population include: the homeless, pensioners with addictions, people recently released from prison, asylum-seekers and refugees.

¹⁰ Internal document.

6.6 Transitions between segments

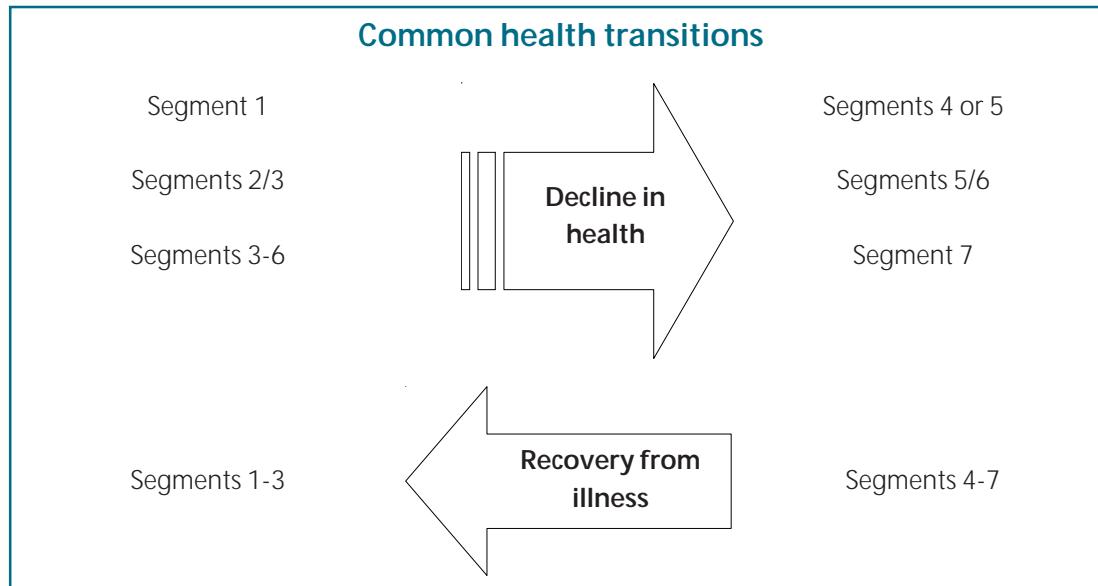
Transitions in older people's life circumstances are inevitably tied to changes in help needs. As noted in Chapter 4, ageing is associated with decline in health and mobility, and these changes become more acute in terms of help needs as older people lose their networks of social support through bereavement and inaccessibility. These life transitions hold implications for the CSM which the DWP recognise in their documentation on the model:

'It is important that The Pension Service can determine which segment its customers fall into, but also that it can track people as they move between segments, and is able to respond to their new needs. Even more importantly, it needs to be able to identify through key indicators, when customers are about to move segments and be able to offer help before the point of crisis is reached.'

(DWP, 2003b)

However, at present, the CSM presents a static picture of pensioners' needs, concentrating on pensioners' current needs and help seeking behaviours, as depicted in Figure 6.1. Identification of key indicators or trigger points for transitions entails mapping probable movements between segments. This is necessary for a fuller understanding of the dynamics behind assisting adjustment to change. Taking for example, an acute change in health, it is possible to map a number of hypothetical transitions between segments, as illustrated in Figure 6.2.

Figure 6.2 Mapping health transitions



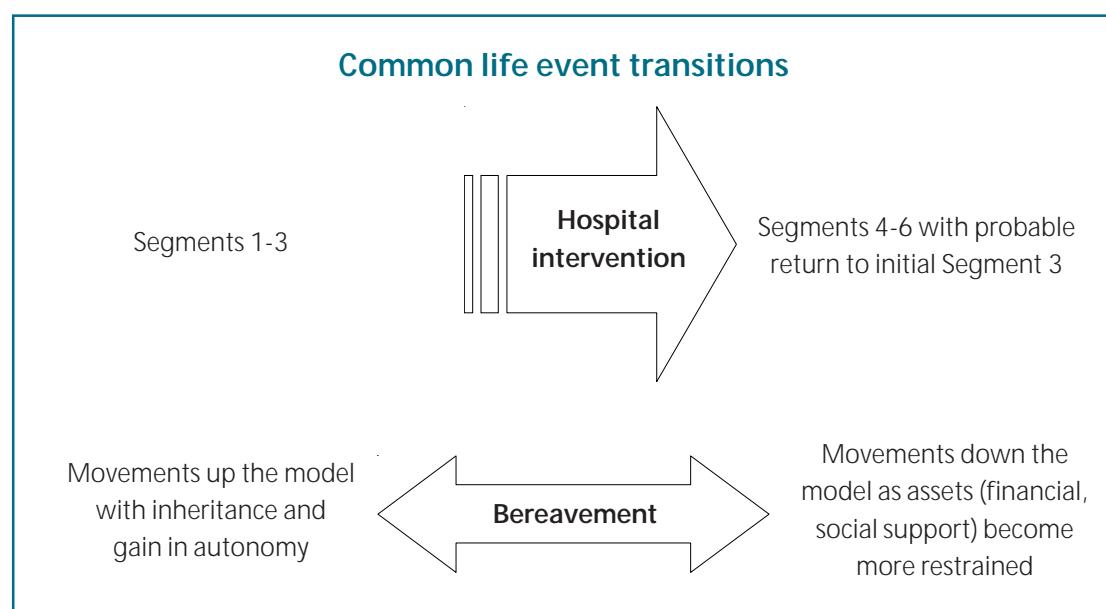
- With the onset of ill-health, from segment one to either segment four or five, depending on the level of social support available.
- From segments two and three into segments five or six, with the onset of ill-health, depending on the level of social support available.
- Conversely, from segments four to six back into segments one through three, where an acute health condition is successfully treated.
- From segments one to three to segment five for couples, with the onset of ill-health.
- From all segments, but in particular from segments three to six, to segment seven, with the intensification of health conditions.

These examples operate within the boundaries set by the model, which dictate pensioner segments according to individuals' levels of health, income and social support, prior to a health transition. The study can contribute to a more multi-dimensional understanding of movements between model segments by drawing from the three case study transitions in later life presented previously in Chapter 4 – moving into an extra care facility, bereavement and a hospital intervention. These cases are particularly useful for understanding singular transitions that move pensioners out of their initial segment and then, with gradual adjustment, back again.

Due to the nature of the life transition, pensioners who are living in an extra care residential facility tend to have health issues, and therefore move from the previously higher needs segments four to six. The map of these people's pathways through the model then terminates with segment seven. The progressive nature in the numbering of segments also implies that segment seven is, in some way, a worse off state than all the other segments. However, as discussed in Section 6.4.3, the model does not adequately account for variations within the segment, as some pensioners who move into segment seven actually experience an improved lifestyle and enhanced feelings of independence. For example, Alan, formerly a segment six, chose to move to a residential home because his arthritis was getting progressively worse and he found it difficult to cope in his own home. The move was a positive experience for him as his practical needs were catered for and he experienced enhanced social contact. Esther's circumstances spell out an example which maps a transition from segment three to segment five after suffering a stroke, and into segment six after losing her husband. She probably provides a relatively typical portrayal of elderly couples' trajectories. When she was interviewed, Esther had limited contact with her extended family and expected to eventually need to move into a residential care home (segment seven).

In contrast to the transition into supported living, cases of bereavement and recovery after a stay in hospital are likely to occur to pensioners within any of the segments one through six. These events are followed by a period of intense need for practical and emotional support (segments four through six), intensifying the needs of people who already had high support needs. After a period of adjustment, these people variously return to their previous positions in the model, or their stabilised circumstances assign them to a new segment. These movements are depicted in Figure 6.3.

Figure 6.3 Mapping life event transitions



A bereavement transition is less likely to have a long lasting effect on health (although pensioners who experienced the loss of a loved one, notably men, often experience a decline in health). This transition can also impact on a person's financial position, through inheritance and liquidation of assets, moving widows and widowers into segments one or two, or from segment six to segment four. By the same token, bereavement of a partner can profoundly decrease a pensioner's financial stability. This was the case for Laurie, whose household income dropped considerably when several disability benefits were reduced when her husband died. Household help, which the couple had qualified for when her husband was alive, was also withdrawn and so her daughter was now helping out. Laurie was finding it difficult to cope on her reduced income and level of support. Although beyond the scope of this study, Laurie's case has implications for both the equivalisation and the extended run-on of disability benefits and services for supporting independence in later life.

Understandably, hospitalisation is associated with a health transition resulting in various short- to long-term lasting effects that can ultimately move older people into the higher needs segments. The case study on the home-from-hospital scheme concentrated on individuals who had mainly undergone a planned procedure that would take them through a period of adaptation and eventual return to the previous segment. As this transition was planned, the interviewees could anticipate help needs and plan their support systems in advance (although this did not always happen). The length of time of recovery was key in this transition. For example, Lesley's hip replacement surgery was followed by complications which extended her caring needs beyond the contracted period of the settling-in service. A widow, she was in her 70s and a segment one prior to the operation. According to the model, her transition phase positioned her in segment four. She expressed her distress over relying on social services for help, as her informal network of family and neighbours could no longer sustain the level of care she needed. The model would anticipate Lesley returning to her initial position at segment one after recovery. However, at the time of interview, she was hovering somewhere on the boundary. Lesley's experience demonstrated how fragile informal support systems can be, especially when the need for intense care persists. It also identified a trigger for formal intervention following routine medical intervention.

6.7 A note on terminology used

Finally, it is clear from the research that 'being independent' spanned the entire spectrum of pensioners, with strong feelings of independence being expressed by older people experiencing a range of circumstances. For this reason, the labels employed in the CSM to describe pensioner groups – 'Independent', 'Assisted' and 'Special Needs' – are not entirely valid and could be construed as patronising or demeaning. The labels imply exclusivity; that people in the 'Independent' category do not have any support needs, and that people in the 'Assisted' and 'Special Needs' categories are not independent. The study clearly showed that independence is subjective, shifting and multi-faceted. If the objective is to identify groups of pensioners with differing help needs, then more useful broad labels for these groups might be 'low support needs', 'moderate support needs' and 'high support needs'.

6.8 Summary

Overall, the CSM broadly reflects the help needs and accessing behaviours of certain subgroups of pensioners. The distinctions between subgroups of pensioners in the model did identify some important conceptual and empirical differences in service accessing patterns. However, the model does not adequately reflect the complex interactions between health, income and social support that

occur in reality. Its conceptual underpinning, a continuum of dependency, was also problematic, since it did not map onto interviewees' own values and priorities in terms of independence. The model would benefit from being applied in a more dynamic way, reflecting the interaction between changed circumstances and help needs, since certain trigger events are likely to influence perceptions of independence and patterns of service accessing behaviour, whether this is temporary or more permanent. Proposed revisions to the model are outlined in Appendix C.

6.8.1 Issues to consider

Subjective **health** reporting varies considerably among those with seemingly similar objective conditions, and under-reporting of health may be itself a coping strategy. Health status can also change rapidly among older people. Where there are large differences between couples in terms of their health status, this makes it difficult to assign them to the model.

Income alone is not necessarily an accurate proxy for living standards and the degree of independence that people enjoy. Savings and home ownership both facilitate increased independence. The model also does not equate for the costs of disability.

The definition of **social support** as being provided within the household, and in particular the use of marriage as a proxy, is problematic, especially where both members of a couple have significant health problems. The research also found that the degree of support enjoyed varied considerably among those living in objectively similar circumstances. Moreover, these relationships were fluid and unpredictable.

Many other factors that affect independence are not taken into account in the CSM. These include some factors which are hard to measure (such as the role of personality in individual decision-making, and temporality), and others which could more easily be factored in, such as household circumstances and area. Clearly these circumstantial factors are key to anticipating the balance between the use of informal and formal sources of help.

There are numerous examples of transitions that characterise later life, particularly those surrounding health. Three transitions were presented, relating to the three case studies explored in Chapter 4: moving into supported living, bereavement and leaving hospital care. What was apparent for understanding transitions was the need to map individuals' movements through the segments, rather than assume typical trajectories that overlooked the complexity of individual support needs. What the case studies did was identify exceptions to what might be identified as anticipated movements, and by implication, trigger points for when informal support systems might fail and when formal support might usefully intervene.

7 Conclusions

7.1 Introduction

This chapter develops the findings presented in the preceding chapters, identifying the main themes to emerge from the research, and analysing these in terms of the current policy context, as well as presenting their implications for the Customer Segmentation Model (CSM).

It looks at the key components of older people's understandings of independence, emphasising their dynamism and interaction with pensioners' changing circumstances. Reflecting the key ways in which concepts of independence change in later life, common transitions are identified, which often denoted alterations in support needs. The ways in which these contrasting needs are met, by a combination of informal and formal means of support, are related to pensioners' feelings about receiving help, and to their personal values and preferences. The study's findings are then related to the DWP's CSM, in its value as a tool for anticipating differential needs, particularly the relative significance of health, income and social support as influences on pensioners' service use patterns. Finally, the results are analysed in terms of their broader policy implications for service delivery processes in meeting the needs of older people.

7.2 Independence in later life

Older people's understandings of independence encompassed a number of interrelated elements, reflecting their circumstances and changes over time. Underlying this were the twin components of autonomy and self-reliance, which formed a dialectical relationship underpinning interviewees' perceptions of what it meant to be independent. The balance between the emphasis 'doing what you want to do' and 'doing things for yourself' shifted to reflect older people's capabilities, social context and expectations about their lifestyles.

Intersecting these priorities, were a series of sub-components to independence. The most important of these was the value that interviewees attached to staying in their own homes, maintaining personal mobility, good health and social contacts, and having sufficient finances to live a comfortable life. The concept of independence was thus multi-dimensional and fluid, and the relative weight older people attributed to particular components reflected their circumstances, as well as their individual values and preferences. So, for example, pensioners with fewer health problems rated ill-health and loss of mobility as events that would compromise their independence, while those who were disabled or had a limiting health condition had often come to terms with this, and defined independence according to factors like being able to exercise control over day-to-day decisions and continuing to live in their

own homes. Household circumstances also had an important effect upon what independence meant to older people, with couples being particularly likely to emphasise the value of interdependency rather than individual self-sufficiency. Older people's understandings of independence were also related to factors like class, cultural or ethnic background and gender, which provided a context for their expectations and influenced the strategies they employed to manage their situations. In particular, income in later life often underpinned the way interviewees framed their independence, since it was often an important determinant of the choices they were able to make.

7.3 Transitions and heightened support needs

Pensioners reflected on different aspects of independence, often in relation to a key life transition (or transitions). So, among individuals, independence was a fluid concept. Support needs frequently changed in later life, often prompting a reassessment of the terms in which pensioners framed their situation. A life crisis or a steady decline in quality of life due to lack of appropriate support, prompted older people to reassess the terms they used to describe independence, increasingly defining themselves as lacking independence or control over their life. A number of common transitions were central to understanding the sorts of changes older people might be undergoing. These transitions included more gradual changes associated with the ageing process and the normative expectation of retirement, in addition to health and domestic transitions, which can be particularly destabilising. They could also occur on their own, in combination with, or in succession with other transitions, complicating the range of changes which older people have to negotiate. Amongst these, domestic transitions, including moving home, family breakdown and bereavement, were particularly wide-ranging in their implications, and tended to be relatively unsupported. Bereavement especially, had important impacts upon interviewees' social networks and expectations of support.

However, transitions were not necessarily uni-directional; for example, older people could recover from illness, or could rebuild effective support networks, including repartnering, following divorce or bereavement. The effects which transitions had upon older people were mediated in important ways by socioeconomic, demographic and personality factors. For example, older people's proximity to their families and the kinds of informal social support which they were able to draw upon, was often a central factor in how they coped with bereavement. At a more structural level, class differences informed how interviewees responded to health crises, with those with higher incomes being more easily able to purchase the kinds of mobility aids and care that enhanced their quality of life.

Supporting the intensity of help needs during pensioners' life transitions was critical to maintaining independence. Analysis of three specialised services have drawn attention to the important role that a raft of support, targeted at critical points in these transitions, can play in older people's maintenance of independence in later life. Looking at a more holistic lifestyle service, that of supported accommodation in both traditional and new-style settings, and comparing this with two more crisis-driven services, a bereavement service, and a leaving hospital service, these specialised services provided a number of lessons for supporting older people's transitions. These included the value of a managed package of support, that is accessible but not imposed upon people, the role of service providers in anticipating and responding to key transitions, and the importance of recognising older people's support preferences and offering multiple points of contact and access.

7.4 Negotiating support in later life

Older people's expectations about family and kinship obligations often had a significant influence upon their support preferences, and were informed by factors such as class, gender and cultural

background. Most interviewees preferred to rely upon family and friends to meet at least part of their support needs. However, this was not always possible or desirable, since families lived some distance away, were occupied by their own jobs and young families, and in some cases, relationships had become strained or broken down completely. A small number of older people had no remaining family.

Interviewees adopted a broad range of routes to find out about services, and there was little agreement regarding which of these were most effective or desirable, suggesting a continued need for services to be publicised broadly and imaginatively. A key issue, however, was that pensioners' preference for obtaining support from a single (trusted) source meant that other services would be accessed only if they were signposted at this point of contact. The most important services for older people were felt to be health services, transport services, and home-based care services, which promoted different aspects of independence, respectively enabling pensioners to manage their quality of health, enjoy enhanced mobility, and to stay in their own homes.

Many interviewees found asking for help problematic, because of the stigma they associated with claiming statutory services, a lack of confidence or knowledge about what was available, perceptions that asking for help was an admission of failure, a strong personal ethos of self-sufficiency, or a concern about not becoming 'a burden' upon friends and family. Often, older people commented that they would feel happier accepting support if it was offered to them proactively, rather than being something which they had to search for themselves, and it seemed likely that worries about asking for help reduced the take up of available support services. Paradoxically, the people who did not ask for help in this way, but who were coping by themselves, were often those who stood to gain most from services that supported independence.

Reflecting pensioners' differential circumstances and needs, the help they received varied, comprising of any one, or a combination of, support drawn from informal support networks, statutory services, the voluntary sector, and, where income was available, private agencies. The balance of these was very much a matter of individual preference, although it sometimes also reflected ease of access.

In terms of unmet needs, the research identified a demand for support services for pensioners, in particular wheelchair users, which enabled to them to be taken out outside the home. Many interviewees also commented that occasional help with domestic chores, such as dusting or hoovering would make a big difference to their lives, and this kind of support would enable older people to remain in their homes for longer. Some people who would have liked to receive care services were not familiar with how to access these, and local waiting lists and restrictive or unreliable care services were referred to. There was also a strong demand for more reliable public transport and improved disability access to transport services. However, the general impression was that older people made low demands on services and had limited knowledge about what was available. As we have already seen, pensioners were often reluctant to ask for help, and sometimes this was the result of previous negative service experiences.

7.5 Interpreting differential needs: the customer support model

In recognition of the influence of pensioners' circumstances on their support use patterns, the DWP's CSM has particular value for identifying groups of customers who are likely to benefit from the targeting of services. In this way it can be used to anticipate the help needs of the pension age population. The pensioner interviews indicated that being independent necessitates not only having their help needs met, but that this is done in ways which respect individual autonomy and choice. The

strong value attached to autonomy by pensioners in a variety of health, income and social support situations has important implications for the model.

What may be less useful is conceptualising support for independence in terms of a sliding scale of 'dependency'. Currently the CSM overlooks the interplay of support and independence, and oversimplifies differences between subgroups of pensioners. Yet pensioners who transgress these distinctions, or who sit on the boundaries between segments, may be marginalised, despite the fact that they may be the most vulnerable groups with specific support needs, or may be going through transitions. The model depicts a highly static view of needs, assuming a continuity of demand within subgroups. Furthermore, experience within segments is diverse, and some older people's help-seeking behaviour will not match the prototype for their segment, such as pension age carers or representatives.

