

**Services for Supporting
Family Carers of Elderly People in Europe:
Characteristics, Coverage and Usage**

EUROFAMCARE

**National Background Report
for the United Kingdom**

Mike Nolan*

Louise Barber*

Ann Edis**

Jayne Brown*

Kevin McKee*

*** University of Sheffield**

****Consultant Solicitor, President Solicitors for the Elderly**

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EUROFAMCARE is co-ordinated by the
University Hospital Hamburg-Eppendorf,
Institute for Medical Sociology,
Dr. Hanneli Döhner
Martinistr. 40
20246 Hamburg
Germany

doehner@uke.uni-hamburg.de

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Contents

Acknowledgements	3
Summary of Main Findings	8
Introduction – An overview on family care	9
1 Profile of family carers of older people.....	12
1.1 Number of carers	12
1.2 Age of carers	12
1.3 Gender of carers	13
1.4 Income of carers.....	13
1.5 Hours of caring and caring tasks, caring for more than one person	13
1.6 Level of education and / or profession / employment of family carer.....	14
1.7 Generation of carer, relationship of carer to OP.....	15
1.8 Residence patterns (household structure, proximity to older person needing care, kinds of housing etc)	15
1.9 Working and caring	15
1.10 General employment rates by age	17
1.11 Positive and negative aspects of caregiving	18
1.12 Profile of migrant care and domestic workers (legal and illegal). Trends in supply and demand.....	26
2 Care policies for family carers and the older person needing care	27
2.1 Introduction: Family ethics and expectations – the national framework of policies and practices for family care of dependent older people	30
2.1.1 What are the expectations and ideology about family care? Is this changing? How far are intergenerational support and reciprocity important?.....	30
2.1.2 Are there any legal or public institutional definitions of dependency – physical and mental? Are these age-related? Are there legal entitlements to benefits for caring?	33
2.1.3 Who is legally responsible for providing, financing and managing care for older people in need of help in daily living (physical care, financial support, psychosocial support or similar)?	34
2.1.4 Is there any relevant case law on the rights and obligations of family carers?.....	36

2.1.5 What is the national legal definition of old age, which confers rights (eg pensions, benefits, etc).....	36
2.2 Currently existing national policies.....	36
2.2.1 Family carers	36
2.2.2 Disabled and / or dependent older people in need of care / support	40
2.2.3 Working carers: Are there any measures to support employed family carers (rights to leave, rights to job share, part-time work etc)?	42
2.3 Are there local or regional policies, or different legal frameworks for carers and dependent older people?	42
2.4 Are there differences between local authority areas in policy and / or provision for family carers and / or older people?	42
3 Services for family carers	44
3.1 Examples	51
3.1.1 Good practices.....	51
3.2 Innovative practices	53
4 Supporting family carers through health and social services for older people	54
4.1 Health and social services	54
4.1.1 Health services	54
4.1.2 Social Services	58
4.2 Quality of formal care services and its impact on family caregivers: systems of evaluation and supervision, implementation and modelling of both home and other support care services	63
4.2.1 Who manages and supervises home care services?	63
4.2.2 Is there a regular quality control of these services and a legal basis for this quality control? Who is authorised to run these quality controls?.....	64
4.2.3 Is there any professional certification for professional (home and residential) care workers? Average length of training?	66
4.2.4 Is training compulsory?	66
4.2.5 Are there problems in the recruitment and retention of care workers?	67
4.3 Case management and integrated care (integration of health and social care at both the sectoral and professional levels)	67
4.3.1 Are family carers' opinions actively sought by health and social care professionals usually?.....	67

5	The cost - benefits of caring	68
5.1	What percentage of public spending is given to pensions, social welfare and health?	68
5.2	How much, private and public, is spent on long-term care (LTC)?	68
5.3	Are there additional costs to users associated with using any public health and social services?	68
5.4	What is the estimated public / private mix in health and social care?	68
5.5	What are the minimum, maximum and average costs of using residential care, in relation to average wages?	69
5.6	To what extent is the funding of care for older people undertaken by the public sector (state, local authorities)?	69
5.7	Funding of family carers	70
5.7.1	Are family carers given any care benefits (cash, pension, credits / night allowance etc) for their care. Are these means tested?	70
5.7.2	Is there any information on the take-up of benefits and services?	71
5.7.3	Are there tax benefits and allowances for family carers?	72
5.7.4	Does inheritance or transfers of property play a role in caregiving situation?	72
5.7.5	Carers' or Users' contribution to elderly care costs	73
6	Current trends and future perspectives	77
6.1	What are the major policy and practice issues debated in family care of older people from the carers' point of view? Are older people and / or carer abuse among these issues?	77
6.2	Do you expect there to be any changing trends in services to support family carers, eg more state or more family support, more services or more cash?	80
6.3	What is the role played by carer groups / organisations, 'pressure groups'?	80
6.4	Are there any tensions between carers' interests and those of older people?	80
6.5	State of research and future research needs (neglected issues and innovations)	81
6.6	New technologies – are there developments which can help in the care of older people and support of family carers?	82
6.7	Comments and recommendations from the authors	84