The model distinguishes between pensioners in terms of three key categories, health, income and social support. While these are clearly important influences on service use and independence in later life, the prioritisation of health above income, and over social support is unhelpful, since one or other factor may be dominant at a given time, as the focus upon transitions has shown. Additionally, the model does not apply the criteria systematically throughout, and in particular, does not recognise the importance of social support to pensioners with fewer or no health problems, although this may be critical in predicting their movements to subsequent segments in later life.

The sociodemographic drivers behind the use of informal and formal types of help are more complex than depicted in the model. This is due both to the fluidity of informal networks, and to the rigid boundaries of what are defined as needs within statutory services. Informal support is likely to be limited by a myriad of boundaries, including the nature of the support needed, the character of the support relationship, the time that the caregiver has available, the time required to perform care tasks, and the overall life of the caring relationship. The intra-complexities of informal care boundaries add to the challenge of predicting formal care needs.

7.6 Implications for policy: promoting independence in later life

While the focus of this research was not The Pension Service or the Third Age Programme, but the day-to-day service use patterns of pensioners, our findings have a number of broader implications, which relate to how services are coordinated between multiple providers. While The Pension Service and the Third Age Programme are mainly invisible to pensioners themselves, the unrolling and development of these has obviously provided a context to current thinking behind service delivery in the areas where the research was conducted. In a number of important senses, these implications complement the shift in thinking in terms of how services are delivered to older people that was stimulated by recent AC/BGOP research (see Chapter 1).

7.6.1 Joined-up services and key points for intervention

Interviewees displayed a preference for relying upon familiar agencies and employing lifelong patterns of service use to access support in later life. This provides a strong argument for joined-up services, which offer multiple legitimate routes into a broader host of services, which cut across a variety of sectors and which reflect the diversity of pensioners' circumstances and expectations. The research's focus on transitions and the critical changes in pensioners' support needs during these times, also provides compelling evidence for integrated service delivery. During periods of transition, pensioners were often particularly vulnerable and lacked confidence; it was at these points that they

would most benefit from access to a range of services delivered proactively and in a holistic way. Often though, older people learnt about services only gradually through word-of-mouth, and sometimes too late to meet their most intensive needs. Joined-up service delivery would enable pensioners to enjoy holistic support through key transitions associated with later life. Service providers should seek to identify trigger points when intervention is required, at which any one agency can jumpstart the facilitation of access to a wider host of relevant services. Single points of contact, such as social workers, who acted as intermediaries in putting pensioners in touch with relevant services, were often popular. These simplified the process of negotiating unfamiliar, and sometimes overwhelming, support systems at times when personal resources were low and the need for help urgent. An ongoing relationship with a trusted individual had particular value in these circumstances.

7.6.2 Equalising accessibility and targeting services

The multitude of ways in which pensioners had, or wished to, find out about support services, provides evidence of the continued need for publicising services broadly and in a number of ways. However, pensioners with the most intensive support needs may not be reached through standard outreach and publicity methods, and require targeting through non-traditional and specialised routes if they are to receive the same opportunity of service access. For example, pensioners with mental health problems, learning difficulties, older people with ESOL needs, and housebound pensioners with visual or hearing impairments, require services to be publicised and delivered in ways that are sensitive to their needs, and very often pensioners are multiply-disadvantaged and are particularly likely to have accessibility issues. Furthermore, it is vital that services aimed at supporting pensioners incorporate a strong element of outreach work, since the research uncovered a deep-seated dislike of asking for help, which reduced take-up and ultimately deprived older people of much needed support.

7.6.3 The need for flexibility

In view of older people's widely varying circumstances, support needs and service preferences, there is clearly need for flexibility in the way that services are provided. In recognition of their changing needs and often low levels of confidence, at the initial point of service access, providers need to maintain an open-door approach which draws attention to the range of support available and emphasises its longer-term accessibility and the fact that it is designed to respond to changes in circumstances.

7.6.4 Communication

Pensioners' patterns of service use were often informed by their pre-existing experiences and by the reports they had of contact from their social networks. The research uncovered many instances in which pensioners' needs had been misunderstood, or when their discussions with service providers had been confusing. It is vital that communication is treated as a priority, and is appropriate to pensioners' needs, for example, being provided in community languages, in British Sign Language (BSL), Braille and type talk formats, and that service providers are able to dedicate the necessary time to offer pensioners relevant support. Notably, pensioners are often at a time of heightened vulnerability when they come in to contact with service providers, and follow-up contact (such as a written confirmation of what has been agreed at a home visit, or a regular phone call to check whether circumstances have changed) may be necessary to ensure that they understand their entitlements to, and are able to access, desired forms of support. It also needs to be made very clear to pensioners that they have alternatives if they have found a response from a provider to be unsatisfactory, for example, that assessments can be appealed, information amended, and that they can see another member of staff if they so wish.

7.6.5 Advocates

Older people's service use was sometimes mediated by advocates, in terms of informal or formal representatives expressing their needs. Advocates play a particular role in negotiating the kinds of service access difficulties described above. There are two issues here. First it is vital that advocates understand older people's desires and communicate them effectively, developing agreement on the kinds of support that are desired, otherwise pensioners' independence will be compromised in important ways. Secondly, there was evidence that some pensioners with specialist needs, had limited or lacked access to appropriately qualified advocates, which seriously restricted their ability to use services, and which made them more reliant upon informal sources of support in order to survive.

7.7 Conclusions

The research has provided evidence that strong, well-managed support systems that coincide with pensioners' priorities about how they would like support to be provided play an important role in maintaining independence in later life. These may consist of informal social support from partners, extended family and friends, or more formalised services from the statutory, voluntary and private sectors. Some of the most successful packages of support drew upon a combination of these sources, which have particular advantages in terms of flexibility and responding to crises. The important issue in terms of independence, was that older people were able to negotiate (or have negotiated for them) a package of support that they felt comfortable with and which reflected their individual needs, values and priorities.

This provides corroboration of the research hypothesis that independence in later life is informed in important ways by the various kinds of formal and informal support that older people draw upon. The DWP's CSM has value in this context and in its role as a marketing tool for differentiating the help needs and accessing behaviours of particular subgroups of pensioners, and it has potential for targeting services towards these groups. However, there are also limitations in terms of how far the CSM can accurately reflecting the complex interactions between health, social support and income in the daily lives of the pensioner population, differences of which service providers are very much aware.

Attention has been drawn in this report to older people's heightened vulnerability during times of transition commonly associated with later life. While the research has illustrated a range of ways in which pensioners' support needs may be met during such times, these will enable older people to maintain their sense of independence only to the extent that critical aspects of lifecourse continuities are prioritised. Older people emphasised that the same things mattered to them as had done throughout their lives. Hence, services need to be aimed at supporting them in maintaining the status quo as far as possible, particularly in relation to remaining in the family home and being able to continue to live as a couple, and in recognising symbolic markers in terms of preserving independence, such as being able to continue to take part in valued leisure activities, or still being able to provide help to friends and family.

References

Abbot, A. and Fisk, M. (1997) *Independence and Involvement: Older People Speaking*, St Albans: Abbeyfield Society.

Appleton, N. and Porteus, J. (2003) 'Extra-care housing for older people: An introduction for commissioners', Department of Health.

Atkin, K. (1998) 'Ageing in a multi-racial Britain: demography, policy and practice', in Bernard, M. and Phillips, J. (eds.) *The Social Policy of Old Age – Moving into the 21st century*, Centre for Policy on Ageing, London.

Audit Commission and Better Government for Older People (2004) *Older People – Independence and well-being: The challenge for public services*, Audit Commission.

Aykan, H. (2003) 'Effect of childlessness on nursing home and home health care use', *Journal of Aging and Social Policy*, 15 (1): 33-53.

Baarsen, B. van, Smit, J.H., Snijders, T.A.B. and Kees, P.M.K. (1999) 'Do personal conditions and circumstances surrounding partner loss explain loneliness in newly-bereaved older adults', *Ageing and Society*, 19 (4): 441-470.

Barnard, H. and Pettigrew, N. (2003) *Delivering Benefits and Services for Black and Minority Ethnic Older People*, Research Report for the Department for Work and Pensions, No. 201.

Barnes, H., Parry, J. and Lakey, J. (2002) *Forging a New Future – the experiences and expectations of people leaving paid work after 50*, Bristol: Policy Press.

Barnes, H., Parry, J. and Taylor, T. (2004) *Working after State Pension Age: Qualitative Research*, DWP Research Report No. 208.

Barnes, H. and Parry, J. (2004) 'Renegotiating identity and relationships: men and women's adjustments to retirement', *Ageing and Society*, 24: 213-233.

Bernard, M. and Phillips, J. (2000) 'The challenge of ageing in tomorrow's Britain', *Ageing and Society*, 20: 33-54.

Berthoud, R., Lakey, J., and McKay, S. (1993) *The Economic Problems of Disabled People*. London: PSI.

Boaz, A., Hayden, C. and Bernard, M. (1999) *Attitudes and Aspirations of Older People: A review of the literature*, DSS Research Report No. 101, Leeds: CDS.

Boneham, M.A. *et al.* (1997) 'Age, Race and Mental Health: Liverpool's Elderly People from Ethnic Minorities', *Health and Social Care*, 2: 113-125.

Borell, K. and Karlsson, S. (2002) 'Reconceptualising intimacy and ageing: living apart together', paper presented to the *Reconceptualising Gender and Ageing* conference at the University of Surrey, Guildford, 25-27 June.

Bottero, W. (2000) 'Gender and the Labour Market at the Turn of the Century: Complexity, Ambiguity and Change' *Work, Employment and Society* 14 (4): 781-791.

Bowling, A., Banister, D., Sutton, S., Evans, O. and Windsor, J. (2002) 'A multidimensional model of the quality of life in older age', *Aging and Mental Health*, 6 (4): 355-371.

Butt, J. and Box, L. (1997) *Supportive Services, Effective Strategies*, York: Joseph Rowntree Foundation.

Butt, J. and O'Neil, A. (2004) *Let's Move On: Black and Minority Ethnic older people's views on research findings*, York: Joseph Rowntree Foundation.

Chang, D., Spicer, N., Irving, A., Sparham, I. and Neeve, L. (2001) *Modernising Service Delivery: The Better Government for Older People Prototypes*, DSS Research Report No. 136, Leeds: CDS.

Chiu, S. and Yu, S. (2001) 'An excess of culture: the myth of shared care in the Chinese community in Britain', *Ageing and Society*, 21: 681-699.

Clark, H., Gough, H. and Macfarlane, A. (2004) *It pays dividends: Direct payments and older people*, Bristol: The Policy Press.

Croucher, K., Pleace, N. and Bevan, M. (2003) *Living at Hartrigg Oaks: Residents' views of the UK's first continuing care retirement community*. York: Joseph Rowntree Foundation.

Currer, C. (2001) *Responding to Grief: Dying, Bereavement and Social Care*, Basingstoke: Palgrave.

Davidson, K. (2001) 'Later Life Widowhood, Selfishness and New Partnership Choices: A Gendered Perspective', *Ageing and Society*, 21 (3): 297-317.

Davis, G., Lindsey, R., Seabourne, G. and Griffiths-Baker, J. (2002) *Experiencing Inquests*, Home Office Research Study 241.

Davis Smith, J. (1997) *The 1997 National Survey on Volunteering* London: Institute for Volunteering Research.

Department for Work and Pensions (2003a) *Households Below Average Income, 2001/02*, Leeds: CDS.

Department for Work and Pensions (2003b) *Internal Departmental Report* (unpublished).

Department for Work and Pensions (2003c) *Households Below Average Income 2002/03*, Leeds: CDS.

Department of Social Security (2000) *Customer Service Strategic Framework*, http://www.dwp.gov.uk/publications/dss/2000/e_business/customer.asp

Disney, R. and Whitehouse, E. (2001) *Cross-Country Comparisons of Pensioners' Incomes*, DSS Research Report No. 142, Leeds: CDS.

Dunnell, K. (2001) 'Policy responses to population ageing and population decline in the United Kingdom', *Population Trends*, 103: 47-52.

Evandrou, M. (2000) 'Social Inequalities in Later Life: the socio-economic position of older people from ethnic minority groups in Britain', *Population Trends*, 101: 11-18.

Ginn, J. and Arber, S. (1996) 'Patterns of employment, gender and pensions: the effect of work history on older women's non-state pensions', *Work, Employment and Society*, 10 (3): 469-490.

Glaser, K. and Grundy, E. (2002) 'Class, Caring and Disability: Evidence from The British Retirement Survey', *Ageing and Society*, 22 (3): 325-342.

Grewal, I., McManus, S., Arthur, S. and Reith, L. (2003) *Continuity through change: the impact of transitions on the provision of support and services to disabled people*, DWP Research Report No. 204, Leeds: CDS.

Grundy, E., Ahlburg, D., Ali, M., Breeze, E. and Slogett, A. (1999) *Disability in Great Britain: Results from the 1996/1997 Disability Survey*, DSS Research Report No. 94, Leeds: CDS.

Grundy, E. and Shelton, N. (2001) 'Contact between adult children and their parents in Great Britain 1986-99', *Environment and Planning A*, 33: 685-697.

Hayden, C., Boaz, A. and Taylor, F. (1999) *Attitudes and Aspirations of Older People: A qualitative study*, DSS Research Report No. 102, Leeds: CDS.

Heaton, J. (2001) 'Hospital discharge and the temporal regulation of bodies', *Time and Society*, 10 (1): 93-112.

Hockey, J., Katz, J. and Small, N. (eds.) (2001) *Grief, Mourning and Death Ritual*, Buckingham: Open University Press.

Leeson, G.W., Harper, S. and Levin, S. (2004) *Independent Living in Later Life: Literature Review*, DWP In-house Research report 137.

Katbamna, S., Baker, R., Ahmad, W., Bhatka, P. and Parker, G. (1997) *The Needs of Asian Carers*, Leicester: Nuffield Community Care Studies Unit, University of Leicester.

Kelly, G., Williams, B., Howat, N. and Kay, S. with Scheer, R. (2004) *The Pension Service Customer Survey 2003*, DWP Research Report No. 205, Leeds: CDS.

Kempson, E., Collard, S. and Taylor, S. (2002) *Social Fund Use Amongst Older People in Britain*, DWP Research Report No. 172, Leeds: CDS.

Kim, S. and Feldman, D.C. (2000) 'Working in Retirement: The antecedents of bridge employment and its consequences for quality of life in retirement' *Academy of Management Journal* 43 (6): 1195-1210.

Kohli, M., Rein, M., Guillemard, A.M., and van Gunsteren, H. (eds.) (1991) *Time for Retirement* Cambridge: Cambridge University Press.

McGlone, F. (1992) *Disability and dependency in old age: A demographic and social audit*, Family Policy Studies Centre, Occasional Paper 14.

Matheson, J. and Summerfield, C. (1999) *Social Focus on Older People*, London: The Stationery Office.

Means, R. (1996) 'Home, independence and community care: time for a wider vision', *Policy and Politics*, 25 (4).

Murray, U. and Brown, D. (1998) *They look after their own, don't they?* London: Social Services Inspectorate.

Netten, A., Darton, R. and Curtis, L. (2002) *Self Funded Admissions to Care Homes*, DWP Research Report No. 159, Leeds: CDS.

Netto, G. (1996) 'No one asked us before', *Addressing the needs of Asian carers of older people in Edinburgh and the Lothians*, Edinburgh: Scottish Ethnic Minorities Research Unit.

OECD (1995) *The Transition from Work to Retirement* Social Policy Studies No. 16, France: OECD.

Oldman, C. and Quiggars, D. (1999) 'The Last Resort? Revisiting Ideas about Older People's Living Arrangements', *Ageing and Society*, 19: 363-384.

Parker, G. (1992) *With this body: caring and disability in marriage*, Bristol: Open University Press.

Patterson, T. (2004) 'Older changing claims', *Benefits*, No. 39, February 2004, 12 (1): 45-47.

Payne, S. (1991) *Women, Health and Poverty: An introduction*, London: Harvester Wheatsheaf.

Phillips, J. and Waterson, J. (2002) 'Care management and social work: a case study of the role of social work in hospital discharge to residential or nursing home care', *European Journal of Social Work*, 5 (2): 171-186.

Reed, J., Cook, G., Sullivan, A. and Burridge, C. (2003) 'Making a Move: Care-Home Residents' Experiences of Relocation', *Ageing and Society*, 23 (2): 225-241.

Secker, J., Hill, R., Villeneau, L. and Parkman, S. (2003) 'Promoting Independence: But Promoting What and How?' *Ageing and Society*, 23 (3): 375-391.

Shaw, C. (2000) '1998-based national population projects for the United Kingdom and constituent countries' *Population Trends* 99, TSO 2000: 4-12.

Shaw, C. (2002, Spring) '2000-based national population projections for the UK and its constituent countries', *Population Trends*, 107: 5-13.

Slevin, K.F. and Wingrove, C.R. (1995) 'Women in Retirement: A Review and Critique of Empirical Research Since 1976' *Sociological Inquiry* 65 (1): 1-21.

Smeaton, D. and McKay, S. (2003) *Working after State Pension Age: Quantitative Analysis*, DWP Research Report No. 182, Leeds: CDS.

Stillion, J.M., McDowell, E.E. & May, J.H. (1989) *Suicide across the Life Span*, Washington DC: Hemisphere.

Summerfield, C. and Babb, P. (2003) *Social Trends*, 33, London: The Stationery Office.

Tanner, D. (2001) 'Sustaining the self in later life: supporting older people in the community', *Ageing and Society*, 21: 255-278.

Taramarcaz, O. (1998) 'Sans travail à 55 ans: et après?', *Revue économique et sociale* 56 (2) pp. 77-82.

Tolich, M. (2004, Spring) 'Internal Confidentiality: When confidentiality assurances fail relational informants', *Qualitative Sociology*, 27 (1): 101-106.

Twigg, J. (1997) 'Deconstructing the 'social bath': help with bathing at home for older and disabled people', *Journal of Social Policy*, 26 (2): 211-232.

Turnbull, J. (1985) *Greenwich's Afro-Caribbean and South Asian Elderly People*, London: Planning and Research Section, London Borough of Greenwich.

Ungerson, C. (2003) 'Care, Work and Feeling', paper presented at *New Sociology of Work* seminar, Policy Studies Institute.

Van Baarsen, B., Smit, J., Snijders, T. and Kipscheer, K. (1999) 'Do personal conditions and circumstances surrounding partner loss explain loneliness in newly bereaved older adults?', *Ageing and Society*, 19: 441-469.

Wenger, G.C., Scott, A. and Patterson, N. (2000) 'How Important is Parenthood? Childlessness and Support in Old Age in England', *Ageing and Society*, 20 (2): 161-182.

Yu, W.K. (2000) *Chinese Older People: A need for social inclusion in two communities*, Bristol: Policy Press.

Other research reports available

No.	<i>Title</i>	ISBN	Price
1.	Thirty Families: Their living standards in unemployment	0 11 761683 4	£6.65
2.	Disability, Household Income & Expenditure	0 11 761755 5	£5.65
3.	Housing Benefit Reviews	0 11 761821 7	£16.50
4.	Social Security & Community Care: The case of the Invalid Care Allowance	0 11 761820 9	£9.70
5.	The Attendance Allowance Medical Examination: Monitoring consumer views	0 11 761819 5	£5.50
6.	Lone Parent Families in the UK	0 11 761868 3	£15.00
7.	Incomes In and Out of Work	0 11 761910 8	£17.20
8.	Working the Social Fund	0 11 761952 3	£9.00
9.	Evaluating the Social Fund	0 11 761953 1	£22.00
10.	Benefits Agency National Customer Survey 1991	0 11 761956 6	£16.00
11.	Customer Perceptions of Resettlement Units	0 11 761976 6	£13.75
12.	Survey of Admissions to London Resettlement Units	0 11 761977 9	£8.00
13.	Researching the Disability Working Allowance Self Assessment Form	0 11 761834 9	£7.25
14.	Child Support Unit National Client Survey 1992	0 11 762060 2	£15.00
15.	Preparing for Council Tax Benefit	0 11 762061 0	£5.65
16.	Contributions Agency Customer Satisfaction Survey 1992	0 11 762064 5	£18.00
17.	Employers' Choice of Pension Schemes: Report of a qualitative study	0 11 762073 4	£5.00

18.	GPs and IVB: A qualitative study of the role of GPs in the award of Invalidity Benefit	0 11 762077 7	£12.00
19.	Invalidity Benefit: A survey of recipients	0 11 762087 4	£10.75
20.	Invalidity Benefit: A longitudinal survey of new recipients	0 11 762088 2	£19.95
21.	Support for Children: A comparison of arrangements in fifteen countries	0 11 762089 0	£22.95
22.	Pension Choices: A survey on personal pensions in comparison with other pension options	0 11 762091 2	£18.95
23.	Crossing National Frontiers	0 11 762131 5	£17.75
24.	Statutory Sick Pay	0 11 762147 1	£23.75
25.	Lone Parents and Work	0 11 762147 X	£12.95
26.	The Effects of Benefit on Housing Decisions	0 11 762157 9	£18.50
27.	Making a Claim for Disability Benefits	0 11 762162 5	£12.95
28.	Contributions Agency Customer Satisfaction Survey 1993	0 11 762220 6	£20.00
29.	Child Support Agency National Client Satisfaction Survey 1993	0 11 762224 9	£33.00
30.	Lone Mothers	0 11 762228 1	£16.75
31.	Educating Employers	0 11 762249 4	£8.50
32.	Employers and Family Credit	0 11 762272 9	£13.50
33.	Direct Payments from Income Support	0 11 762290 7	£16.50
34.	Incomes and Living Standards of Older People	0 11 762299 0	£24.95
35.	Choosing Advice on Benefits	0 11 762316 4	£13.95
36.	First-time Customers	0 11 762317 2	£25.00
37.	Contributions Agency National Client Satisfaction Survey 1994	0 11 762339 3	£21.00
38.	Managing Money in Later Life	0 11 762340 7	£22.00
39.	Child Support Agency National Client Satisfaction Survey 1994	0 11 762341 5	£35.00
40.	Changes in Lone Parenthood	0 11 7632349 0	£20.00
41.	Evaluation of Disability Living Allowance and Attendance Allowance	0 11 762351 2	£40.00
42.	War Pensions Agency Customer Satisfaction Survey 1994	0 11 762358 X	£18.00
43.	Paying for Rented Housing	0 11 762370 9	£19.00
44.	Resettlement Agency Customer Satisfaction Survey 1994	0 11 762371 7	£16.00

45.	Changing Lives and the Role of Income Support	0 11 762405 5	£20.00
46.	Social Assistance in OECD Countries: Synthesis Report	0 11 762407 1	£22.00
47.	Social Assistance in OECD Countries: Country Report	0 11 762408 X	£47.00
48.	Leaving Family Credit	0 11 762411 X	£18.00
49.	Women and Pensions	0 11 762422 5	£35.00
50.	Pensions and Divorce	0 11 762423 5	£25.00
51.	Child Support Agency Client Satisfaction Survey 1995	0 11 762424 1	£22.00
52.	Take Up of Second Adult Rebate	0 11 762390 3	£17.00
53.	Moving off Income Support	0 11 762394 6	£26.00
54.	Disability, Benefits and Employment	0 11 762398 9	£30.00
55.	Housing Benefit and Service Charges	0 11 762399 7	£25.00
56.	Confidentiality: The public view	0 11 762434 9	£25.00
57.	Helping Disabled Workers	0 11 762440 3	£25.00
58.	Employers' Pension Provision 1994	0 11 762443 8	£30.00
59.	Delivering Social Security: A cross-national study	0 11 762447 0	£35.00
60.	A Comparative Study of Housing Allowances	0 11 762448 9	£26.00
61.	Lone Parents, Work and Benefits	0 11 762450 0	£25.00
62.	Unemployment and Jobseeking	0 11 762452 7	£30.00
63.	Exploring Customer Satisfaction	0 11 762468 3	£20.00
64.	Social Security Fraud: The role of penalties	0 11 762471 3	£30.00
65.	Customer Contact with the Benefits Agency	0 11 762533 7	£30.00
66.	Pension Scheme Inquiries and Disputes	0 11 762534 5	£30.00
67.	Maternity Rights and Benefits in Britain	0 11 762536 1	£35.00
68.	Claimants' Perceptions of the Claim Process	0 11 762541 8	£23.00
69.	Delivering Benefits to Unemployed People	0 11 762553 1	£27.00
70.	Delivering Benefits to Unemployed 16–17 year olds	0 11 762557 4	£20.00
71.	Stepping-Stones to Employment	0 11 762568 X	£27.00
72.	Dynamics of Retirement	0 11 762571 X	£36.00
73.	Unemployment and Jobseeking before Jobseeker's Allowance	0 11 762576 0	£34.00
74.	Customer views on Service Delivery in the Child Support Agency	0 11 762583 3	£27.00

75.	Experiences of Occupational Pension Scheme Wind-Up	0 11 762584 1	£27.00
76.	Recruiting Long-Term Unemployed People	0 11 762585 X	£27.00
77.	What Happens to Lone Parents	0 11 762598 3	£31.00
78.	Lone Parents Lives	0 11 762598 1	£34.00
79.	Moving into Work: Bridging Housing Costs	0 11 762599 X	£33.00
80.	Lone Parents on the Margins of Work	1 84123 000 6	£26.00
81.	The Role of Pension Scheme Trustees	1 84123 001 4	£28.00
82.	Pension Scheme Investment Policies	1 84123 002 2	£28.00
83.	Pensions and Retirement Planning	1 84123 003 0	£28.00
84.	Self-Employed People and National Insurance Contributions	1 84123 004 9	£28.00
85.	Getting the Message Across	1 84123 052 9	£26.00
86.	Leaving Incapacity Benefit	1 84123 087 1	£34.00
87.	Unemployment and Jobseeking: Two Years On	1 84123 088 X	£38.00
88.	Attitudes to the Welfare State and the Response to Reform	1 84123 098 7	£36.00
89.	New Deal for Lone Parents: Evaluation of Innovative Schemes	1 84123 101 0	£26.00
90.	Modernising service delivery: The Lone Parent Prototype	1 84123 103 7	£26.00
91.	Housing Benefit exceptional hardship payments	1 84123 104 5	£26.00
92.	New Deal for Lone Parents: Learning from the Prototype Areas	1 84123 107 X	£29.00
93.	Housing Benefit and Supported Accommodation	1 84123 118 5	£31.50
94.	Disability in Great Britain	1 84123 119 3	£35.00
95.	Low paid work in Britain	1 84123 120 7	£37.00
96.	Keeping in touch with the Labour Market	1 84123 126 6	£28.50
97.	Housing Benefit and Council Tax Benefit delivery: Claimant experiences	1 84123 127 4	£24.00
98.	Employers' Pension Provision 1996	1 84123 138 X	£31.50
99.	Unemployment and jobseeking after the introduction of Jobseeker's Allowance	1 84123 146 0	£33.00
100.	Overcoming barriers: Older people and Income Support	1 84123 148 7	£29.00
101.	Attitudes and aspirations of older people: A review of the literature	1 84123 144 4	£34.00
102.	Attitudes and aspirations of older people: A qualitative study	1 84123 158 4	£29.00

103.	Relying on the state, relying on each other	1 84123 163 0	£27.00
104.	Modernising Service Delivery: The Integrated Services Prototype	1 84123 162 2	£27.00
105.	Helping pensioners: Evaluation of the Income Support Pilots	1 84123 164 9	£30.00
106.	New Deal for disabled people: Early implementation	1 84123 165 7	£39.50
107.	Parents and employment: An analysis of low income families in the British Household Panel Survey	1 84123 167 3	£28.50
108.	Evaluation of the New Deal for Lone Parents: Early lessons from the Phase One Prototype Synthesis Report	1 84123 187 8	£27.50
109.	Evaluation of the New Deal for Lone Parents: Early lessons from the Phase One Prototype Findings of Surveys	1 84123 3190 8	£42.50
110.	Evaluation of the New Deal for Lone Parents: Early lessons from the Phase One Prototype Cost-benefit and econometric analyses	1 84123 188 6	£29.50
111.	Understanding the Impact of Jobseeker's Allowance	1 84123 192 4	£37.50
112.	The First Effects of Earnings Top-up	1 84123 193 2	£39.50
113.	Piloting change: Interim Qualitative Findings from the Earnings Top-up Evaluation	1 84123 194 0	£28.50
114.	Building Up Pension Rights	1 84123 195 9	£33.50
115.	Prospects of part-time work: The impact of the Back to Work Bonus	1 84123 196 7	£29.00
116.	Evaluating Jobseeker's Allowance	1 84123 197 5	£16.00
117.	Pensions and divorce: The 1998 Survey	1 84123 198 3	£36.00
118.	Pensions and divorce: Exploring financial settlements	1 84123 199 1	£24.00
119.	Local Authorities and Benefit Overpayments	1 84123 200 9	£26.50
120.	Lifetime Experiences of Self-Employment	1 84123 218 1	£31.50
121.	Evaluation of the Pension Power for you Helpline	1 84123 221 1	£28.50
122.	Lone Parents and Personal Advisers: Roles and Relationships	1 84123 242 4	£29.00
123.	Employers' Pension Provision	1 84123 269 6	£35.00
124.	The Changing Role of the Occupational Pension Scheme Trustee	1 84123 267 X	£25.00
125.	Saving and Borrowing	1 84123 277 7	£28.50
126.	First Effects of ONE	1 84123 281 5	£38.50
127.	Why not ONE?	1 84123 282 3	£25.00

128.	The British Lone Parent Cohort 1991 to 1998	1 84123 283 1	£34.00
129.	Housing Benefits and the Appeals Service	1 84123 294 7	£26.00
130.	Pensions 2000 (Attitudes to retirement planning)	1 84123 295 5	£33.00
131.	Earnings Top-up Evaluation: Effects on Unemployed People	1 84123 289 0	£38.00
132.	Earnings Top-up Evaluation: Employers' Reactions	1 84123 290 4	£29.50
133.	Earnings Top-up Evaluation: Qualitative Evidence	1 84123 291 2	£30.00
134.	Earnings Top-up Evaluation: Effects on Low Paid Workers	1 84123 292 0	£37.00
135.	Earnings Top-up Evaluation: The Synthesis Report	1 84123 293 9	£27.50
136.	Modernising Service Delivery: The Better Government for Older People Prototypes	1 84123 300 5	£28.00
137.	The Verification Framework: Early Experiences of Implementation	1 84123 303 X	£27.00
138.	Low-income families in Britain: Work, welfare and social security in 1999	1 84123 312 9	£53.00
139.	Recruiting benefit claimants: A survey of employers in ONE pilot areas	1 84123 349 8	£26.50
140.	Moving towards work: The short term impact of ONE	1 84123 352 8	£27.50
141.	Incapacity Benefits and Work Incentives	1 84123 350 1	£28.00
142.	Cross-country comparisons of pensioners' incomes	1 84123 351 X	£33.00
143.	Evaluation of the New Deal for Disabled People Innovative Schemes pilots	1 84123 353 6	£36.00
144.	Evaluation of the New Deal for Disabled People Personal Adviser Service pilot	1 84123 354 4	£44.00
145.	'Well enough to work?'	1 84123 360 9	£31.00
146.	Payments of pensions and benefits: A survey of social security recipients paid by order book or girocheque	1 84123 370 6	£34.50
147.	Evaluation of the Minimum Income Guarantee Claim Line	1 84123 381 6	£27.50
148.	The role of GPs in sickness certification	1 84123 389 7	£28.50
149.	The medium-term effects of voluntary participation in ONE	1 84123 393 5	£34.50
150.	Recruiting Benefit Claimants: A qualitative study of employers who recruited benefit claimants	1 84123 394 3	£25.00
151.	Moving between sickness and work	1 84123 397 8	£37.00
152.	National Survey of Child Support Agency Clients	1 84123 398 6	£39.00
153.	Families, poverty, work and care	1 84123 406 0	£38.50

154.	ONE year on: clients' medium-term experiences of ONE	1 84123 407 9	£28.00
155.	Barriers to employment for offenders and ex-offenders	1 84123 415 X	£53.00
156.	Short term effects of compulsory participation in ONE	1 84123 416 8	£46.50
157.	The Dynamics of Poverty in Britain	1 84123 417 6	£32.00
158.	Outcomes for children of poverty	1 84123 418 4	£33.00
159.	Self-Funded Admissions to Care Homes	1 84123 420 6	£35.00
160.	New Deal for Disabled People: National Survey of incapacity benefits claimants	1 84123 421 4	£33.50
161.	Low/moderate-income families in Britain: Work, Working Families' Tax Credit and childcare in 2000	1 84123 426 5	£31.00
162.	Evaluation of the Capability Report: Identifying the work-related capabilities of incapacity benefits claimants	1 84123 437 0	£29.00
163.	Employers' Pension Provision 2000	1 84123 419 2	£36.50
164.	Low/moderate-income families in Britain: Changes in Living Standards 1999-2000	1 84123 438 9	£32.50
165.	Low- and moderate-income families in Britain: Changes in 1999 and 2000	1 84123 452 4	£35.00
166.	Delivering a work-focused service: Final findings from ONE case studies and staff research	1 84123 450 8	£35.00
167.	Delivering a work-focused service: Views and experiences of clients	1 84123 451 6	£30.50
168.	Findings from the Macro evaluation of the New Deal for Young People	1 84123 464 8	£26.50
169.	Costs and benefits to service providers of making reasonable adjustments under Part III of the Disability Discrimination Act	1 84123 476 1	£42.00
170.	From job seekers to job keepers: Job retention, advancement and the role of in-work support programmes	1 84123 477 X	£41.00
171.	Qualitative research with clients: Longer term experiences of a work-focused service	1 84123 478 8	£30.00
172.	Social Fund use amongst older people	1 84123 485 0	£29.50
173.	'Disabled for life?' attitudes towards, and experiences of, disability in Britain	1 84123 493 1	£46.00
174.	A comparison of Child Benefit packages in 22 countries	1 84123 506 7	£54.00
175.	Easing the transition to work	1 84123 507 5	£34.00
176.	Electronic government at DWP: Attitudes to electronic methods of conducting benefit business	1 84123 508 3	£32.50

177.	Self-employment as a route off benefit	1 84123 509 1	£31.50
178.	The wider benefits of education and training: a comparative longitudinal study	1 84123 517 2	£30.00
179.	Refugees' opportunities and barriers in employment and training	1 84123 518 0	£34.50
180.	Family change 1999 to 2001	1 84123 530 X	£39.00
181.	Working Families' Tax Credit in 2001	1 84123 531 8	£27.50
182.	Working after State Pension Age	1 84123 532 6	£27.50
183.	The final effects of ONE	1 84123 540 7	£50.00
184.	Business start-up support for young people delivered by The Prince's Trust: a comparative study of labour market outcomes	1 84123 550 4	£39.50
185.	Employer engagement and the London labour market	1 84123 551 2	£34.00
186.	Easing the transition into work (part 2 – client survey)	1 84123 560 1	£37.00
187.	Experiences of lone parents from minority ethnic communities	1 84123 569 5	£25.00
188.	Diversity in disability	1 84123 570 9	£34.00
189.	Medical evidence and Incapacity Benefit: Evaluation of a pilot study	1 84123 594 6	£35.00
190.	Families and children 2001: Living standards and the children	1 84123 595 4	£41.00
191.	Families and children 2001: Work and childcare	1 84123 596 2	£43.00
192.	Low-income families and household spending	1 84123 597 0	£33.00
193.	Pensions 2002: Public attitudes to pensions and saving for retirement	1 84123 599 7	£40.00
194.	Savings and life events	1 84123 610 1	£31.50
195.	The Myners Principles & occupational pension schemes Volume 1 of 2	1 84123 619 5	£33.00
196.	Profiling benefit claimants in Britain	1 84123 620 9	£34.00
197.	Entitled but not claiming? Pensioners, the Minimum Income Guarantee and the Pension Credit	1 84123 616 0	£36.00
198.	Evaluation of the community sentences and withdrawal of benefits pilots	1 84123 621 7	£30.00
199.	Pension scheme changes and retirement policies: An employer and employee perspective	1 84123 625 X	£28.00

200. Factors affecting the labour market participation of older workers	1 84123 626 8	£38.00
201. Delivering benefits and services for black and minority ethnic older people	1 84123 636 5	£31.00
202. Disability in the workplace: Employers' and service providers' responses to the Disability Discrimination Act in 2003 and preparation for 2004 changes	1 84123 642 X	£48.00
203. Working lives: The role of day centres in supporting people with learning disabilities into employments	1 84123 643 8	£38.50
204. Making the transition: Addressing barriers in services for disabled people	1 84123 651 9	£44.00
205. The Pension Service Customer Survey 2003	1 84123 654 3	£41.50
206. Families and children in Britain Findings from the 2002 Families and Children Study (FACS)	1 84123 655 1	£60.00
207. Employers' Pension Provision Survey 2003	1 84123 656 X	£42.00
208. Working after State Pension Age: Qualitative research	1 84123 657 8	£31.00
209. The British Lone Parent Cohort and their Children 1991 to 2001	1 84123 682 9	£54.50
210. Experiences and consequences of being refused a Community Care Grant	1 84123 685 3	£29.00
211. Characteristics of families in debt and the nature of indebtedness	1 84123 693 4	£31.00
212. Combined Pension Forecasts	1 84123 695 0	£30.00
213. The Myners Principles & occupational pension schemes Volume 2 of 2	1 84123 713 2	£51.00
214. Lone parents, health and work	1 84123 719 1	£51.50
215. Financial support for 16 to 19 year olds Social Security Research Yearbook 1990-91 Social Security Research Yearbook 1991-92 Social Security Research Yearbook 1992-93 Social Security Research Yearbook 1993-94 Social Security Research Yearbook 1994-95 Social Security Research Yearbook 1995-96 Social Security Research Yearbook 1996-97 Social Security Research Yearbook 1997-98	0 11 761747 4 0 11 761833 0 0 11 762150 1 0 11 762302 4 0 11 762362 8 0 11 761446 2 0 11 762570 1 1 84123 086 3	£8.00 £12.00 £13.75 £16.50 £20.00 £20.00 £27.00 £34.00

Social Security Research Yearbook 1998-99	1 84123 161 4	£30.00
Social Security Research Yearbook 1999-2000	1 84123 286 6	£27.50
Social Security Research Yearbook 2000-2001	1 84123 427 3	£27.50

Further information regarding the content of the above may be obtained from:

Department for Work and Pensions
Attn. Paul Noakes
Social Research Division
Information and Analysis Directorate
4-26 Adelphi
1-11 John Adam Street
London WC2N 6HT

Appendix A

Details of methodology

A.1 Sampling

Reflecting the project's iterative design, sampling methods were built upon in subsequent stages of fieldwork, to reflect emerging issues. Further details of this process are provided below:

A.1.1 Tranche one

Within areas one and two, ward level statistics were used to identify a subset of wards with an above average proportion of pensioners and which represented a range of sociodemographic circumstances. The statistics used for this purpose included recent benefits and ethnicity data, and the multiple index of deprivation, which combines local information on health, housing, income, employment, education and access to services from the 2001 census to provide an overall ranking score. Key informants also advised on wards' characteristics and their suitability as sampling sites. Special attention was devoted to mapping ward boundary changes since 2001 to ensure that no areas were excluded for this reason.