7	Appendix for the National Background Report for the United Kingdom	85
7.1	Socio-demographic data	85
7.1.1	Profile of the elderly population – past trends and future projections	85
7.2	Examples of good or innovative practices in support services	90
8	References to the National Background Report for the UK	92

Summary of Main Findings

no summary provided

Introduction – An overview on family care

Nationally representative data relating to family care in the UK have been collected for nearly 20 years. Recent statistics indicate that one in six people (16 %) over the age of 16 provide family care (defined as 'someone looking after or providing some regular service for a sick, disabled or elderly person living in their own or another household). This represents about 6.8 million people. Women are more likely to be carers than men (18 % / 14 %), are more likely to be the main supporter, and to provide more than 20 % of care a week. The peak age of caring is between 45-64 years (see section 1).

A longitudinal analysis of caring patterns over time conducted by the Social Policy Research Unit (SPRU) at the University of York (SPRU 2001) reached the following conclusions:

Although the population of adult carers in Britain declined during the 1990s, the proportion of those heavily involved in providing informal care increased. This trend towards more intensive caregiving is associated with an increasing number of caring relationships that typically make heavy demands on carers: caring for a spouse, child or elderly parent. At the same time, less intensive caregiving between households declined, particularly between friends and neighbours. However, elderly parents were increasingly looked after in their own homes by non-resident daughters.

Until the early 1990s most spouse carers were women. Subsequently more men than women took on the role of a spouse carer and by the end of the decade as many men as women provided informal care for a spouse or partner.

These trends reflect broader changes in society including: 'rising numbers of frail older people, increased chances of living with a spouse in old age, higher rates of home ownership among more recent cohorts of older people, and continuing improvements in the life expectancy of severely disabled children' (SPRU 2001, p2).

The demography of the UK is such that the demand for care is likely to increase with there currently being 12 million people over the age of 60, with 1.1 million over the age of 85, a three fold increase in the last 4 decades. In the next 20 years the greatest increases will be in the older age groups, who are usually the most in need of care and support. Simultaneously a number of trends, including falling birth rates and greater female participation in the workforce, suggest that competing demands may limit the number of available carers as the need for them increases.

The family continues to provide the vast majority of help and support that older people require, although it has to be remembered that most older people are relatively independent and indeed contribute significantly to the family in several roles, especially grand-parenting. Most family relationships are therefore

reciprocal. Although the majority of carers are family members, mostly spouses and children / children-in-law; friends and neighbours, nevertheless make a contribution.

The patterns and nature of caring relationships among several minority ethnic groups are less well known.

The majority of care services for older people are provided by the state, with main responsibility being divided between the health service and local authority social service departments. Boundaries between agencies are often blurred and there can be considerable local variation in the services available. Service fragmentation and 'boundary disputes' have often compounded difficulties. The picture is also complicated by potential differences between the four countries of the UK.

However, there have been several recent initiatives designed both to improve the care that older people and their carers receive, and to enhance coordination between agencies. These have included the introduction of a National Service Framework (NSF) for older people intended to ensure that there is a comprehensive strategy for high quality integrated health and social care for older people, as well as new legislation improving carers rights. Implementation of the NSF has been via Local Strategic Partnerships (LSP) that provide a mechanism for developing policies that cut across responsibilities of previously largely separate organisations. The LSPs have an overarching responsibility for developing community strategies that promote economic, social and environmental well being for older people based on a 'whole system approach'. There is therefore an increasing emphasis on interdependence with the sharing of: a vision; objectives; actions; resources and risks (see section 2 for fuller account).

There has been a significant growth in the provision of care by the independent sector in the UK including private for profit, and not for profit, organisations, as well as charities. The majority of care within care homes is now provided by the independent sector, but most residents' fees are supported in part or in full by the local authority on a means-tested basis. Similarly, the provision of home care services are increasingly being delivered by the independent sector, but usually under contract to the local authority.

The majority of services remain targeted on the older person, but there are a growing number of services designed specifically to support carers of older people, and indeed carers generally.

Older people and carers may of course purchase their own care, either from their own resources, or via a system of 'direct payments' made by local authorities.

Little is known about a 'grey' or 'black' market of care in the UK.

There are numerous charitable and voluntary organisations in the UK that focus specifically on the needs of older people and / or carers. Several of the better known include Age Concern, Help the Aged, Carers UK, The Princes Royal Trust for Carers, and the Alzheimer's Society. These organisations provide a range of services from information and advice, political lobbying and advocacy, to the provision of direct care. In particular the needs of minority ethnic groups are often addressed by specialist organisations either locally or nationally. The provision of help by friends and neighbours is often significant.

A series of recent policy documents produced by the Audit Commission in the UK has provided a new vision for developing services for older people that, instead of seeing them simply in terms of dependency, disability and as recipients of care, recognises that several interdependencies exist, and that older people both give and receive care and support. While independence is still the goal a wider view is promoted that is based not simply on physical needs, but rather on the ability of older people to make choices and to contribute as active citizens.

Notwithstanding this, it is recognised that frail older people will continue to need support. It is estimated that over half of people aged 75-84 have long-term illness that limits what they can do, and that this figure rises to 70 % at 85+. Particular need for support is recognised in those older people with dementia. Of people aged 65-79 living at home 35 % of both men and women report at least one of five types of disability (locomotor, personal care, hearing, sight and communication). At the age of 80+ these figures are 62 % of men and 64 % of women. The proportion of men and women aged 65-79 that report personal care disability is 14 %, with this being 24 % for men and 25 % for women over the age of 80.

Health care in the UK is free at the point of delivery and is funded from general taxation, not insurance. The majority of social care is provided by local authorities and is means-tested with a modest personal contribution usually being required.

Current socio-political debates do not figure prominently on the nature of insurance but rather on ensuring a more coordinated and integrated approach to service provision for older people and their carers. See above, and in particular sections 2 and 3.

With respect to the situation of family carers and the provision of services for both carers and older people in the UK, there have been several recent developments. These have included the introduction of a new Act of Parliament – The Carers (Equal Opportunities) Act, major reviews on services for older people and carers (Audit Commission 2004a, b, c, d, e), and an overhaul of the way in which services are inspected in both the health and social care domains. Greater detail on these developments is provided at various points in the report.

1 Profile of family carers of older people

Nationally representative statistics relating to family carers in the UK have been collected regularly since the 1985 General Household Survey (GHS) (OPCS 1989). The figures used here are primarily taken from the 2000 GHS, as reported by Maher and Green (2002), which comprised a sample of approximately 14,000 adults living in private households in the UK. For the purposes of the survey a carer was defined as 'someone looking after or providing some regular service for a sick, disabled or elderly person living in their own or another household'.

Unless otherwise stated, all the statistics provided in this section come from the 2000 GHS. NB these figures do not necessarily relate specifically to those providing care for older people.

1.1 Number of carers

One in six people (16 %) over the age of 16 are currently carers in the UK, with one in five households containing a carer. This represents 6.8 million people in 5 million households. However, these figures mask regional variations with the percentage of the population who are carers being highest in the North East (20 %) and lowest in London (11 %). The percentage in the North West, South West and Wales is 18-19 %.

1.2 Age of carers

The percentage of the population that are carers increases with age to a peak at 45-64, when it decreases aged 65+. The national figures are as follows:

Table 1: Informal carers who live in households: by age and sex, 2001

Age	All providing care (thousands)	
	Males	Females
5-15	53	61
16-24	125	165
25-34	230	376
35-44	422	665
45-54	613	896
55-64	519	697
65-74	319	370
75-84	155	149
85 and over	24	20
Total	2,460	3,399

Source: Census 2001, Office for National Statistics, Census 2001, General Register Office for Scotland, Census 2001, Northern Ireland Statistics and Research Agency

1.3 Gender of carers

Women are more likely than men to be carers (18 % / 14 %) but there are no gender variations in the proportions of men and women who are co-resident carers. However, women are more likely than men to: provide care for someone in another household (12 % / 9 %); to be the main supporter whether in the same (35 % / 30 %) or another household (25 % / 19 %); and to provide 20 hours or more care per week (29 % / 26 %).

Two thirds of people cared for are female, reflecting the greater proportion of older women in need of support.

1.4 Income of carers

A series of analysis of longitudinal data sets conducted by SPRU (2001) reached the following conclusions:

- 'Differences in the employment patterns of carers and non-carers influence their relative incomes.
- Caregiving chiefly affects labour market incomes which decline relative to similar non-carers for longer episodes of care.
- Personal and household incomes are less affected, and benefit and pension incomes seem to compensate for lack of earnings. However, although the household incomes of carers and non-carers appear similar, the living standards of carer households would be lower by the costs of disability of the cared-for person.
- There is little evidence in the relatively short time period available in the data that incomes catch up after caregiving ends'. (SPRU 2001, p3)

1.5 Hours of caring and caring tasks, caring for more than one person

According to the GHS 2000 one in four carers (28 %) spend at least 20 hours per week caring, with one in ten providing more than 50 per week. One in five carers have been caring for at least 10 years and nearly half (45 %) for five years or more. As might be expected, the type of care provided varies by residency, as illustrated in the table below:

Table 2: Type of help given by informal carers 2000 / 2001

Type of activity	Carers with main person cared for		All carers (%)
	In the same household (%)	In another private household (%)	
Giving medicines	44	11	22
Personal care (eg washing)	51	15	26
Physical help (eg with walking)	57	25	35
Paperwork or financial matters	41	38	39
Taking out	49	53	52
Keeping company	49	58	55
Keeping an eye on person cared for	62	59	60
Other practical help	69	73	71

Source: General Household Survey, Office for National Statistics

Three percent of adults currently care for two or more people, 1 % in co-resident situations and 2 % in other locations (Maher and Green 2002).