At this stage in the fieldwork, two distinctive sampling methods were used: sampling via DWP-held benefit records, and sampling of specific areas within selected wards. Together these ensured that a range of customer segments were targeted. The rationale for the first approach was that receipt of certain benefit combinations provided a proxy indication of individuals' segment positions, although this had the disadvantage of potentially excluding pensioners who were eligible for benefits but who were not claiming them (a group on which further research is likely to be beneficial). These proxy indicators were:

Segment 3: receipt of Retirement Pension (RP) and Minimum Income Guarantee (MIG)

Segment 4: receipt of RP and Attendance Allowance (AA)/Disability Living Allowance (DLA)

Segment 5: receipt of RP and MIG and AA/DLA

Segment 6: receipt of RP and MIG and AA/DLA and Severe Disability Premium (SDP)

The DWP Information Centre provided 2000 individual records from its administrative database, based upon our specification (which included a gender distribution that broadly matched the population profile, and that the sample was equally distributed across the wards and covered the four

segments listed above). After further refinement of the sample, 1,800 screening questionnaires were distributed to pensioners (1,000 in area one and 800 in area two), over-sampling in terms of expected segments five and six, who were likely to be more deprived and possibly more housebound.

A sampling frame for pensioners anticipated as sitting in segments one and two (high and moderate incomes, no limiting health conditions) was informed by key informants in the case study areas as well as using ACORN¹¹ classifications. Screening questionnaires were hand-delivered to addresses in these areas (approximately 200 in each area). Since it was likely that some of these questionnaires would not be received by pensioners (being targeted by location rather than through a personal mailing), the introductory letter to the research included a disclaimer for this event and asked recipients to feel free to pass the screening questionnaire on to pensioners who might be interested in taking part.

Targeted pensioners received a letter introducing the study, in addition to a screening questionnaire, which they were invited to complete and return in a pre-paid envelope if they wished to take part in the research. Introductory letters stressed the voluntary nature of the research, explained PSI's independence in conducting the research, and provided details of the £20 incentive that was given to pensioners for taking the time to be interviewed. Telephone numbers were provided as an alternative to filling in screening questionnaires, and a number of respondents used advocates such as friends and family to fill in questionnaires. Screening questionnaires asked for detailed demographic information concerning age, gender, health, income and social support. This enabled a more detailed picture to be developed of respondents' theoretical positioning within the CSM, one that was experientially based rather than determined by particular benefit receipt. Using these methods, 101 usable (contact details provided and consent for being interview given) completed screening questionnaires were returned.

A.1.2 Tranche two

In tranche two, similar sampling methods were used, which were refined to reach a broader range of pensioners. During this stage of the fieldwork, pensioners were targeted in two new areas in addition to the two original areas, and sampling was conducted through RP as well as benefit records, in order to increase the proportion of 'healthy moderate-high income' pensioners in the sample. 200 RP-only records and 1,700 benefits records were provided by the DWP for this stage of the research. Secondly, targeted sampling was conducted through two supported living schemes (see Chapters 2 and 4 for further details) in area one, to reach segment seven pensioners. Using this method, 125 usable completed screening questionnaires were returned.

A.1.3 Tranche three

In tranche three, sampling was strategic and mediated by particular service providers. The topical focus was developed in consultation with the DWP and drew upon priorities which had emerged from interim findings in terms of key transitions in later life. This sampling approach made use of relationships developed with service providers in the earlier stages of the research.

For the home-from-hospital scheme in area three, screening questionnaires were distributed by the service provider to recent users of the service. Due to sensitivity issues, users of the bereavement service in area one were directly approached by the service's project manager, who was known to

¹¹ ACORN is a geo-demographic tool which uses census data to classify the UK population on an area basis into groups with particular characteristics, which can be used to predict their use of services. Some of the classifications relevant for this research include type 07 'older people, detached houses', and type 32 'retired home owners'. See <http://www.caci.co.uk/acorn/> for further details.

them. It was the manager's role to explain about the research and to ask if individuals wanted to participate. This research strategy got round the issue of client confidentiality while ensuring that we only approached pensioners who had been informed about the project and who had voluntarily opted into the research process.

A.2 Developing the interview sample

Based upon the information provided in the screening questionnaires, all respondents were assigned to a customer segment and provided with a unique (anonymised) identifier label. Their details were entered into a secure database from which the interview samples were developed. In the first tranche of fieldwork, the primary concern in developing the interview sample was to ensure that all customer segments were represented. The second tranche of fieldwork also covered a range of pensioner characteristics, but sought in particular to fill gaps that had emerged in tranche one, in terms of hard-to-reach groups or segments, as well as pensioners whose circumstances seemed to place them on the boundaries between segments in some way. The distribution of pensioners within the CSM in successive stages of the fieldwork is provided in table one below.

Table A.1 CSM distribution of pensioners over the course of the fieldwork

Segment	1	2	3	4	5	6	7	Total
Tranche 1	7	2	5	5	12	9	2	42
Tranche 2	9	11	9	6	10	9	7	61
Tranche 3	7	2	1	1	2	2	-	15
	23	15	15	12	24	20	9	118

However, following analysis of the interviews and the more detailed and comparable information on personal circumstances provided in these, 25 of the 118 interviewees were reassigned to another customer segment which more accurately reflected their circumstances. The details of these reassessments are provided in table two below.

Table A.2 Reassignment of pensioners within the CSM over the course of the research

Segment	1	2	3	4	5	6	7
Positioning using screening questionnaire	23	15	15	12	24	20	9
Post-interview allocation	20	11	16	19	28	15	9

For each stage of the fieldwork, interviewers reported back on contact made on a case-by-case basis, so that when pensioners were unavailable for interview a demographically similar individual was substituted into the sample.

A.3 Interviewing the older people

As far as was practicable, interviewers were 'matched' to interviewees on the basis of gender and ethnicity, to maximise rapport and interviewees' comfort levels. Details of the main characteristics of the interview sample are provided in Appendix B. Interviewers approached pensioners by telephone

(or in writing where no telephone number had been given in their returned screening questionnaire), introducing themselves and the research, and setting up a convenient time for the interview.

The interviews were qualitative in nature, drawing upon a semi-structured topic guide, which provided signposting to cover different aspects of pensioners' experience and relevant probes. At each stage of the fieldwork, a different topic guide was used to reflect emerging concerns. Tranche one interviews also included tools for conceptualising pensioners' activity and service use patterns and their social support networks (see Appendix D). Due to the lengths of the topic guides used in this study, they have not been included in the appendices. Copies of the topic guides can be found on the DWP Social Research Division website, together with the report.

The research was explained again to informants before the interview commenced, together with the taping process, to ensure that informed consent had been established. All interviews were taped and transcribed verbatim. Interviews ranged in time, with an average of just over an hour. At the end of the interview, informants were given a £20 gift in appreciation of the time they had taken to be interviewed, a technique which is particularly useful in gaining access to low-income groups.

In addition to the interview transcript, each interview also produced fieldwork notes. These provided important contextual information for the analysis as well as early feedback of emerging issues that could inform subsequent sampling. Fieldwork notes covered any unusual features of the interview, biographical summary information, notes on where the interview took place, details of pertinent off-tape discussions, and feedback from interviewers on using on the topic guide which facilitated subsequent refinement of research instruments.

A.3.1 Ethical issues

The existence of vulnerable groups in the pension age population raised important ethical issues, which have informed our methodology throughout the research process. Special attention was given to access and facilitation issues to ensure that the research methodology did not prevent anyone from taking part. An access budget promoted this process, and enabled us to employ a specialist disability consultancy to conduct some of the interviews. Techniques adopted to ensure maximum accessibility included conducting all interviews in the pensioners' own homes, interviewing in other languages, using interpreters, British Sign Language and type talk, and interviews being facilitated by wardens, relatives and carers.

In light of the sensitive issues that were covered, such as health crises and bereavement, some of the interviews provoked heightened emotional responses. In these instances it was necessary for the interviewer to employ discretion and use the topic guide flexibly. We always stressed that we were happy to turn off the tape recorder at any time, that we could avoid particular subjects, and that the interview could be discontinued. In some cases this was necessary. Whilst clearly individuals' responses to sensitive issues varied, most of the people found it helpful to have the time and space to discuss these matters, and on several occasions people noted that it had been the first time that they had talked about their feelings.

In recognition of the investment which our informants made in the research process, and the obvious interest that many had in the issues being explored, we have committed to providing all participants with a research summary, with the option of requesting the full report.

A.3.2 Interviewing couples

Interviewing couples was an important sub-component of this research because it enabled us to explore how the different and shared experiences of couples inform their perceptions of independence and support needs. In order to probe individuals' experiences, whenever feasible, we interviewed couples separately but simultaneously using two separate interviewers, in separate rooms. This technique proved particularly fruitful because it ensured that information divulged by one partner was kept confidential from the other partner. The use of separate interviewers also respected the dignity of individuals so that, for instance, in cases where a partner was the giver or receiver of care, private emotions would not be inappropriately provoked in front of their spouse.

A.4 Analysing the data

All transcripts and fieldwork notes were imported into QSR NVivo, a qualitative software package, and were categorised using a coding framework. This was refined over the course of the three tranches to reflect the focus of each topic guide (see Appendix D for the pensioner interview coding framework). This combined structural information drew upon the topic guides and emerging themes in the interviews. The coding structure consisted of a series of 'tree nodes' (categories that nest subcategories within them), and categorisations that were more conceptual or exploratory in nature, which were coded as 'free nodes'. For example, 'free nodes' included categories like 'ageism' and 'lonely', while a simple (one-level) tree node was 'retirement', which included child subnodes of 'how long', 'reasons for retiring', feelings about retirement' and 'partner's retirement'. Quantitative data on the interviews was stored as NVivo 'attributes' (e.g. age, gender, ethnicity, income band).

The analytical technique, facilitated by NVivo, consisted of systematically reviewing the data, comparing and contrasting perceptions, accounts or experiences, searching for patterns or connections within the data, and seeking explanations internally within the data set. NVivo enabled us to search the data on the basis of the aforementioned nodes, and to group responses in terms of particular characteristics, such as gender, area and stage in the fieldwork. As each tranche of interviews was added to NVivo, a selection of new transcripts was double coded by the researchers and then compared in order to ensure reliability of the coding system. The system also allowed for new nodes to be added so that emerging themes and topics could be incorporated into the analysis. The analytical process was tracked by researchers through coding memos, which enabled emerging concerns to be shared and built upon.

A.5 Anonymity

Two stages of anonymisation have taken place to ensure that informants' identities are protected. At the first stage, interviewees were given an anonymised identifier, which indicated to the research team the stage of fieldwork at which they were interviewed, the area in which they lived, and their anticipated positioning in the CSM. This identifier was used on all documentation and in NVivo. Secondly, at the reporting stage, this identifier was converted into a unique pseudonym, which was crosschecked against our interview sample database to ensure that it did not replicate any interviewees' real names. These pseudonyms reflected informants' true gender and ethnicity. Care was also taken in the way quotations were presented and in how informants were introduced in the report, to avoid any distinctive personal information that might make people identifiable.

Appendix B

Characteristics of the interview sample

Throughout the course of the fieldwork 118 interviews were conducted. 20 of these were with couples, where each partner was interviewed separately; a total of 98 households were covered. 44 of the interviews were with men and 74 with women.

Other characteristics of the sample include:

Table B.1 Age range¹² (n = 117) Average age = 73.4 years

55-59 ¹	60-64	65-69	70-74	75-79	80-84	85+
1	13	27	17	32	13	14

¹ At 59, this respondent was included since she was married to a pensioner and was herself retired.

Table B.2 Self-defined ethnicity (n = 118)

Pakistani	Indian	African Black	Afro-Caribbean	Turkish	Jewish	White European	White British
1	2	1	2	1	2	3	106

Table B.3 Living arrangements (n = 118)

Divorced	Widowed	Single	Living alone			Living with others		
			Other arrangement	As a couple	With extended family	With partner & extended family	In supported living accomm'n	
						partner & extended family		
15	34	5	2	43	6	4	9	

¹² Missing data for one informant.

Table B.4 Reported weekly income bands (n = 85)

High (>£140 single/ >£205 couple)	Medium (£105-140 single/ £160-205 couple)	Low (<£105 single/ <£160 couple)
32	29	24

Table B.5 Reported health problems or disabilities (n = 57)

Health problem/disability	Number of cases
Arthritis	23
Angina/heart problems/stroke	16
Difficulty walking/mobility problems	11
Diabetes	7
Asthma/respiratory problems	6
Deafness/hearing difficulties	4
Osteoporosis	3
Blindness/eyesight difficulties	2
Cancer	2
Mental health problems	2
Other	8

Table B.6 Benefit receipt (n = 65)

Benefit	Number of cases
Council Tax	52
Housing Benefit	36
Attendance Allowance	20
Disability Living Allowance	19
MIG/PC	18
Severe Disability Premium	3
Don't Know	2

Table B.7 Source of social support for those who need help (n = 27)

Support source	Number of cases
Family	14
Partner	8
Voluntary agency	6
Statutory agency	5
Friends	3
Neighbours	2

Table B.8 Segment seven pensioners' health problems, support needs and movements into supported accommodation

Pensioner case characteristics	Health problems	Previous living arrangements and support needs
Elizabeth – her 90s Living in a traditional home, for almost a decade	Angina	No longer able to cope with living on her own; activities became severely limited
Arthur – late 80s In a traditional home, for the last year.	Arthritis and rheumatism	Found it increasing difficult to manage in own home. Needed help from carers with many daily household tasks
Teresa – late 80s In a traditional home, for last 18 months	Lots of health problems, not very mobile	Moved to a bungalow when became unable to manage the cleaning. Daughter helped out on a daily basis, but support ended by daughter's illness
Anne – late 70s In a traditional home, for the last year	Osteoporosis and cancer	Happy to stay in her own home, but could not manage, though had carers coming to do the cleaning
Anthony – late 60s In a traditional home, for over two years	Heart attack, followed by ongoing ill-health	Marriage broke down following illness. Needed carer support which caused problems in the relationship
Marion – late 80s In a new style home, for the last 18 months	Severe arthritis and incontinence	Found it increasingly difficult to manage in rented accommodation after husband's death
Caroline – late 70s - and John – early 80s In a new style home, for the last three years	Strokes and degenerative conditions (both)	A carer supported John with personal care in their own home, but he became unable to manage the stairs needed more intensive support
Henry – mid 70s In a new style home, for the last three years	Long-standing illness; multiple black outs	Had been living alone

Appendix C

Notes on revised proposed CSM for today's pensioners

A proposed revised CSM is presented here. It amends the existing model, incorporating the feedback from the study evidence. This is a theoretical model and no attempt has been made to extrapolate to the general pensioner population.

The proposed revised CSM identifies ten pensioner segments, denoted by letters 'a' through 'j' (see Figure C.1). These differentiate them from the original model and make a continuum somewhat less apparent. The revised model builds from the framework based on analyses of pensioner data from the Family Resources Survey. The current logic derives from analysis of depth interviews with 118 pension age individuals. At this point, the revised logic needs to be tested on a wider population. Only then can its strengths and limitations be truly assessed.

In summary, the suggested revisions are as follows:

- The ten segments are divided on type of accommodation and then by level of health, designated as 'lower' and 'higher' support needs.
- Pensioners are then classified according to their level of social support. Informal social support is more likely to be reliable if the people performing the support are sharing the same residence. Level of social support seemed important for 'lower' needs pensioners, particularly when anticipating their needs in the event of a health transition, for example.
- Finally, level of income was important for deciding service access. High income pensioners were more likely to buy in services. This applies to both the 'higher' and 'lower' support needs groups. There was little distinction between low and moderate income pensioners regarding their access behaviours (in terms of buying in services) so these groups were joined into one category.

The ways in which this refined model relates to the original model are illustrated in Table C.1. The Table draws comparisons on a segment by segment basis. The new model differs from the previous in that 'level of social support' is considered an important factor for pensioners with 'no limiting health condition or disability' especially when anticipating future transitions. In addition, to acknowledge growing trends in supported living, the new model sub-divides previous segment seven pensioners into two groups according to their level of health.

Table C.1 How the revised model corresponds to the current CSM

Previous segment	Revised segment
S1	Sa – with social support Sc – no social support
S2, S3	Sb – with social support Sd – no social support
S4	Sg
S5	Se – high income Sf – low/moderate income
S6	Sh
S7	Si – no limiting physical/mental health problem or disability Sj – has a limiting physical/mental health problem or disability

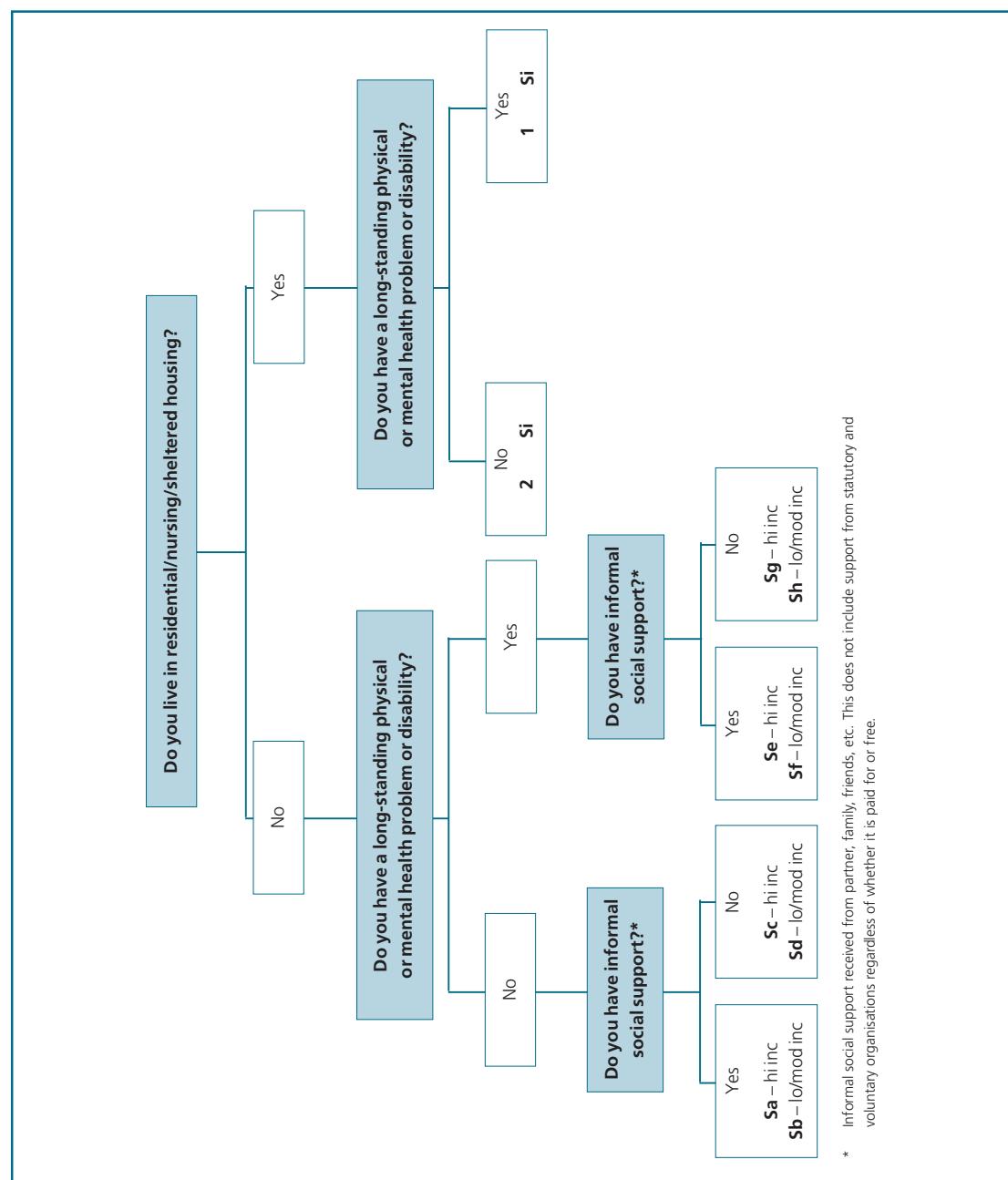
Figure C.1 Proposed revised Customer Segmentation Model segmentation of today's pensioners – organisation chart

Table C.2 identifies the segments of the new model according to the key factors of health, social support and income.