1.6 Level of education and / or profession / employment of family carer

The longitudinal analysis of the effects of caring over time conducted by SPRU reached the following conclusions:

- 'A major policy objective is to encourage carers to remain in paid work as this enables them to have an independent life and avoid hardship. It is also considered to help sustain the caring role.
- In general employment status changes little immediately following the transition to informal care: 83 per cent under pension age remain in the same position as before care started. Generally eighty-five per cent of those in paid work remain in work, but fewer, 70 per cent, of those working part time (mostly women) did so.
- As the duration of caregiving increases, however, there is a significant reduction in the likelihood of being in paid work compared with non-carers. After the third year of informal care those providing 20 or more hours care per week are considerably less likely to be in paid work.
- Combining employment and informal care substantially decreases the spare time available: estimates of the time devoted to caregiving, paid work and travel to work show that a quarter of carers spent 12 hours or more per day on these activities compared with seven per cent of non-carers. Because more men work full-time, 54 per cent of men compared

with 39 per cent of women spent ten or more hours per day on paid work, travel and caregiving.

- Part-time workers looking after someone in the same household are less likely to be in permanent jobs and jobs with annual increments than non-carers. The private sector is less likely to employ those with caring responsibilities.
- Looking after a spouse or partner reduces the likelihood of remaining in paid work compared with other caring relationships.
- Heavily involved carers are significantly less likely to be in paid work when caregiving ends; not only do they take longer to return to work but the number in paid work continues to decline beyond the caring episode.
- For women, working part-time while providing informal care increases their chances of being in work after caregiving ends relative to those not working; working fulltime increases them even more'. (SPRU 2001, p3)

1.7 Generation of carer, relationship of carer to OP

It is not possible to give precise figures here but the relationship of the carer to the cared for person would suggest that for carers in general 60 % come from a different generation (52 % a younger generation, 8 % an older generation) and 18 % from the same generation (spouses). As the remainder of carers support other relatives or friends / neighbours it is not possible to say whether they come from the same or different generation. For carers in general 52 % are looking after a parent or parent-in-law, 18 % are caring for a spouse. The remainder provide care for another relative or friend / neighbour.

1.8 Residence patterns (household structure, proximity to older person needing care, kinds of housing etc)

One third of carers co-reside with the person they are caring for, while two thirds live in another household. Co-resident carers are more likely to be spending 20 hours a week or longer providing care (63 % / 11 %). As noted in Table 2, there is also variation in the type of care provided. Spouses comprise the majority of co-resident carers, especially in the older age groups (75+).

1.9 Working and caring

The impact of caring on employment was addressed in 1.5. With regard to carers in the workforce there are approximately 4 million carers who continue work and care (Maher and Green 2002), with it being estimated that one in nine women and one in ten men combine work with the support of a frail older person.

The Audit Commission has recently published a major literature review on ‘Caring for Older People and Employment’ (2004) conducted by Linda Pickard at the Personal Social Services Research Unit, London School of Economics. In summarising the literature Pickard (2004) concludes:

‘In summary, although most carers also work, caring tends to have a negative effect on employment. Provision of informal care is associated with shorter working hours / part-time work; withdrawal from labour market; early retirement; lower incomes; diminished career prospects, and reduced occupational and personal pensions. Combining caring and work can cause adverse effects on the carer, although for many carers, paid work has positive effects.’ (p5)

The employment needs of carers were addressed in the Carers National Strategy ‘Caring about Carers’ (DoH 1999) with the aim being to promote a balance between caring commitments and work so that carers are able to work if they wish, or to return to work after an episode of care. To this end the UK Government places considerable importance on flexible employment practice. Pickard (2004) provides an overview of recent legislative and policy initiatives as follows:

‘The 1999 Employment Relations Act gave employees the right to ‘reasonable’ time off to deal with unexpected or sudden situations relating to those they care for, although it is at the discretion of the employer whether time off is paid or unpaid. At the same time, the Department for Education and Employment launched the Employers for Work-Life Balance Initiative and the Work-Life Balance Campaign. The former initiative encourages organisations to make a commitment to support carers in the workforce, while the latter aims to raise employers’ awareness of the business benefits of introducing policies and practices which help employees obtain a better balance between work and the rest of their lives. More recently still, in 2001, the Government set up the Work-Life Balance Challenge Fund of £10.5 million. This offers advice, consultancy and support to businesses wanting to examine their practices in order to see if different and flexible working patterns could improve profitability and help employees balance work and family life.’ (p6)

In her consideration of the literature Pickard (2004) suggests that particular measures such as time off for emergencies, flexible work hours, and working from home would be most likely to benefit carers, and she stresses the importance of tailoring arrangements to carers’ needs, rather than those individuals with childcare responsibilities.

She subsequently considers in detail a number of initiatives aimed at carers in employment, primarily in the public sector workforce where arrangements are more advanced than in the private sector. The initiatives included:

- Carers’ leave
- Flexible working – such as part-time, flexible, job-sharing

- Career breaks
- Working from home
- Counselling services

However, provision is patchy and many such initiatives are not widespread. Moreover, the take-up of such initiatives is limited by a number of factors, including a lack of awareness, the complexity of procedures for accessing support, and the fact that carers feel ‘labelled’ as being in need of help, or not coping well if they avail themselves of such opportunities. Furthermore, employment policies for carers are discretionary rather than mandatory, and their success depends in large measure on a supportive manager.

1.10 General employment rates by age

Table 3: Overall percentage of the working population in various occupational groups

	Men (%)	Women (%)
Professional	8	3
Intermediate	27	24
Skilled non-manual	11	31
Skilled manual	27	7
Partly skilled	14	16
Unskilled manual	4	5
Other	10	16

Source: Social Trends 30, Spring 1999

Table 4: Percentages employed full-time, part-time or self-employed by age and gender

Age	Men				Women			
	Employees		Self-employed		Employees		Self-employed	
	F / T (%)	P / T (%)	F / T (%)	P / T (%)	F / T (%)	P / T (%)	F / T (%)	P / T (%)
16-24	60	9	3	1	46	16	1	1
25-34	73	3	9	1	44	21	2	2
35-44	70	2	13	0	35	31	4	3
45-54	64	2	15	1	36	29	3	3
55-59	47	5	13	2	23	26	3	3
60-64	27	4	9	3	8	13	1	3
65-74	2	3	2	3	1	3	1	1
75-84	1	1	0	1	0	0	0	0
85+	1	0	0	0	0	0	0	0

Source: Office of National Statistics: Social Trends, Spring 1999

NB: Figures do not add up to 100 as certain categories, eg retired, permanently sick / disabled, looking after family / home, have not been included.

1.11 Positive and negative aspects of caregiving

The last 20 years has witnessed an 'explosion' of research in the field of family care (Fortinsky 2001), much of which has been dominated by a stress-burden model that has focussed primarily on the burden and difficulty that carers experience. Consequently, as Schulz and Williamson (1997) note: 'Relatively little attention has been paid to the assessment of positive aspects of caregiving' (p123). Recently, however, more comprehensive and holistic approaches to exploring the varying dimensions of caring have emerged that seek to provide a more balanced view of the difficulties and satisfactions of caring and the varying ways in which carers cope with and manage their situation. Several studies suggest that whilst carers undoubtedly experience major sources of difficulty, for the majority of carers the satisfactions they gain usually outweigh the difficulties. Moreover, carers often develop several innovative and creative ways of managing their situation. Data from the UK collected as part of the Carer of Older People in Europe (COPE) project provide an indication of this complex situation.

The data below were collected as part of the COPE project, funded by the European Union with the aim of developing a first stage assessment tool for use with carers of older people. The tool was designed to identify carers who might be in need of a more detailed consideration of their needs. The tool, called COPE, comprised questions that reflected the difficulties carers faced, some of the satisfactions they experienced, and the ways in which they might cope / were supported in their caring role. Conceptually the work was in the main underpinned by 3 more comprehensive assessment instruments that looked in

detail at the difficulties carers face (CADI – The Carers' Assessment of Difficulties Index, Nolan and Grant 1992), the satisfaction they experience (CASI – The Carers Assessment of Satisfaction Index, Nolan and Grant 1992), and the coping or managing approaches that they might use (CAMI – The Carers' Assessment of Managing Index, Nolan et al 1995). Each instrument contains a number of statements (30 CADI, 30 CASI and 38 CAMI). For CADI and CASI carers indicate if each item does not apply to them, applies but does not cause difficulty / satisfaction, applies and causes some difficulty / satisfaction, or applies and causes a great deal of difficulty / satisfaction. For CAMI carers indicated if they do not use a particular coping tactic; use it but do not find it helpful; use it and find it quite helpful; use it and find it very helpful. The 3 instruments are not intended to be scored but rather to produce an individual profile of difficulties, satisfactions and coping strategies, or to be used to identify the most frequent sources of difficulties, satisfactions that carers experience, and the most useful coping strategies. It is the latter use that is illustrated here.

It is important to point out that the data used here cannot be considered as representative as they were drawn from a non-random sample. However, broadly similar results have been obtained from several studies using one or all of the instruments, not only in the UK (Nolan et al 1996), but also Sweden (Lundh 1998), Australia (Nolan et al 2003), Finland and Japan (Sasaki 2004). Furthermore, studies in the UK have not been confined to the English language, but have also explored the experience of a number of minority ethnic groups in the UK. All provide consistent results illustrating that overall the extent of caregiving satisfactions outnumber difficulties, and that carers often use and find helpful a disparate range of coping strategies. This is not to say that caring presents few difficulties, these are often numerous. Rather, the key message is that to fully understand a complex caregiving situation it is vital to consider the dynamics of the relationship, particularly the interplay between difficulties and satisfactions. Furthermore, if services are best to support family carers there is a need, not only to appreciate the dynamics of care, but to recognise and give credit for carers' own expertise and coping strategies, whilst also helping them to develop new caring skills when it is clear that carers either do not have the requisite knowledge, or their current approaches are not the most appropriate. The data below provide some important pointers, dealing first with the perceived difficulties of caring.

The table below illustrates those aspects of caring that over 50 % of the sample (n = 106) said applied to them and that they considered to be either stressful or very stressful. These have been categorised into five broad headings entitled: instrumental aspects of caring; effects of caring; restrictions of caring; dynamics of caring relationships and, lack of support.