Table C.2 Summary of segmentation by levels of health, social support and income

Segment	Lower support needs (has no limiting physical/ mental health problem or disability)				Higher support needs (has a limiting physical/ mental health problem or disability)				Supported Accommodation*	
	Sa	Sb	Sc	Sd	Se	Sf	Sg	Sh	Si	Sj
Social Support	X	X			X	X			X	X
High income	X		X		X		X			

Note: Segments b, d, f, h, i, and j need to be monitored for financial support needs.

* Pensioners belonging to segments i and j are distinguished by virtue of their type of accommodation and the staff assistance available to them. Si pensioners are not likely to have a limiting health problem or disability so they align with the 'Lower support needs' sub-segments. Si pensioners reflect the rising trend towards innovative communal living where extra care is available on site when needed. Sj pensioners are likely to have a limiting health problem or disability so they align with the 'Higher support needs' sub-segments. These pensioners are also likely to need and use the care facilities available on site. However, the understanding of help needs that go beyond those supplied within the accommodation is limited. Further research into this area is vital given the expected expansion of these pensioner groups within the ageing population.

Appendix D

Research instruments

D.1 Social network map

This research instrument was used as an aid to complement the social support/networks section of the topic guide in tranche one of the fieldwork. Its purpose was not to provide an extensive mapping of personal communities, but to gauge the character of pensioners' support networks, and to provide a visual map of their support preferences and the relative ease or difficulty they anticipated experiencing in accessing support in a range of different crisis situations. The distinctive nature of the suggested crises enabled comparisons to be drawn as to whether different scenarios were associated with qualitatively different preferences for social support, and/or whether particular individual circumstances were associated with particular support profiles or preferences.

The 'map' provided information on a number of aspects of pensioners' experiences:

- an individualised picture of a range of different forms of social support (e.g. family, friends, extended family, neighbours, statutory and voluntary agencies);
- the relative proximity of individuals to existing or desired forms of social support; and
- support preferences in relation to qualitatively different support needs (e.g. emotional, practical, financial, informational).

The standardised maps created during the interviews provided a complex snapshot of pensioners' support structures, which were compared against one another to draw out central similarities, differences, and the rationales for particular preferences or arrangements. Social network mapping is particularly effective as a participatory research tool, which engages informants in the research process, and is useful in highlighting gaps in provision.

D.1.1 Method

The social network map designed for this research consisted of a large circle divided into segments depicting the three main types of scenarios covered in the topic guide: personal crisis, practical day-to-day help, and help given to others (see Figure D.1). This holistic approach enabled the research to be situated in the context of recent research findings stressing the importance of reciprocity in older people's perceptions of independence. The idea is that nominated individuals and/or services are

mapped onto this framework, nearer or further away from the centre as gauged from the questioning route. The map was printed onto a large sheet of paper, with a new map being created for each interview.

Colour coded stickers were placed onto the segments of the map to represent different types of social resources identified by interviews in response to the different scenarios:

- blue for family;
- red/orange for friends;
- green for neighbours;
- yellow for statutory agencies;
- white for voluntary agencies/participation in voluntary work.'

The name and/or relationship to the informant of the suggested person or agency was written on the stickers by interviewers, which were then placed onto the map and reviewed with interviewees.

Parallelogram stickers were rotated to depict analytical distinctions between experienced or anticipated scenarios, i.e. placed on the map in a square formation to signify real situations experienced by interviewees, and in a diamond formation to represent speculated circumstances.

When people changed their mind about a response, a blank white sticker was placed over the top of the coloured sticker.

The person or persons whom the interviewee lived with was written at the top of the social network map sheet, and these persons were positioned on the map (or not) again according to older people's responses to the research questions.

Interviewers gauged the relative ease with which informants would be able to draw upon various sources of help in each circumstance, and reflecting this, placed stickers more or less near to the centre of the circle.

The 'Personal crisis' segment included social networks relating to:

- bereavement;
- illness/hospitalisation;
- financial crisis;
- being a victim of crime.

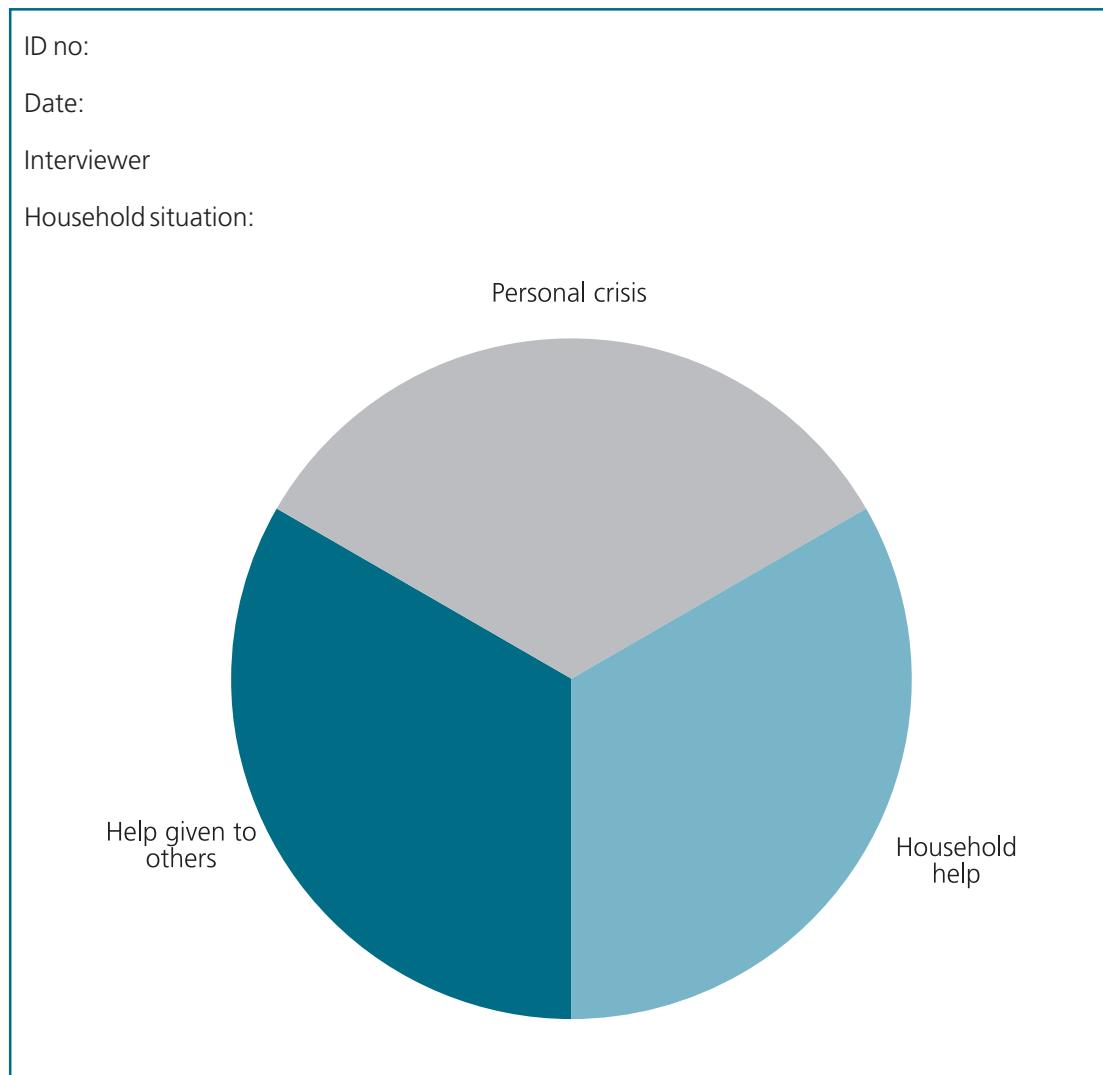
The 'Household help' segment included social networks relating to:

- physical restrictions (including mobility);
- personal care issues;
- day-to-day support;
- practical help.

The 'Help given to others' segment included the ways in which respondents supported their:

- family/friends;
- neighbours;
- community through participation in voluntary work.

Figure D.1 Social Network Map



D.2 Service use diary

Service use diaries provided a record of the services that people used regularly or more infrequently, and was used conjunction with the 'Service use and needs' section of the topic guide (and is also known as the service use calendar) in tranche one of the fieldwork. It took the form of a sheet subdivided into squares to depict the days of a calendar month. Interviewers filled in the boxes to depict on the days of the week on which people used particular services, such as Wheels on Meals, public transport or the doctor's. Where service use was less patterned or more irregular, this was noted and an approximation of frequency of use made on the bottom of the activity sheet.

Figure D.2 Service use diary (printed to fill A4 sheet)

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Week 1							
Week 2							
Week 3							
Week 4							

D.3 Coding framework for pensioner interviews

Free nodes

Access issues
 Ageism
 Area issues
 Bereavement
 Community
 Computers
 Coping Strategies
 Crime & fear of crime
 Depression
 Disability
 Discomfort
 Ethnicity
 Gender Issues
 Getting older
 Holidays
 Incentive
 Independence scale
 Interdependency
 Interview tone & circumstances
 Leaving hospital
 Life-changing/unexpected events
 Lonely
 Making the best of it
 Mobility
 Personal qualities
 Pets
 Physical activity

Planning ahead
 Privacy issues
 Racism
 Scapegoats
 Segmentation issues
 Self-reliant
 Service use patterns
 Stress
 Transition
 Wardened-controlled housing
 What's this about?

Tree nodes

Living	Length of current arrangements
	Current arrangements
	Feelings about current arrangements
	Attachment to the area
	Major changes in arrangements
Extended family	Composition
	Nearby
	Distance
	None
Finances	Type of pensions
	Benefits received
	Self
	Time receiving
	How applied
	DLA component - self
	Partner
	Time receiving
	How applied
	DLA component - partner
	Non-claims
	Income range
	Discrepancies with SQ
	Savings
Housing costs	None
	Other sources of income
	Feelings about finances
	Financial strategies
	Priorities
	Problems
	Constraints
	Being on your own
	Health-related outlay

Paid work	Current Prior to retirement Main job Feelings about paid work Loose labour market attachment Partner's main job
Retirement	How long Reasons for retiring Feelings about retirement Partner's retirement
Health	General description Specific health problems and disabilities Impact on relationship No problems Mental health Changes in health Health limitations
	At home Outside the home No limitations
Partner's health	No problems Specific problems Changes in health Health limitations
	Support received Support provides partner Feelings on support provision
Independence	
	Subjective meaning
	Going out Living in own home Choosing where to live
	Staying in own home Personal decision-making Financial security Access to support Maintain health Practical resources Mobility

Maintaining social networks		
Lifestyle factors		
Local involvement		
Doing things yourself		
Personal security		
Holidays		
Privacy		
Income re independence	T2 plus £20 if uncomfortable	
	T2 less £20 if comfortable	
	T2 spontaneous use of £20	
Benefits re independence		
Changing feelings on independence	No change	
	Things that seem more important	
	Things that seem less important	
Changed behaviour, strategies		
Most valued aspects of independence	Health	
	Choosing where to live	
	Staying in your home	
	Financial security	
	Support from friends and family	
	Social activity	
	Personal decision-making	
	Personal security	
	Mobility	
	Doing things for yourself	
	Being able to help others	
	Going out	
	Can't prioritise	
Worries about loosing independence		
Ways independence is compromised	When this started	
Choice about things that matter	Help desired making decisions	
Things that help		
Health re independence		
T2 Help re independence	Actual help received	If unavailable
	Hypothetical help	After a fall
		Transport breakdown
		Unexpected bill

Service use	Health	Doctor Local hospital Dentist Optician District nurse Alternative practitioner Counselling services Chiropodist Occupational therapist
	Practical	Transport Meals-on-wheels Shopmobility Domestic services Community care/respite care Personal care Community alarm service Hairdresser
	Social and community services	Housing Housing associations and trusts Pensions Benefits Social Services Support groups Voluntary groups Religious groups
Leisure		Community centre, club, class, library Sports Activities, trips organised by groups Travel Reading, bingo, crossword, tv, etc. Pubs Other
Other		Bank Legal, financial adviser, CAB Shops Information lines, web Police Aids and adaptations

No support needed		
Priority services for older people		
Personal priorities		
Support lacking		
Adequacy of local services		
Services no longer used	Why	
Anticipated service use		
Finding out about services		
Services that help maintain independence		
Best things about services		
Worst things about services		
Service accessibility issues		
Service improvement		
Other services needed for independence		
Non-users	Things to help them use service	
	Alternative strategies to meet needs	
	Reasons for non-use	
	Off-putting things	
	Would prefer service to family support	
Residential/sheltered home residents		
	Reason for the move	
	Length of time in housing	
	Deciding on the housing	
	Feelings about how it affects independence	
	External participation	None
	Personal mobility	
	Choice in day-to-day activities	
	Quality of life issues	
Social networks		
Local integration		
Local networks		
Involvement in voluntary activity		
Support in crisis situations	Personal crisis	Anticipated
		Actual
	Financial crisis	Anticipated
		Actual

	Own or partner illness	
	Anticipated	
	Actual	
	Crime	Anticipated
	Actual	
Support for household	Personal care	Anticipated
	Actual	
	Physical help	Anticipated
	Actual	
	Day to day support	Anticipated
	Actual	
	Practical help	Anticipated
	Actual	
Help given to others	Type of help given	
	Who help is given to	
	Frequency of help given	
	Feelings about providing help	
	No help given	
Preferences on sources of help	Unified source preferred	
	Multiple source preferred	
Multiple sources of help needed		
Main sources of regular help		
Informal	Living in household	
	Partner	
	Extended family	
	Other	
	Out of household	
	Extended family	
	Friends	
	Neighbours	
	Other	
Formal	Statutory agency	
	Voluntary agency	
Mutual support		
Not needed		
Needed but not received		
Multiple sources of help needed		
Feelings about receiving help		
Situations would seek formal help		
Situations would seek informal help		

Expectations & Feelings	Overall satisfaction
	Things would change
	Hopes, future plans
	Things that need to happen first
Bereavement	
Time widowed	
Non partner-related bereavement	Effects
Circumstances of death	Sudden
	Prolonged illness
Aftermath	Practical impact on circumstances
Feelings	
Help gaps	
Role of local services	
Contact with Bereavement Centre	How heard about
Reaction to Bereavement Centre service	
Other (non BC) services used	
Leaving hospital	
How long ago	
Nature of hospitalisation	Planned
	Emergency
Recovery	Practical impact on circumstances
Feelings about	
Help gaps	
Home-from-hospital scheme	How heard about
	Use of services
	Length of involvement
	Opinion of
	Relationship with volunteer
	Voluntary organisation
Alternative sources of help	

Appendix four: research instruments

Item 1: Screening questionnaire



Living Independently in Later Life

If you require a large print version of this questionnaire, please contact *[researchers' details]*

As part of the first stage of our research into the lives of older people, we are asking a number of people to complete this questionnaire. This information will help us to select a range of people in different circumstances to be interviewed over the summer. Please be assured that any information you choose to provide will be treated entirely confidentially, and will only be seen by the small group of researchers at PSI.

If you are willing to be interviewed, please provide your details below before completing the remainder of the questionnaire.

We are offering a £20 cash gift to everyone chosen to be interviewed.

Title (Mr/Mrs/Miss/Ms/Dr):
.....

Name(s):
.....

Address:
.....
..... Post code.....

1. What is your gender? *Please tick ✓*

Male Female

2. How old are you? *Yourself*

Partner/Spouse (if applicable)

3. Do you live? *Please tick ✓*

Alone	<input type="checkbox"/>
With family	<input type="checkbox"/>
With a partner/spouse	<input type="checkbox"/>

Other arrangements, *please specify*

.....

4. How would you describe your housing situation?

Please tick ✓ all boxes that apply

Own house (repaid mortgage)	<input type="checkbox"/>
Buying own house (repaying mortgage)	<input type="checkbox"/>
Rented from Council	<input type="checkbox"/>
Rented from Housing Association	<input type="checkbox"/>
Private tenant	<input type="checkbox"/>
Residential/nursing care	<input type="checkbox"/>
Sheltered housing	<input type="checkbox"/>
Living in family's housing	<input type="checkbox"/>

Other, *please specify*

5. Which of the following best describes your current work status?

Please tick ✓ any that apply

Retired	<input type="checkbox"/>
Full-time employment	<input type="checkbox"/>
Voluntary work	<input type="checkbox"/>
Part-time employment	<input type="checkbox"/>
Self employment	<input type="checkbox"/>

If you do not live with a partner/spouse, please go straight to Question 7.

6. Which of the following best describes your partners'/spouse's current work status?

Please tick ✓ any that apply

Retired	<input type="checkbox"/>
Full-time employed	<input type="checkbox"/>
Voluntary work	<input type="checkbox"/>
Part-time employed	<input type="checkbox"/>
Self-employed	<input type="checkbox"/>

7. Do you or your partner/spouse currently receive income from any of the following sources? *Please tick ✓ any that apply*

State retirement pension	<input type="checkbox"/>
Occupational/Works/Company pension	<input type="checkbox"/>
Private pension	<input type="checkbox"/>
Employment	<input type="checkbox"/>
Benefits	<input type="checkbox"/>

Other, *please specify*

8. If you (or your partner/spouse) are in receipt of benefits, do you receive any of the following?

Please tick any that apply ✓

	<i> Yourself</i>	<i> Partner/Spouse (if applicable)</i>
Attendance Allowance	<input type="checkbox"/>	<input type="checkbox"/>
Disability Living Allowance	<input type="checkbox"/>	<input type="checkbox"/>
Housing Benefit	<input type="checkbox"/>	<input type="checkbox"/>
Council Tax Benefit	<input type="checkbox"/>	<input type="checkbox"/>
Minimum Income Guarantee/Pension Credit	<input type="checkbox"/>	<input type="checkbox"/>
Severe Disability Premium	<input type="checkbox"/>	<input type="checkbox"/>
Not sure/don't know	<input type="checkbox"/>	<input type="checkbox"/>

Other, *please specify*

9. Do you, or your partner/spouse, have a health problem or disability that affects your everyday activities? If yes, *please briefly specify and let us know if you need any help with the interview:*

Yourself

.....

.....

Partner/Spouse (if applicable)

.....

10. Do you receive support from your partner, other family members or statutory or voluntary organisations e.g. social services or Age Concern?

By support we mean do you receive help with any of the following: **personal care** (e.g. help with dressing), **physical help** (e.g. help with walking), **practical help** (e.g. preparing meals) or help with **paper work or financial matters** (e.g. filling in forms)?

Yes
No

If yes who do you receive this support from? Please tick any that apply ✓

Partner
Other member of the family
Friends
Neighbours
Statutory Organisation
Voluntary Organisation

Other, please specify

11. Does your partner receive support from you, other family members or statutory or voluntary organisations e.g. social services or Age Concern?

By support we mean do you receive help with any of the following: **personal care** (e.g. help with dressing), **physical help** (help with walking), **practical help** (e.g. preparing meals) or help with **paper work or financial matters** (e.g. filling in forms)?

Yes
No

If yes who do they receive this support from? Please tick any that apply ✓

You
Other member of the family
Friends
Neighbours
Statutory Organisation
Voluntary Organisation

Other, please specify

The next question asks about the income you (and your partner/spouse) receive, whether on a weekly or monthly basis.