Table 5: Stressful or very stressful aspects of caring

Type of stressor	Percentage seeing as stressful or very stressful (%)
Instrumental Care	
Caring is physically tiring	71
Cared for person has mobility problems	54
Cared for person needs help with personal care	53
Effects of caring	
Emotional health suffers	58
Sleep is affected	54
Carer cannot relax because of worrying about caring	53
Restrictions of caring	
Caring restricts social life	53
Not enough private time for self	50
Dynamics of caring	
Cared for person is too demanding	59
Carer sometimes feels angry towards cared for person	53
Cared for person takes advantage of carer	53
Carer feels out of control of situation	51
Caring strains family relationships	50
Lack of support	
Professionals do not appreciate carers' situations	54

Taken together these data paint a very interesting picture that provides a far more complex overview than that usually gained when assessing carers' needs. Most often assessment of, and eligibility for, services are determined primarily, if not exclusively, by the instrumental aspects of caring. That is, it is the amount of help that the carer provides, usually with regard to activities of living, that largely determine both **if** the carer is seen to need support and the type and amount of support that is required. The above data suggest that such instrumental aspects certainly need to be taken into account. For example, the physically tiring nature of care was the single most stressful perceived difficulty. Meeting mobility needs and providing personal care are also seen as stressful. Support in these areas, if appropriate and sensitive to carers' routines and ways of coping (see later when CAMI data are discussed), would undoubtedly be of help.

However, to focus mainly, or exclusively, on these areas is obviously not sufficient. The restrictions of caring, with regard to social life and private time to oneself, highlight the need for sufficient respite from care, and it is also clear that caring impacts on emotional health, sleep, and causes considerable worry to carers. This suggests the need for a range of psychological support ser-

vices. Interestingly, however, it seems that a lack of professional appreciation of the difficulties carers face is a major cause of stress. Such findings mirror those of a recent major report on carer support (Audit Commission 2004e), which concluded that the attitudes professionals' display towards carers often leaves a lot to be desired. However, what is potentially the most telling message from these data relates to the 'dynamics' of care. The data illustrate that carers often perceive the person they care for to be too demanding and of taking advantage of them, which may help to explain why over 50 % of the sample admit to feeling angry towards the person they care for. Given these range of emotions it is not surprising that many carers feel out of control of their situation and that the emotional effects of caring often spill over into other family relationships. Despite their obvious importance, such emotional dimensions of the dynamics of care are rarely considered in carers' assessments, nor routinely addressed in intervention and support packages.

However, despite these obvious tensions a differing picture is obtained if attention is turned to the satisfactions that carers experience. Of the 30 items on CADI only 14 were seen as being either stressful, or very stressful, by the sample. However, of the 30 items on CASI, 18 were seen to be either satisfying or very satisfying by the majority of the sample, and generally at much higher levels than responses to CADI.

Table 6 below considers items on CASI in 3 main categories. These are: sources of satisfaction that suggest an altruistic concern for the welfare of the cared for person; sources of satisfaction that relate to the interpersonal dynamics between the carer and the cared for person; and sources of satisfaction that are indicative of some more direct or personal gain for the carer themselves.

Table 6: Satisfactions of caring

Source of satisfaction	Percentage reporting as satisfying or very satisfying (%)
Altruistic concern for cared for person	
It's good to give pleasure to cared for	93
Maintaining dignity of cared for is important	90
Ensuring cared for is clean and comfortable is important	90
Helping cared for overcome difficulties and challenges	87
Knowing cared for better than anyone, I can give the best care	85
Tending to needs of cared for is important	80
Keeping cared for out of an institution is important	70
Interpersonal dynamics / relationships	
Expression of love for cared for	84
Repaying past kindness	72
Closer to cared for person	61
Better family relationships	51
Benefit for carer	
I get pleasure from seeing cared for happy	94
At the end of the day I know I will have done my best	90
I am the sort of person who likes helping others	84
Caring has helped me grow and develop as a person	72
Caring helps me fulfil a sense of duty	70
Caring provides me with a challenge	61
Caring has given me a new purpose in life	57

As can be seen, caring provides a complex and multi-faceted array of satisfactions that paint an altogether different view of caring than if difficulties alone are considered. As has been argued elsewhere (Nolan et al 1996, 2003), an overview of satisfactions is more than of theoretical interest and may also provide insights into:

- carers who may be in 'at risk' situations based on fragile relationships in which they gain little or no satisfaction;
- new forms of therapeutic interventions that help carers to reappraise their situation and heighten potential satisfactions;
- the qualities carers expect of services intended to support the cared for person and themselves. (see Nolan et al 1996, 1998)

As well as paying more attention to the balance between the difficulties and satisfactions of caring, appropriate assessment and support services also need to work more closely with carers to enhance what they do well, and to

help them to develop new skills in areas where they might struggle. This requires a fuller appreciation of the type of coping tactics that carers both use and see as helpful. This is the purpose of CAMI.

CAMI comprises 38 items and asks carers if they use them, and if so how helpful they find them. Of these 38 items 26 were used and found either helpful or very helpful by 50 % or more of the sample. This provides an indication of the extensive range of coping strategies that carers often draw upon.