12. What is the income after housing costs that you receive? By *after housing costs* we mean income after payment of rent or mortgage payments. This is before payment of bills, Council Tax or any other charges you pay.

Please answer one of the following:

a) If you are single and it is easier for you to calculate your income on a weekly basis:

Please tick ✓ one only

More than £140 per week
Between £105 and £140 per week
Less than £105 per week

b) If you are single and it is easier for you to calculate your income on a monthly basis:

Please tick ✓ one only

More than £610 per month
Between £455 and £610 per month
Less than £455 per month

c) If you live with a partner/spouse and it is easier for you to calculate your joint income on a weekly basis:

Please tick ✓ one only

More than £205 per week
Between £160 and £205 per week
Less than £160 per week

d) If you live with a partner/spouse and it is easier for you to calculate your joint income on a monthly basis:

Please tick ✓ one only

More than £890 per month
Between £695 and £890 per month
Less than £695 per month

13. How would you describe your ethnic background?

Please tick ✓ one only

White - British
White - Irish
White - Any other white background
Mixed - White and Black Caribbean
Mixed - White and Black Caribbean
Mixed - White and Black African

Mixed - White and Asian	<input type="checkbox"/>
Mixed - Any other mixed background	<input type="checkbox"/>
Asian or Asian British - Indian	<input type="checkbox"/>
Asian or Asian British - Pakistani	<input type="checkbox"/>
Asian or Asian British - Bangladeshi	<input type="checkbox"/>
Asian or Asian British - Any other Asian background	<input type="checkbox"/>
Black or Black British - Caribbean	<input type="checkbox"/>
Black or Black British - African	<input type="checkbox"/>
Black or Black British - Any other Black background	<input type="checkbox"/>
Other ethnic groups - Chinese	<input type="checkbox"/>

Other, *Please specify*

If you are willing to be interviewed, please provide your preferred contact details:

Telephone: Email:

Best time to ring:

If you do not have a phone please indicate which days and times of the week would be convenient for you to be interviewed. We will write to you and suggest a date.

.....
e.g. Thursday afternoons, Wednesdays only, any morning

If you live with a partner/spouse:

For some of the interviews we will be interviewing couples. Would your partner also be willing to be interviewed (**your partner/spouse would be interviewed separately and also receive a £20 cash gift**)

Please tick ✓ one

My partner/spouse is willing to be interviewed

My partner/spouse is NOT willing to be interviewed

If you or your partner/spouse have difficulties with English, please state the language you would prefer to be interviewed in

Yourself

Partner/Spouse(if applicable)

Please write in

Thank-you for your help. If you have any further questions about the research, please contact *[researchers' contact details]*

Please return your completed form to us in the enclosed pre-paid envelope.

Item 2: Tranche one topic guide

INTRODUCTION

1. My name is [] and I work for the Policy Studies Institute [*give card*]. This is an independent research institute and is not part of any government department.¹ The Department for Work and Pensions has asked us to do research on what helps people to maintain independence in later life, and what services people need and use to help them remain independent. Anything you tell me is confidential and all views will be reported anonymously so no individual will be identified in our report.
2. Most of these questions are open-ended, so feel free to say as much or as little as you want on them. Because people's lives are so different, some of them will be more relevant to you than others.
3. The sorts of things we will be covering in the interview include
 - A bit about your background;
 - Your feelings about independence;
 - Your experiences of receiving help and using services;
 - Who you would go to for particular types of help;
 - Any support or help you provide to other people at the moment;
 - The kinds of services you or your family might use in the future; and
 - The kinds of service you would like to see that are not currently available.
4. Is it okay to tape our conversation? This is just because it's difficult to take the sorts of detailed notes I'd like, and it won't be heard by anyone outside the research team. All tapes are given an anonymous number and the Department for Work and Pension won't be told who we've spoken to at any point. [*note interview can only go ahead once permission has been established for taping*]
5. Do you have any questions before I begin?

¹ Note if asked who DWP is: the DWP is a government department, which has responsibility for enabling older people to maintain their independence in later life. The DWP through The Pensions Service is responsible for delivering benefits including the state pension to people over state pension age.

BACKGROUND

I'd like to start off by talking about the background information you supplied in the questionnaire. Is this information still correct?

Review information on: *INTERVIEWERS NOTE ANY CHANGES HERE*

- age, marital status, retirement status of self and spouse (if applicable);
- other members of household – if extended family, how long living in these arrangements?;
- types of pension and benefits received;
- tenure, ask how long living in current residence, how long in community ethnicity/first language.

1. Are you involved in any paid work at the moment? [probe for type and context]
2. *If no:* How long have you been retired?
3. What was the reason for retiring when you did? Were/are you OK with this?
4. What was your (and spouse's) main occupation before retiring?

Can I ask you a few questions about your (and your partner's) sources of income?

In the Questionnaire you say the income you receive each week ranges between *X* and *X*. Is this correct?

[Background note: 'Income after housing costs is the income you have after payment of rent or mortgage payments. This is before any payment of bills, Council Tax or other charges that you pay.']}

If question proves problematic, probe on: How much is your rent/mortgage? What does this include? (e.g. heating? warden?) Do you have to pay this out of the amount you told me, or had you already deducted the rent?

1. Does this income include money from:
 - Pensions (private, occupational)
 - Employment
 - Benefits – specify (RP, MIG/PC, DLA/AA,SDP, HB, CTB)
2. Do you mind telling me, how much you get each week from each of these sources? (Prompt if actual amounts not forthcoming or to confirm: What proportion of your income comes from each of these sources: (ask about each in turn - all or nearly all/half/less than half/very little)
3. Do you have any savings? About how much savings do you currently have?
Probe:
No savings; Less than £6,000; £6,000-£12,000; More than £12,000
4. Do you have any regular income that comes from any other sources? e.g. income from lodgers, regular contributions from friends, etc.

5. Do you feel your income allows you to live a comfortable lifestyle? Please explain.
(*prompts*: are you able to go out socially/have a holiday/do household repairs/replace major appliances)

HEALTH (*limit this section to 10 minutes max*)

1. I would also like to ask you a few questions about your health? First of all how would you describe your health at the moment?

Probe/check for:

Nature of any illness/disability?

Any changes in health since retired/recently?

Do you feel your health stops you doing things you would like to do/used to do? In what way? (Probe in the home, outside the home, either on their own or with support.)

Probes: Do you need?

Personal help e.g. dressing, bathing, washing

Physical help e.g. walking, getting up and down stairs

Financial matters e.g. filling in forms, paying bills

Practical help e.g. preparing meals, shopping

2. Do you depend on other people to do some things for you? Examples?

Probes: Who helps with?

Personal help e.g. dressing, bathing, washing

Physical help e.g. with walking, getting up and down stairs

Financial matters e.g. filling in forms, paying bills

Practical help e.g. preparing meals, shopping

Who does this for you?

How do you feel about this?

Do you mind about this?

Level of care received from partner/extended family/friends/social services/other organisations, where relevant

Do you pay for any care you receive?

3. How would you describe your partner's health at the moment?

Probe/check for:

Nature of illness/disability- in very general terms only

Any changes in health recently?

Do you feel that your partner's health stops you from doing things which you'd like to do? (in the home, outside the home) How much does it affect your lifestyle?

Level of care provided for partner/extent provided by social services, where relevant

4. Does your partner depend on you to do some things for them? Examples?

Probes:

Personal help e.g. dressing, bathing, washing
Physical help e.g. walking, getting up and down stairs
Financial matters e.g. filling in forms, paying bills
Practical help e.g. preparing meals, childcare, shopping
How often?
How do you feel about this?
Do you mind about this?

INDEPENDENCE

We are very interested in finding out what 'being independent' means to people in later life. I'd like to ask you a few questions on this.

1. What does 'independence' mean to you?

*Prompt only if necessary (*priorities for prompting)*

- *Being able to live/stay in your own home
- *Being able to live in the place of your choice
- *Being able to make your own decisions
- *Having enough money to be able to live in the way that you want to and being able to pay for things that you need or want.
- *Having access to reliable help and support
- *Being in good health
- Having access to appropriate equipment and aids
- Getting out and about
- Seeing family and friends
- Doing what you want when you want
- Helping other people/making a contribution
- Being able to join in community activities
- Being able to keep a car/be mobile
- Being able to do certain things for yourself (examples)
- Not being frightened to go out

2. Do you feel that your income impacts on your ability to live independently? Probe- Does it enable you do what you want to do? Does it restrict what you want to do in anyway?
3. [If relevant] Do you feel the state benefits you receive help or hinder your feelings of independence? (Including RP.)
Probe:
Why do you feel like this?

4. Have you changed your ideas on the meaning of independence in recent years, say, compared to when you (or your spouse) were [younger/working/in better health]?

Probes:

In what ways?

What things seem more important to you now?

What things seem less important?

5. What aspects of independence would you say you most value or would find it hardest to give up? Why is this?

Probe:

Relative importance of?

- Being in good health
- Being able to live where you want to live
- Having enough money to be able to live in the way that you want to and being able to pay for things that you need or want.
- Having the help and support of family, friends and others
- Participating in activities, meeting people and maintaining contact with friends, neighbours etc...
- Being able to make your own decisions/feeling in control
- Feeling safe and not in danger from others
- Being mobile and having access to transport
- Having the ability to perform personal/practical tasks
- Having the ability to give support to others when you'd like to

6. (*Show scale*) On a scale from 1 to 10, where 10 is completely independent, where would you place yourself? Why is that?

(refer back to probes above, as appropriate)

7. Do you ever worry about losing your independence? Or do you feel that your independence has been compromised in any way?

Probes:

If so, can you say when you started to worry about this?

Did anything prompt this?

What sort of things would make you/have made you personally feel less independent? How?

8. Do you feel able to make choices about the things that matter to you?

What would help you to make these decisions? *Probe – access to information, access to support*

SERVICE USE AND NEEDS

[The service use diary will be used as an aid in this section]

The next set of questions deal with activities you do and the help you use. We are interested in what you do on a regular basis as well as what services you use occasionally.

First of all, can you tell me what activities you do and services you use at present, say over a typical month?

[Fill in calendar with outings and services used. Then probe for less frequent activities/services over past 6 months.]

Probes : Activity/Service Categories (examples)

Health	Doctor's surgery Local hospital (NHS/private) Dentist District nurse Chiropodist Alternative practitioners – chiropractor, acupuncturist, etc. Counselling service – bereavement, religious visitor
Practical	Transportation (public, private (taxi)) Meals-on-wheels Shopmobility Cleaning, cooking (private individual or agency), gardening Home help/community care/respite care Personal care – hair, manicure (in home, out-of-home) Community alarm services
Social and community services	[Local or independent, regional/national] Housing Housing Associations and Trusts Pensions (From: The Pension Service? Other organisations?) Benefits (From: The Pension Service? Other organisations?) Social Services Support groups Voluntary groups (e.g. Help the Aged) Churches and religious groups
Leisure	Community centre, club, exercise classes, library (travelling or fixed site), museums, art galleries, adult education classes Sports, e.g. golf Activities and trips organised by local groups Travel Reading, Bingo, crosswords, watching T.V

Other	Bank Legal/financial adviser – Citizen's Advice Bureau Community alarm service, community safety Information lines (telephone, internet)
-------	---

1. For each service mentioned check how often used, how found out about, how provided (e.g. home-based or office-based, by phone), any recent changes, any ways they could be improved)
2. What do you think are the most important services (locally or nationally) for older people?
3. What are the most important ones for you personally? (prioritise 5)
4. Is there anything that you need support in that you are not getting?
5. Do you feel that the services in your local area are adequate? (*Probe-* how do these compare to your previous or friends' experiences in other areas where possible).
6. Are there any services which were useful to you in the past, but you no longer use? What were they? Why did you stop using them?
7. Are there any additional services that you think you might need to use at some point in the future? Do you have any anxieties about this at the moment?

If service user:

1. Are there any services which help/helped you to maintain your independence?
Probe- Identify what the service provides help with:
 - Helps you with personal care
 - Helps you with household tasks
 - Helps you with physical tasks e.g. mobility
 - Enables you to participate in activities/maintain contact with family, friends and neighbours
 - Helps you with formal correspondence/filling forms, banking etc.
 - Gives you financial advice and support
2. How does it do this?
3. What is it about this service that is particularly useful or important to you?
4. Are there any services that make you feel less independent?
Probe - identify what help the service should be providing
5. Why is this?
Probes:
 - Is there anything that makes it difficult or uncomfortable for you to use this service? (e.g. finding out about it, getting to venue, using phone, attitudes and

manner of staff, language difficulties, problems reading printed literature, need someone to accompany them).

- How does it make you feel?
- If you could change anything about how this service was provided, what would it be?

6. What other things help or would help you to maintain your independence?

[probe for external factors which have facilitated/promoted independence, personal resources, social support, personality traits, proposals for support services]

If non-user:

- What would make you use a particular service if you needed to?
- If you did not want to use a service how else would you meet your need? Why wouldn't you use this service? / What puts you off it?
- Is there any help that your family provides you with that you would prefer to be provided in another way/by someone else?

Segment 7 only (residential or sheltered home residents):

- 1.Why did you move into X? When was this? How did you decide which residential home/sheltered housing was best for you?
- 2.Do you feel that living in this residence affects your independence? [Probe: In what ways?]
3. How much contact/participation in activities do you have outside the home?
Probe - How easy is this? (also probe re access to telephone)
- 4.Visitors - are there any restrictions on visitors. Do you mind about this?
- 5.How easy is it for you to get out and do things you want to do (not in a group)?
- 6.How much choice do you have over your daily activities? (Probe bedtime, meals, bathing, who assists you, etc.) How do you feel about this?
- 7.Do you have access to activities you enjoy / do the things that you like doing?

SOCIAL SUPPORT/NETWORKS

[the social network map will be used as an aid to this section]

Start by establishing place in the community.

Recap: You say you've been living in your current home for **X** number of years/months.

Probes:

- How well would you say you know the area?
- Do you have any friends or relatives living nearby?
- Do you do any volunteer work?

Now I want you to think about who you would contact for help in particular situations. I'm going to put a number of situations to you, and I want you to think about who or what service would be the first place you would go to for help in each case, and why. For instance, it might be a neighbour, friends or family (including the person you live with), some sort of local authority, voluntary or private service, or any other person or agency you can think of. Please feel free to make your own suggestions if you would like to get help in a way that doesn't seem to be available at the moment. There are no right or wrong answers in this part of the interview, we're just interested in the different ways that people would approach problems. [Interviewers to explain what coloured stickers represent and focus on 1-2 areas per heading. Initial focus should be on situations experienced drawing on information obtained in the interview, but if not applicable move on hypothetical situations, and differentiate responses which relate to help received or needed and speculated sources of help on the social network map):

Personal crisis:

- personal crisis, e.g. a bereavement
- financial crisis, e.g. not having the money to pay an unexpected bill. *[interviewers to probe 'anyone else?' on sources of informal help who respondents could borrow £100 from if needed]*
- your own or your partner's illness, e.g. a heart attack, getting help if ill in bed *[interviewers to probe 'anyone else' whom respondents would turn to for informal help]*.
- being a victim of crime, *[Interviewers to probe 'anyone else?' whom the respondent could turn to in a serious personal crisis, & whether these people live nearby]*

Household help:

- help with personal care, e.g. help washing, shaving, cutting nails, using the toilet, getting out of the bath or shower, or dressing.
- physical help with impaired mobility, e.g. with walking, getting up and down stairs, getting into and out of bed.
- day to day support, e.g. filling in a form, writing letters, banking, or paying a bill if your eyesight was making it difficult to read small print, using the telephone.
- practical help, e.g. laundry, preparing meals, getting to the doctor's, gardening, shopping, housework, household repairs, getting a lift somewhere urgently.

Help given to others:

[Interviewers map using responses to question 4 below]

1. Would you say that you feel more comfortable obtaining or receiving help from particular people or agencies? Who are these, and why do you feel like this? Are there instances where you need help from more than one source in dealing with an issue? (if so, would you prefer to get all the help you need from one source? Ideally, from whom?)

2. Who do you receive help from in your day-to-day life at the moment? e.g. personal care, financial advice, practical help.
3. Can you think of particular situations that you would seek outside help in? (i.e. help from an outside organisation) What about help from the family? Friends?
4. Do you provide help or support to any other people at the moment? (e.g. spouse, family (parents, siblings, children, etc.), neighbours, friends). What do you do for these? How often? Are you involved in any voluntary work? [what does this involve, where, how often?] [interviewers try & pick up on informal forms of voluntary work & community activities]

EXPECTATIONS AND FEELINGS

We've talked about the services you use, the forms of support you use and provide to others at the moment, and your feelings about maintaining independence in later life.

1. On balance, and taking into account how these things make you feel, how satisfied would you say you feel with life at the moment? What do you enjoy most about your life?
2. Is there anything you'd like to change?
3. Do you have any particular hopes and plans for the next few years?
4. Is there anything that needs to happen before you can put these plans into action?
5. Is there anything else about local services and independence that you wanted to talk about today or which seems relevant, which we haven't discussed?

Thanks, pay incentive, get receipt signed, and close.

Item 3: Tranche two topic guide

INTRODUCTION

1. My name is [] and I work for the Policy Studies Institute [*give card*]. This is an independent research institute and is not part of any government department. The Department for Work and Pensions has asked us to do research on what helps people to maintain independence in later life, and what services people need and use to help them remain independent. Anything you tell me is confidential and all views will be reported anonymously so no individual will be identified in our report.
2. Most of these questions are open-ended, so feel free to say as much or as little as you want on them. Because people's lives are so different, some of them will be more relevant to you than others.
3. The sorts of things we will be covering in the interview include
 - A bit about your background;
 - Your feelings about independence;
 - Your experiences of receiving help and using services;
 - Who you would go to for particular types of help;
 - Any support or help you provide to other people at the moment;
 - The kinds of services you or your family might use in the future; and
 - The kinds of service you would like to see that are not currently available.
4. Is it okay to tape our conversation? This is just because it's difficult to take the sorts of detailed notes I'd like, and it won't be heard by anyone outside the research team. All tapes are given an anonymous number and the Department for Work and Pension won't be told who we've spoken to at any point. [*note interview can only go ahead once permission has been established for taping*]
5. Do you have any questions before I begin?

BACKGROUND

I'd like to start off by checking the background information you supplied in the questionnaire, just to make sure it's still up to date.

Review information on:

- age, marital status (if single ask if ever married), retirement status of self and spouse (if applicable);
- other members of household – if extended family, how long living in these arrangements?;
- types of pension and benefits received;
- tenure, ask how long living in current residence, how long in community
- ethnicity/first language

1. Are you involved in any paid work at the moment? *[probe for type and context]*
2. *If no:* How long have you been retired?
3. Any voluntary work? *[probe for type and context]*
4. What was the reason for retiring when you did? Were/are you OK with this?
5. What was your (and spouse's) main occupation before retiring?

INCOME

Can I ask you a few questions about your (and your partner's) sources of income?

In the Questionnaire you say the income you receive each week ranges between *X* and *X*. Is this correct?

[Background note: 'Income after housing costs is the income you have after payment of rent or mortgage payments. This is before any payment of bills, Council Tax or other charges that you pay. ']

If question proves problematic, interviewers to probe on: How much is your rent/mortgage? What does this include? (e.g. heating? warden?) Do you have to pay this out of the amount you told me, or had you already deducted the rent?