Table 7 below presents data from CAMI divided into 3 broad types of coping strategy; direct action to address an issue; some form of cognitive reappraisal of the situation; action to reduce or eliminate stress.

Table 7: Carers' coping strategies

Strategies	Percentage using and finding helpful / very helpful (%)
Problem solving tactics	
Get as much information as possible	83
Get as much help as possible from services	75
Rely on own expertise	74
Establish priorities and stick to them	73
Alter home environment to make caring easier	72
Keep cared for person active	71
Establish and stick to a routine	69
Cognitive tactics	
Take one day at a time	89
Realise cared for person is not to blame	86
See the funny side of things	85
Realise there is always someone worse off	83
Remember the good times with the cared for person	79
Look for the positives in the situation	77
Grin and bear it	77
Stress reduction	
Talk over problems with someone you trust	79
Keep some time to yourself	79
Maintain interests outside caring	66

Rather than portraying a passive, reactive stance to caring the data suggest an active, proactive approach in which carers rely on a spectrum of coping tactics. Clearly it is important that service providers are aware of these. So, for example, it is apparent that carers prioritise and set routines and that support services should be sensitive to these and ensure that whenever possible the help provided is consistent with existing caring patterns. Carers also see themselves as being 'experts' in certain aspects of their role, and their knowl-

edge and understanding should be actively sought by professionals. Cognitive coping also plays a significant role and carers can be helped to further strengthen these approaches. A confidant is very important, as is keeping free time and maintaining outside interests. Once again these need to be reflected in the range of support that carers are offered.

Notwithstanding the above it is important to recognise that caring can, and does, impact on carers' health, and that not all caring relationships are positive, and some may even be abusive (see below).

In their series of studies exploring 'Caring Relationships Over Time', SPRU (2001) reached the following main conclusions:

- 'By investigating representative samples of carers and non-carers over time, the research produced new evidence on the risk of common mental health problems:
- Taking on caring roles is associated with adverse effects on carers' mental health including risk of onset of and delayed recovery from symptoms of anxiety and depression.
- Distress levels in the carer population increase during the first year of caregiving and do not return to former levels as caring continues.
- The risk of anxiety and depression rises progressively with the number of hours devoted to caring each week.
- Among those taking on full-time or continuous care, women are almost twice as likely as men to report increased distress'. (SPRU 2001, p2, 3)

Elder abuse

With regard to elder abuse a House of Commons Health Committee (2004) has recently published a major report on this topic. The report was wide-ranging and made a number of recommendations, which it is not possible to report in full here. A verbatim reproduction of the summary to the report (pages 3 and 4) is presented below.

'Abuse of older people is a hidden, and often ignored, problem in society. The profile of child abuse has been dramatically raised in the past few years and the Government has acted to introduce controls and measures to identify and tackle that problem; but abuse of older people remains in the background. It has been put to us that 500,000 older people in England are being abused at any one time, yet many people are unaware of the problem and few measures have been taken to address it. Moreover, we are disappointed that the Department has not commissioned research to establish a more precise figure. Abuse occurs in institutional settings, but more often in the home. It can be perpetrated by care staff, relatives, friends and strangers, and can take many forms – sexual abuse, financial abuse, abuse of medication in controlling and sedating patients, physical abuse, neglect and behaviour designed to degrade and humiliate.

Much abuse is not reported because many older people are unable, frightened or embarrassed to report its presence. Often care staff take no action because they lack training in identifying abuse or are ignorant of the reporting procedures. The lack of reporting results in difficulties in determining the true scale of the problem and this is compounded by a dearth of research. Further, varying definitions of 'elder abuse' exist within the health and social care sectors. To enable the extent of the problem to be accurately determined and for uniformity we recommend that an agreed, consistent and comprehensive definition should be applied by all government departments, statutory agencies, independent bodies, charities and organisations. We further recommend that performance indicators should be established as soon as possible to enable accurate measurement to be undertaken. We call for the National Minimum Standards for domiciliary care to require reporting of adverse incidents.

We recommend that the Department reviews the frequency and effectiveness of the inspection of NHS establishments providing care for older people and, in recognising the importance of lay personnel having an input into the inspection process, we urge that further measures are taken to increase user engagement.

The over-prescription of medication is sometimes used in the care environment as a tool for managing residents, and for care staff it can be a means to ease the burden of care of the elderly, especially of those with dementia. The frequency of review of medication and the administration of drugs by unqualified staff is of particular concern to us. We therefore recommend measures are taken to ensure compliance with the National Service Framework target that all people over 75 years of age should normally have their medicines reviewed at least annually, and those taking four or more medicines should have a review every six months. We further recommend that the National Care Standards Commission and its successor body should ensure that medication systems within care homes and domiciliary care reflect good practice and that they disseminate procedures that exceed the national minimum standard.

We have concern about the incidence of financial abuse of older people. We advocate that the prevention, detection and remedying of financial abuse should be included as specific areas of policy development by adult protection committees and we endorse the recommendations in the Draft Mental Capacity Bill relating to the abuse of powers of attorney.