1. Does this income include money from:
 - Pensions (private, occupational)
 - Employment
 - Benefits – specify (RP, MIG/PC, DLA/AA, SDP, HB, CTB) – need to specify what component of DLA (care or mobility)
2. Do you mind telling me, how much you get each week from each of these sources? *(Prompt if actual amounts not forthcoming or to confirm: What proportion of your income comes from each of these sources: (ask about each in turn - all or nearly all/half/less than half/very little))*
3. Do you have any savings? About how much savings do you currently have?
Probe:
No savings; Less than £6,000; £6,000-£12,000; More than £12,000

4. Do you have any regular income that comes from any other sources? e.g. income from lodgers, regular contributions from family, friends, etc.

Probe: for regular help with paying for groceries, clothes, holidays, etc. & who this help comes from.

HEALTH

1. I would also like to ask you a few questions about your health. First of all how would you describe your health at the moment?

Probe/check for:

Nature of any illness/disability?

Any changes in health since retired/recently?

If health problem – how long have you experienced this problem with your health?

If applicable – You say you have been receiving x [and x, etc.] disability benefits. Roughly how long have you been receiving x disability benefit(s)? How did this come about? (e.g. did someone help them claim?)

2. Do you feel your health stops you doing things you would like to do/used to do? In what way? (Probe in the home, outside the home, either on their own or with support.

Probes: Do you need?

Practical help e.g. preparing meals, shopping

Financial matters e.g. filling in forms, paying bills

Physical help e.g. with walking, getting up and down stairs

Personal help e.g. dressing, bathing, washing

3. Do you need help from other people to do some things? What sort of things?

Probes: Who helps with?

Practical help e.g. transportation, preparing meals, shopping

Financial matters e.g. filling in forms, paying bills

Physical help e.g. with walking, getting up and down stairs

Personal help e.g. dressing, bathing, washing

Who does this for you?

How do you feel about this?

Do you mind about this?

Any help received from (*specify*):

Partner

Extended family

Friends/neighbours

Social services

Other organisations (Please specify, e.g. Age Concern, Citizens' Advice, etc.)

Do you pay for any care you receive?

Probe:

Which help do you pay for?

How much?

4. *[if applicable]* How would you describe your partner's health at the moment?

Probe/check for:

Nature of illness/disability - in very general terms only

Any changes in health recently?

Do you feel that your partner's health stops you from doing things you'd like to do? (in the home, outside the home) How much does it affect your lifestyle?

Level of care provided for partner/extent provided by social services, where relevant

5. If applicable – You say your partner receives x [and x, etc.] disability benefits. Roughly how long have they been receiving x disability benefit(s)? How did this come about?

6. Does your partner need help from you to do things? Examples?

Probes:

Practical help e.g. preparing meals, childcare, shopping

Financial matters e.g. filling in forms, paying bills

Physical help e.g. with walking, getting up and down stairs

Personal help e.g. dressing, bathing, washing

How often?

How do you feel about this?

Do you mind about this?

INDEPENDENCE

We are very interested in finding out what 'being independent' means to people in later life. I'd like to ask you a few questions on this.

1. What does 'independence' mean to you? *[probe, concentrating on starred suggestions]*

What aspects would you find it hardest to give up?

*Prompt only if necessary (*priorities for prompting)*

*Being able to live/stay in your own home

*Being able to live in the place of your choice

*Being able to make your own decisions

*Having sufficient income in retirement

*Having access to reliable help and support

*Being in good health

Having access to appropriate equipment and aids

Getting out and about

Seeing family and friends
 Doing what you want when you want
 Helping other people/making a contribution
 Being able to join in community activities
 Being able to keep a car/be mobile
 Being able to do certain things for yourself (what things are most important to you?)
 Not being frightened to go out

2. Is there anything in your life right now that you feel gets in the way of your independence?
Probes: [do not probe until respondent gives spontaneous answer]
 - Your health? In what way? Has this changed recently?
 - Your mobility? If yes, what would help?
 - Your transportation? If yes, what would help?
 - Your financial situation? If yes, what would help?
 - Your benefits? If yes, what would help?
 - Your accommodation? If yes, what would help?
 - Anything else?

3. As you've got older, has your life changed? Why do you say that?

4. As you've got older, has your view of being independent changed? Why do you say that?

5. Do you feel your income allows you to live a comfortable lifestyle?
 Can you explain a bit ...
(prompts: are you able to go out socially?/have a holiday?/do household repairs?/replace or fix major appliances when they go wrong?)

Probe:
(Ask if currently comfortable)
 What things would you have to give up if your income fell by say £20 a week?

(Ask if currently not comfortable)
 What amount of money would you say you need to live on to be comfortable?
 How much extra would you need?

 What things would you gain if you received an extra £20 a week?

6. I'm going to ask you a few questions now to see how your sense of independence is affected by the ways in which other people help you, might help you in the future, or by the help that you give to others.

Part A: Interviewers to ask people who rely on others (formally or informally) for regular help and support (see question 4 in health section).

*If more than one form of support is given, repeat the question with two or three examples.
If no regular help or support is received, go to Part B.*

You told me earlier that your (partner/family/service) helps you with (e.g. transport/cleaning/paying bills).

Would you say that this help enables you to be independent? Alternatively, has it changed your feelings about being independent in any way?

How would you feel if (your partner/family/service) wasn't there to help you?

Probe:

- Would you know what to do?
- Who would you turn to for help instead?
- Would you know where to go for information about getting alternative help? (Where?)

Part B: Interviewers to ask all: choose one or two scenarios which seem appropriate to situation.

- i. If you suffered a fall and had to rest at home for a few weeks, who would you turn to help with getting the shopping/household chores etc.? Who would be your next point of call?

How would you feel about asking them for help? Would anything make it difficult? (Probe)

Would you prefer to ask a family/friend/neighbour/statutory body for this kind of short-term help?

What about if it was a longer term condition, would you ask the same person/agency to help? (If not, why not?)

- ii. If you were unable to drive (or travel the way you normally travel) for some reason, who would you approach for getting a lift to your doctors/getting to the supermarket/getting to the bank, etc? Who/what would be your second choice? How would you feel about asking them for help? Would anything make it difficult? (Probe)

- iii. If you received an unexpected bill which you were unable to pay, who would be your first port of call for advice? (CAB, family, friends, etc.)

Who would be your second choice?

How would you feel about asking for help?

Part C: Interviewers ask all

Do you provide help or support to any people at the moment? (e.g., spouse, family (parents, siblings, children, etc.), neighbours, friends).

What do you do?

How often?

How do you feel about this? Would you be happy to do more of this if you were asked? Would you like to do any less? Does it limit you in any way? (Probe)

7. Do you ever worry about losing your independence? Or do you feel that your independence has been compromised in any way?

Probes:

If so, can you say when you started to worry about this?

Did anything prompt this?

What sort of things would make you/have made you personally feel less independent? How?

8. Do you feel able to make choices about the things that matter to you?
What would help you to make these decisions? *Probe* – access to information, access to support.

SERVICE USE AND NEEDS

I'm going to ask you some questions now about your feelings and expectations about services available locally, taking into account any services you use at the moment or think that you might use in the future. By services we mean social and community services like libraries, doctor's surgeries, benefits advice, community centres, legal aide, meals on wheels, etc.

1. What do you think are the most important services (locally or nationally) for older people?
2. What are the most important ones for you personally? (prioritise 5) Do you use these at the moment/in the past?
3. Is there anything that you need help with that you are not getting?
4. Do you feel that the services in your local area are adequate? (*Probe*- how do these compare to your previous or friends' experiences in other areas where possible).
5. Is there anything you would want changed?
6. Are there any additional services that you think you might need to use at some point in the future?

Probe:

Do you have any anxieties about this at the moment?

If service user:

1. What sorts of services (if any) would you say help, or have in the past helped you to maintain your independence?
Probe- Identify what the service provides help with:
 - Helps you with personal care
 - Helps you with household tasks
 - Helps you with physical tasks e.g. mobility

- Enables you to participate in activities/maintain contact with family, friends and neighbours
- Helps you with formal correspondence/filling forms, banking etc...
- Gives you financial advice and support

2. How do they do this?

3. What is it about this service that is particularly useful or important to you?

4. Have any services made you feel less independent in some way?

Probe - identify what help the service should be providing:

- Helps you with personal care
- Helps you with household tasks
- Helps you with physical tasks e.g. mobility
- Enables you to participate in activities/maintain contact with family, friends and neighbours
- Helps you with formal correspondence/filling forms, banking etc...
- Gives you financial advice and support

5. How?

Probes:

- Is there anything that makes it difficult or uncomfortable for you to use this service? (e.g. finding out about it, getting to venue, using phone, attitudes and manner of staff, language difficulties, problems reading printed literature, need someone to accompany them).
- How does it make you feel?

6. How long have you been using these services? (*ask this of all services identified regardless if it made them feel more or less independent.*)

7. Can I just check on how often you use these services?

Probes:

Has it changed recently? (when/how?)

How do you contact the service? (how does the service reach you?)
Phone/post/you visit them/home based service?

8. How did you find out about these services? (*ask this of all services identified regardless if it made them feel more or less independent.*)

Probes:

How easy was it to find out about?

Did anyone help you to get this service?

9. Are there any ways in which you think these services could be improved? (*ask this of all services identified regardless of if it made them feel more or less independent.*)

Probes:

- Hours/venue/staffing/access
- large print/induction loop/phones/internet access/translated materials/more flexible appointments/request staff of particular gender, age or ethnicity/help completing forms)
- If you could change anything about how this service was provided, what would it be?

If non-user:

- What would make you use a particular service if you needed to?
- If you did not want to use a service how else would you meet your need?
- Is there any help that your family provides you with that you would prefer to be provided in another way?
- Why wouldn't you use this service? / What puts you off it?

Ask all:

1. Was there any service you used in the past that you no longer have?

Probes:

What are these?

Why did you stop using it?

(If this would still be useful) What have you done/ are you doing instead?

Segment 7 only (residential or sheltered home residents):

- 1.Why did you move into X?
- 2.Do you feel that living in this residence affects your independence? Probe in what way?
- 3.How much contact/participation in activities do you have outside the home?
Probe- How easy is this? (also probe re access to telephone)
- 4.Visitors- are there any restrictions on visitors? Do you mind about this?
- 5.How easy is it for you to get out and do things you want to do (not in a group)?
- 6.How much choice do you have over your daily activities? (Probe bedtime, meals, bathing, who assists you, etc.) How do you feel about this?
- 7.Do you have access to activities you enjoy / do the things that you like doing?

EXPECTATIONS AND FEELINGS

We've talked about the services you use, the forms of support you use and provide to others at the moment, and your feelings about maintaining independence in later life. *[NB questions 1-4 to be omitted if very unwell or unsatisfied with life and has indicated that believes no change possible]*

1. On balance, and taking into account how these things make you feel, how satisfied would you say you feel with life at the moment? What do you enjoy most about your life?
2. Is there anything you'd like to change?
3. Do you have any particular hopes and plans for the next few years?
4. Is there anything that needs to happen before you can put these plans into action?
5. Is there anything else about local services and independence that you wanted to talk about today or which seems relevant, which we haven't discussed?

Thanks, pay incentive, get receipt signed, and close.

Item 4: Tranche three topic guide: for users of home from hospital service

INTRODUCTION

1. My name is [] and I work for the Policy Studies Institute *[give card]*. This is an independent research institute and is not part of any government department. The Department for Work and Pensions has asked us to do research on what helps people to maintain independence in later life, and what services people need and use to help them remain independent. Anything you tell me is confidential and all views will be reported anonymously so no individual will be identified in our report.
2. Most of these questions are open-ended, so feel free to say as much or as little as you want on them. Because people's lives are so different, some of them will be more relevant to you than others.
3. The sorts of things we will be covering in the interview include
 - A bit about your background;
 - Your feelings about independence;
 - Your experiences of receiving help and using services;
 - Who you would go to for particular types of help;
 - Any support or help you provide to other people at the moment;
 - The kinds of service you would like to see that are not currently available.
4. Is it okay to tape our conversation? This is just because it's difficult to take the sorts of detailed notes I'd like, and it won't be heard by anyone outside the research team. All tapes are given an anonymous number and the Department for Work and Pension won't be told who we've spoken to at any point. *[note interview can only go ahead once permission has been established for taping]*
5. Do you have any questions before I begin?

BACKGROUND

I'd like to start off by checking the background information you supplied in the questionnaire, just to make sure it's still up to date.

Review information on:

- age, marital status (if single ask if ever married), retirement status of self and spouse (if applicable);
- other members of household – if extended family, how long living in these arrangements?;
- types of pension and benefits received;
- tenure, ask how long living in current residence, how long in community
- ethnicity/first language

1. Are you involved in any paid work at the moment? [probe for type and context]
2. *If no:* How long have you been retired?
3. Any voluntary work? [probe for type and context]
4. What was the reason for retiring when you did? Were/are you OK with this?
5. What was your (and spouse's) main occupation before retiring?

INCOME

Can I ask you a few questions about your (and your partner's) sources of income?

In the Questionnaire you say the income you receive each week ranges between *X* and *X*. Is this correct?

[Background note: 'Income after housing costs is the income you have after payment of rent or mortgage payments. This is before any payment of bills, Council Tax or other charges that you pay.']

If question proves problematic, probe on: How much is your rent/mortgage? What does this include? (e.g. heating? warden?) Do you have to pay this out of the amount you told me, or had you already deducted the rent?

1. Does this income include money from:
 - Pensions (private, occupational)
 - Employment
 - Benefits – specify (RP, MIG/PC, DLA/AA, SDP, HB, CTB) – need to specify what component of DLA (care or mobility)
2. Do you mind telling me, how much you get each week from each of these sources? (Prompt if actual amounts not forthcoming or to confirm: What proportion of your income comes from each of these sources: (ask about each in turn - all or nearly all/half/less than half/very little)
3. Do you have any savings? About how much savings do you currently have?

Probe:

No savings; Less than £6,000; £6,000-£12,000; More than £12,000

4. Do you have any regular income that comes from any other sources? e.g. income from lodgers, regular contributions from family, friends, etc.
Probe for regular help with paying for groceries, clothes, holidays, etc. & who this help comes from.

HEALTH

1. I would like to ask you a few questions about your health. First of all, how would you describe your health at the moment?
Probe/check for:
Nature of any illness/disability?
Any changes in health since retired/recently?
If health problem – how long have you experienced this problem with your health?
2. I understand you recently came out of hospital [establish when this was]. Can you tell me about your experience of leaving hospital?
Probe:
Why were you in the hospital? How long had you been in hospital? [was it a specialist hospital?]
Did you feel ready to leave hospital when you did? [Probe on any returns to hospital].
3. How did you find out about the 'Home from Hospital' scheme?
Probe:
Was everything arranged while you were still in hospital?
Who did the arranging for you? Did you have to qualify?
When and how did you get in touch with your volunteer helper?
4. What sort of help did you need after leaving hospital?
Probes: Did you need?
Practical help e.g. preparing meals, shopping
Financial matters e.g. filling in forms, paying bills
Physical help e.g. with walking, getting up and down stairs
Personal help e.g. dressing, bathing, washing
5. Did you need this/these kinds of help before your stay in hospital?
Probes: Did you need?
Practical help e.g. preparing meals, shopping
Financial matters e.g. filling in forms, paying bills
Physical help e.g. with walking, getting up and down stairs
Personal help e.g. dressing, bathing, washing

6. What kind of help did 'Home from Hospital' provide?

Probe on various sorts of help offered :

shopping, bills, prescriptions, errands, meal preparation, foot care, providing company)

7. What is your overall impression of the Home from Hospital service?

Probe:

What were the best aspects about the service?

How did you get on with your volunteer? (are you still in contact with them?)

Would you use it again if there was the need?

Would you recommend it to a friend who was in hospital?

Did it seem to be available for the right length of time?

Do you think it helped your recovery process? – in what way?

8. Is there anything that could be changed or improved about the Home from Hospital service?

9. Did it make any difference to you knowing that the Home from Hospital service was provided by volunteers in *[insert name of voluntary organisation]*?

Probe:

What's your general perception of *[insert name of voluntary organisation]*?

Do you think other agencies could work together to offer a similar or extended service?

Would you have liked Social Services to be involved?

10. Overall, how smooth was the transition for you going from hospital to home? Did you experience a change in lifestyle? And, if so, has this continued?

11. Who would you have gone to for help if Home from Hospital hadn't existed? (e.g. respite care, relied exclusively on partner, gone to stay with family, asked neighbours for help, struggled on alone)

12. Do you still need any of the help provided by the Home from Hospital volunteer?

Any additional help?

Probes: Do you need ...?

Practical help, e.g. preparing meals, shopping

Financial matters, e.g. filling in forms, paying bills

Physical help, e.g. with walking, getting up and down stairs

Personal help, e.g. dressing, bathing, washing

If so, do you pay for any care you receive?

Probe:

Which help do you pay for?

How much?

13. What are the most important services for you personally? (*prioritise 5*)

14. Is there anything that you need help with that you are not getting?
15. Have you had any contact with other agencies since you left the hospital? [e.g. district nurse, GP, social workers, occupational therapists, Age Concern]

If Applicable ...

16. Do you mind telling me about your partner's health? How would you describe your partner's health at the moment?

Probe/check for:

Nature of illness/disability - in very general terms only

Any changes in health recently?

Do you feel that your partner's health stops you from doing things you'd like to do? (in the home, outside the home) How much does it affect your lifestyle?

Level of care provided for partner/extent provided by social services, where relevant

17. Does your partner need help from you to do things? Examples?

Probes:

Practical help e.g. preparing meals, childcare, shopping

Financial matters e.g. filling in forms, paying bills

Physical help e.g. with walking, getting up and down stairs

Personal help e.g. dressing, bathing, washing

How often?

How do you feel about this? Do you mind about this?

INDEPENDENCE

We are very interested in finding out what 'being independent' means to people in later life. I'd like to ask you a few questions on this.

1. What does 'being independent' mean to you? *[probe, concentrating on starred suggestions]* What aspects would you find it hardest to give up?

*Prompt only if necessary (*priorities for prompting)*

*Being able to live/stay in your own home

*Being able to live in the place of your choice

*Being able to make your own decisions

*Having sufficient income in retirement

*Having access to reliable help and support

*Being in good health

Having access to appropriate equipment and aids

Getting out and about

Seeing family and friends

Doing what you want when you want

Helping other people/making a contribution

Being able to join in community activities
Being able to keep a car/be mobile
Being able to do certain things for yourself (what things are most important?)
Not being frightened to go out

2. How would you say taking part in Home from Hospital affected your independence?

Probe:

Did it enable you to feel more independent/less independent?
In what way?

3. Generally, as you've got older, has your life changed? Why do you say that?
4. As you've got older, has your view of being independent changed? Why do you say that?
5. Do you provide help or support to any people at the moment? (e.g., spouse, family (parents, siblings, children, etc.), neighbours, friends).
What do you do?
How often?
How do you feel about this? Would you be happy to do more of this if you were asked? Would you like to do any less? Does it limit you in any way?
(Probe how)
6. Do you ever worry about losing your independence? Or do you feel that your independence has been compromised in any way?

Probes:

If so, can you say when you started to worry about this?
Did anything prompt this?
What sort of things would make you/have made you personally feel less independent? How?

7. Do you feel able to make choices about the things that matter to you?
What would help you to make these decisions? *Probe* – access to information, access to support.

EXPECTATIONS AND FEELINGS

We've talked about the services you use, the forms of support you use and provide to others at the moment, and your feelings about maintaining independence in later life.

On balance, and taking into account how do these things make you feel, how satisfied would you say you feel with life at the moment? What do you enjoy most about your life?

Thanks, pay incentive, get receipt signed, and close.

Item 5: Tranche three topic guide: for users of bereavement centre

INTRODUCTION

1. My name is [] and I work for the Policy Studies Institute [*give card*]. This is an independent research institute and is not part of any government department. The Department for Work and Pensions has asked us to do research on what helps people to maintain independence in later life, and what services people need and use to help them remain independent. **We are interested in the major changes affecting people and are looking at a group of people who have been recently bereaved and a group that have been recently discharged from hospital.** Anything you tell me is confidential and all views will be reported anonymously so no individual will be identified in our report.
2. Most of these questions are open-ended, so feel free to say as much or as little as you want on them. Because people's lives are so different, some of them will be more relevant to you than others.
3. The sorts of things we will be covering in the interview include
 - A bit about your background;
 - Your feelings about independence;
 - Your experiences of receiving help and using services, and in particular the bereavement centre;
 - Who you would go to for particular types of help;
 - Any support or help you provide to other people at the moment;
 - The kinds of services you might use in the future; and
 - The kinds of service you would like to see that are not currently available.
4. Is it okay to tape our conversation? This is just because it's difficult to take the sorts of detailed notes I'd like, and it won't be heard by anyone outside the research team. All tapes are given an anonymous number and the Department for Work and Pension won't be told who we've spoken to at any point. [*note interview can only go ahead once permission has been established for taping*]
5. Do you have any questions before I begin?

2. BACKGROUND

We recently sent you a questionnaire and I'd like to start off by reviewing the background information you supplied in the questionnaire. Did you experience any difficulties completing it?

1. Are you involved in any paid work at the moment? [probe for type and context]
2. *If no:* How long have you been retired?
3. Any voluntary work? [probe for type and context]
4. What was the reason for retiring when you did? Were/are you OK with this?
5. What was your main occupation before retiring? (And what was your husband's job? Did your wife work outside the home?)

3. INCOME

Can I ask you a few questions about your sources of income?

In the Questionnaire you say the income you receive each week ranges between *X* and *X*. Is this correct?

[Background note: 'Income after housing costs is the income you have after payment of rent or mortgage payments. This is before any payment of bills, Council Tax or other charges that you pay.]

If question proves problematic, interviewers to probe on: How much is your rent/mortgage? What does this include? (e.g. heating? warden?) Do you have to pay this out of the amount you told me, or had you already deducted the rent?

1. Does this income include money from:
 - Pensions (private, occupational)
 - Employment
 - Benefits – specify (RP, MIG/PC, DLA/AA, SDP, HB, CTB) – need to specify what component of DLA (care or mobility)
2. Do you mind telling me, how much you get each week from each of these sources? (Prompt if actual amounts not forthcoming or to confirm: What proportion of your income comes from each of these sources: (ask about each in turn - all or nearly all/half/less than half/very little)
3. Do you have any savings? About how much savings do you currently have?
Probe:
No savings; Less than £6,000; £6,000-£12,000; More than £12,000
4. Do you have any regular income that comes from any other sources? e.g. income from lodgers, regular contributions from family, friends, etc.
Probe for regular help with paying for groceries, clothes, holidays, etc. & who this help comes from.

HEALTH

1. I would also like to ask you a few questions about your health. First of all how would you describe your health at the moment?

Probe/check for:

Nature of any illness/disability?

Any changes in health since retired/recently?

If health problem – how long have you experienced this problem with your health?

2. If applicable – You say you have been receiving x [and x, etc.] disability benefits. Roughly how long have you been receiving x disability benefit(s)? How did this come about? (e.g. did someone help them claim?)
3. Do you feel your health stops you doing things you would like to do/used to do? In what way? (Probe in the home, outside the home, either on their own or with support)

Probes: Do you need?

Practical help e.g. preparing meals, shopping

Financial matters e.g. filling in forms, paying bills

Physical help e.g. with walking, getting up and down stairs

Personal help e.g. dressing, bathing, washing

4. Do you need help from other people to do some things? What sort of things?

Probes: Who helps with?

Practical help e.g. transportation, preparing meals, shopping

Financial matters e.g. filling in forms, paying bills

Physical help e.g. with walking, getting up and down stairs

Personal help e.g. dressing, bathing, washing

Who does this for you?

How long have they been helping with this?

How do you feel about this?

Do you mind about this?

Any help received from (specify):

Extended family

Friends/neighbours

Social services

Other organisations (Please specify, e.g. Age Concern, Citizens' Advice, etc.)

5. Do you pay for any care you receive?

Probe:

Which help do you pay for?

How much?

How long have you been paying for this help?

BEREAVEMENT

1. Do you mind me asking, how long is it since you lost your husband/wife/mother?

2. Had s/he been ill for a long time, or did it happen suddenly?

3. Would you say your loss affected your health in any way? How?

Experience of using the Wolverhampton Bereavement Centre

1. How did you find out about the bereavement centre?

Probe:

Leaflet, GP, hospital, friend, neighbour

2. Can you describe the kind of support that the centre was able to provide to you?

3. What did you think of the service that you received?

Probe:

How would you say it helped you?

Which people/staff did you see at the centre?

Whether found staff knowledgeable

Whether found staff helpful and supportive

4. How much contact did you have with the bereavement centre?

Probe:

Was this enough to meet your needs?

Are you still in contact with the centre?

5. Was there anything that you disliked about using the centre?

6. Was there anything that the centre could not help you with?

Probe:

Did you ask the staff about it?

What was the response?

How did you feel about this?

7. Do you feel the need for ongoing support and advice following the loss of your partner/parent?

Probe:

In what ways?

Is anyone providing you with this support and advice? Who?

How do you feel about this?

8. What was your overall impression of the kind of service supplied by the bereavement centre?

9. What, in your experience, are the advantages of having a bereavement centre like this in the local community?

Probe:

Could you have got the support from anyone else if the centre had not been there?

10. How do you think the services of the bereavement centre could be made more widely known?

INDEPENDENCE

We are very interested in finding out what 'being independent' means to people in later life and the ways this can change over time. I'd like to ask you a few questions on this.

1. What does 'independence' mean to you?

2. Have your thoughts on independence changed since your loss? How?

3. Has your loss made it difficult for you to make ends meet?

Probe:

How has that affected your day to day life?

4. Do you feel your income allows you to live a comfortable lifestyle?

Can you explain a bit ...

5. Do you provide help or support to any people at the moment? e.g. family (parents, siblings, children, etc.), neighbours, friends).

Probes:

What do you do?

How often?

How do you feel about this? Would you be happy to do more of this if you were asked? Would you like to do any less? Does it limit you in any way? (Probe)

6. Do you ever worry about losing your independence?

Probes:

Why?

7. At present, do you feel that there is anything that is hindering your independence? What would help?

EXPECTATIONS AND FEELINGS

We've talked about the your recent bereavement, the services you use, the forms of support you use and provide to others at the moment, and your feelings about maintaining independence in later life.

1. On balance, and taking into account how these things make you feel, how would you say you are feeling about life at the moment?

2. Is there anything else you wanted to talk about today or which seems relevant, which we haven't discussed?

Thanks, pay incentive, get receipt signed, and close.

Item 6: Social network map

This research instrument was used as an aid to complement the social support/networks section of the topic guide in tranche one of the fieldwork. Its purpose was not to provide an extensive mapping of personal communities, but to gauge the character of pensioners' support networks, and to provide a visual map of their support preferences and the relative ease or difficulty they anticipated experiencing in accessing support in a range of different crisis situations. The distinctive nature of the suggested crises enabled comparisons to be drawn as to whether different scenarios were associated with qualitatively different preferences for social support, and/or whether particular individual circumstances were associated with particular support profiles or preferences.

The 'map' provided information on a number of aspects of pensioners' experiences:

- an individualised picture of a range of different forms of social support (e.g. family, friends, extended family, neighbours, statutory and voluntary agencies);
- the relative proximity of individuals to existing or desired forms of social support; and
- support preferences in relation to qualitatively different support needs (e.g. emotional, practical, financial, informational).

The standardised maps created during the interviews provided a complex snapshot of pensioners' support structures, which were compared against one another to draw out central similarities, differences, and the rationales for particular preferences or arrangements. Social network mapping is particularly effective as a participatory research tool, which engages informants in the research process, and is useful in highlighting gaps in provision.

Method

The social network map designed for this research consisted of a large circle divided into segments depicting the three main types of scenarios covered in the topic guide: personal crisis, practical day-to-day help, and help given to others (see diagram below). This holistic approach enabled the research to be situated in the context of recent research findings stressing the importance of reciprocity in older people's perceptions of independence. The idea is that nominated individuals and/or services are mapped onto this framework, nearer or further away from the centre as gauged from the questioning route. The map was printed onto a large sheet of paper, with a new map being created for each interview.

Colour coded stickers were placed onto the segments of the map to represent different types of social resources identified by interviews in response to the different scenarios:

- blue for family
- red/orange for friends
- green for neighbours
- yellow for statutory agencies
- white for voluntary agencies/participation in voluntary work

The name and/or relationship to the informant of the suggested person or agency was written on the stickers by interviewers, which were then placed onto the map and reviewed with interviewees.

Parallelogram stickers were rotated to depict analytical distinctions between experienced or anticipated scenarios, i.e. placed on the map in a square formation to signify real situations experienced by interviewees, and in a diamond formation to represent speculated circumstances.

When people changed their mind about a response, a blank white sticker was placed over the top of the colour sticker.

The person or persons whom the interviewee lived with was written at the top of the social network map sheet, and these persons were positioned on the map (or not) again according to older people's responses to the research questions.

Interviewers gauged the relative ease with which informants would be able to draw upon various sources of help in each circumstance, and reflecting this, placed stickers more or less near to the centre of the circle.

The 'personal crisis' segment included social networks relating to:

- bereavement
- illness/hospitalisation
- financial crisis
- being a victim of crime

The 'Household help' segment included social networks relating to:

- physical restrictions (including mobility)
- personal care issues
- day-to-day support
- practical help

The 'help given to others' segment included the ways in which respondents supported their:

- family/friends
- neighbours
- community through participation in voluntary work

Social Network Map

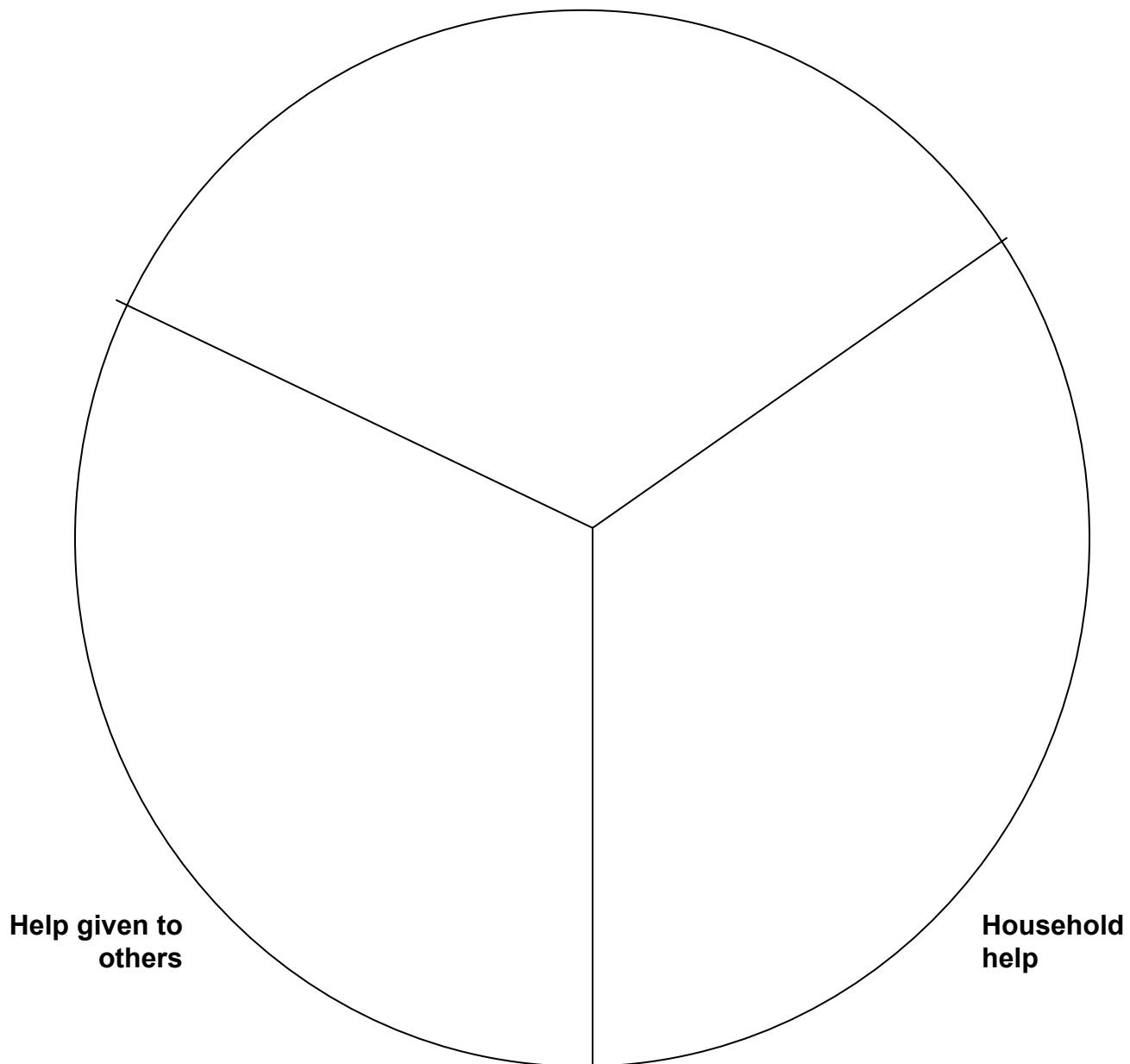
ID no:

Date:

Interviewer

Household situation:

Personal crisis



Item 7: Service use diary

Service use diaries provided a record of the services that people used regularly or more infrequently, and was used conjunction with the ‘Service use and needs’ section of the topic guide (and is also known as the service use calendar) in tranche one of the fieldwork. It took the form of a sheet subdivided into squares to depict the days of a calendar month. Interviewers filled in the boxes to depict on the days of the week on which people used particular services, such as Wheels on Meals, public transport or the doctor’s. Where service use was less patterned or more irregular, this was noted and an approximation of frequency of use made on the bottom of the activity sheet.

Service use diary (printed to fill A4 sheet)

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Week 1							
Week 2							
Week 3							
Week 4							

Item 8: coding framework for pensioner interviews

Free nodes

Access issues
Ageism
Area issues
Bereavement
Community
Computers
Coping Strategies
Crime & fear of crime
Depression
Disability
Discomfort
Ethnicity
Gender Issues
Getting older
Holidays
Incentive
Independence scale
Interdependency
Interview tone & circumstances
Leaving hospital
Life-changing/unexpected events
Lonely
Making the best of it
Mobility
Personal qualities
Pets
Physical activity
Planning ahead
Privacy issues
Racism
Scapegoats
Segmentation issues
Self-reliant
Service use patterns
Stress
Transition
Warden-controlled housing
What's this about?

Tree nodes

Living	Length of current arrangements		
	Current arrangements		
	Feelings about current arrangements		
	Attachment to the area		
	Major changes in arrangements		
	Extended family	Composition	
		Nearby	
		Distance	
		None	
Finances	Type of pensions		
	Benefits received	Self	Time receiving
			How applied
		Partner	DLA component - self
			Time receiving
			How applied
			DLA component - partner
	Non-claims		
	Income range		
	Discrepancies with SQ		
	Savings	None	
	Housing costs		
	Other sources of income		
	Feelings about finances		
	Financial strategies		
	Priorities		
	Problems		
	Constraints		
	Being on your own		
	Health-related outlay		
Paid work	Current		
	Prior to retirement		
	Main job		
	Feelings about paid work		
	Loose labour market attachment		
	Partner's main job		
Retirement	How long		
	Reasons for retiring		
	Feelings about retirement		
	Partner's retirement		

Health	General description Specific health problems and disabilities Impact on relationship No problems Mental health Changes in health Health limitations	At home Outside the home No limitations No problems Specific problems Changes in health Health limitations	Support received Support provides partner Feelings on support provision
Independence			
Subjective meaning	Going out Living in own home Choosing where to live Personal decision-making Financial security Access to support Maintain health Practical resources Mobility Maintaining social networks Lifestyle factors Local involvement Doing things yourself Personal security Holidays Privacy Income re independence	Staying in own home	
			T2 plus £20 if uncomfortable T2 less £20 if comfortable T2 spontaneous use of £20
Benefits re independence Changing feelings on independence		No change Things that seem more important Things that seem less important	
Changed behaviour, strategies Most valued aspects of independence	Health Choosing where to live Staying in your home Financial security Support from friends and family		

		Social activity
		Personal decision-making
		Personal security
		Mobility
		Doing things for yourself
		Being able to help others
		Going out
		Can't prioritise
Worries about loosing independence		
Ways independence is compromised		
Choice about things that matter		
Things that help		
Health re independence		
T2 Help re independence	Actual help received	If unavailable
	Hypothetical help	After a fall
		Transport breakdown
		Unexpected bill

Service use	
Health	Doctor Local hospital Dentist Optician District nurse Alternative practitioner Counselling services Chiropodist Occupational therapist
Practical	Transport Meals-on-wheels Shopmobility Domestic services Community care/respite care Personal care Community alarm service Hairdresser
Social and community services	Housing Housing associations and trusts Pensions Benefits Social Services Support groups Voluntary groups Religious groups

Leisure	Community centre, club, class, library Sports Activities, trips organised by groups Travel Reading, bingo, crossword, tv, etc. Pubs Other
Other	Bank Legal, financial adviser, CAB Shops Information lines, web Police Aids and adaptations
	No support needed
	Priority services for older people
	Personal priorities
	Support lacking
	Adequacy of local services
	Services no longer used Why
	Anticipated service use
	Finding out about services
	Services that help maintain independence
	Best things about services
	Worst things about services
	Service accessibility issues
	Service improvement
	Other services needed for independence
Non-users	Things to help them use service Alternative strategies to meet needs Reasons for non-use Off-putting things Would prefer service to family support
Residential/sheltered home residents	Reason for the move Length of time in housing Deciding on the housing Feelings about how it affects independence External participation None Personal mobility Choice in day-to-day activities Quality of life issues
Social networks	Local integration Local networks Involvement in voluntary activity Support in crisis situations Personal crisis Anticipated

		Actual
	Financial crisis	Anticipated
		Actual
	Own or partner illness	Anticipated
		Actual
	Crime	Anticipated
		Actual
Support for household	Personal care	Anticipated
		Actual
	Physical help	Anticipated
		Actual
	Day to day support	Anticipated
		Actual
	Practical help	Anticipated
		Actual
Help given to others	Type of help given	
	Who help is given to	
	Frequency of help given	
	Feelings about providing help	
	No help given	
Preferences on sources of help	Unified source preferred	
	Multiple source preferred	
Multiple sources of help needed		
Main sources of regular help		
Informal	Living in household	
	Partner	
	Extended family	
	Other	
Out of household		
	Extended family	
	Friends	
	Neighbours	
	Other	
Formal	Statutory agency	
	Voluntary agency	
Mutual support		
Not needed		
Needed but not received		
Multiple sources of help needed		
Feelings about receiving help		
Situations would seek formal help		
Situations would seek informal help		
Expectations & Feelings	Overall satisfaction	
	Things would change	

Hopes, future plans Things that need to happen first

Bereavement

Time widowed	
Non partner-related bereavement	Effects
Circumstances of death	Sudden
	Prolonged illness
Aftermath	Practical impact on circumstances
Feelings	
Help gaps	
Role of local services	
Contact with Bereavement Centre	How heard about
Reaction to Bereavement Centre service	
Other (non BC) services used	

Leaving hospital

How long ago	
Nature of hospitalisation	Planned
	Emergency
Recovery	Practical impact on circumstances
Feelings about	
Help gaps	
Home from Hospital scheme	
How heard about	
Use of services	Length of involvement
Opinion of	
Relationship with volunteer	
Voluntary organisation	
Alternative sources of help	