The lack of training in issues relating to elder abuse (for example, identification, prevention and reporting) is encountered in all the settings in which abuse occurs. We call for mandatory training in the recognition, reporting and treatment of elder abuse for those professionals working and caring for older people. We also recommend that signed-off induction training of domiciliary and other social care workers approved by the appropriate sector skills council should be sufficient for them to apply for registration with the GSCC.

We recognise that there is a case for further guidance to require all local authorities to establish multi-agency vulnerable adults' protection committees and we strongly endorse any measures that make available advocacy services for older people. We further recommend that advocates on elder abuse drawn from black and minority ethnic communities should be identified, trained and deployed. Additionally, we recommend that as a part of the general training of social care workers, issues of ethnicity and culture be included in the curriculum.

While welcoming the introduction of the Single Assessment Process, and the opportunities that it presents for regularly reviewing the care of older people, we believe it is vital that these targets are met in all authorities. We recommend that the Department should monitor the compliance of authorities, and should report on the outcomes of the process. Currently there are no standards for adult protection contained within the National Service Framework. In order to ensure consistent good practice we recommend that this omission is rectified.

The registration of workers in the care environment was of particular concern to us. We propose that the Government should attend to the issue of registering domiciliary care workers as a matter of the utmost urgency. We urge the Government to expedite the implementation of the Protection of Vulnerable Adults list fully across both health and social care settings. We also recommend that the Department keeps under review the operation of the scheme.

We call for CSCI and CHAI to publish at an early date their joint plans for regulation and to ensure that the health care needs of residents in those settings registered as social care provision are met; for the Minister to require the annual reports of CSCI and CHAI to include details of their joint working and of the experience of the adequacy of the regulation of the health care aspects of care home services provision; and for the Government to keep under review the operation of the respective Commissions.

We call for implementation of stricter controls to ensure that certification of the death of a resident in a care home owned or managed by a GP, or a close relative, should be performed by a GP other than the owner / manager. We further recommend that the practice of the payment of retainer fees to GPs should be abolished.' (House of Commons Health Committee 2004, p3, 4)

1.12 Profile of migrant care and domestic workers (legal and illegal). Trends in supply and demand

no data available

2 Care policies for family carers and the older person needing care

Policy, with respect to both family carers and older people, has undergone significant change over recent years. Specific initiatives are described in detail later (see sections 2.2.1 and 2.2.2), but such developments are part of an overall trend, apparent since the mid 1990s, towards closer cooperation between organisations and government departments in the delivery of public services (Audit Commission 2002). This has resulted in the creation of several 'multi-agency, cross-cutting structures' (Audit Commission 2002) and the development of local strategic partnerships (LSPs) within authorities that have provided a framework for policies that cut across the responsibilities of hitherto separate organisations. LSPs have an overarching responsibility for developing community strategies that promote economic, social and environmental well-being, whilst also having a role in promoting a more integrated approach to health by monitoring the implementation of the National Service Frameworks (NSFs) (see section 2.2.2).

Underpinning recent policy initiatives is the desire to create a 'whole system approach' to service delivery that not only requires that organisations and agencies work in partnership, but also that:

- Services are organised around the user.
- All of the players recognise that they are interdependent and understand that action in one part of the system has an impact elsewhere.
- The following are all shared:
 - vision,
 - objectives,
 - action, including redesigning services,
 - resources and
 - risk.
- Users experience services as seamless, and the boundaries between organisations are not apparent to them. (Audit Commission 2002, p10)

A whole system approach is seen to be particularly important in respect of services for older people because of their complex needs, which frequently require input from multiple agencies. The potential benefits of whole system working are considerable, and are seen to include those listed in Table 8.

Table 8: The benefits of whole system working

Working as a whole system brings benefits for all groups and organisations.

Older people benefit by:
<ul style="list-style-type: none"> ■ having all of their needs considered, not just health and social care needs in isolation; ■ having their aspirations, priorities and hopes taken into account; ■ having choice and control; ■ having information about what is available; ■ remaining integrated in the community; ■ avoiding repetition and frustration; ■ being offered simpler and faster access to services; and ■ being a partner in the whole system.
All organisations providing services to older people benefit by:
<ul style="list-style-type: none"> ■ gaining a greater sense of control through a more managed system, with fewer crises and greater control over resources; ■ allowing each organisation to play to its strengths; ■ rebalancing and redesigning the system to place more emphasis on preventative services; ■ sharing risk with others; ■ improving information sharing; and ■ using resources better.
All staff benefit by:
<ul style="list-style-type: none"> ■ having a clearer sense of their role and how it fits into the bigger picture; ■ supporting people to be safe and well at home, rather than in hospital, nursing or residential care; ■ knowing who else can help; ■ delivering better care; and ■ achieving greater job satisfaction.
Social services departments benefit because they can:
<ul style="list-style-type: none"> ■ achieve a better balance between care at home and residential placements; ■ avoid a culture of blame and financial penalties for delayed transfers; ■ get better recognition and appreciation of the department; and ■ make better use of resources and so achieve better outcomes.

Social services practitioners benefit because they can:
<ul style="list-style-type: none"> ■ shift towards helping people to live independently rather than responding to crisis; and ■ are able to work in a person centred way.
Primary care trusts benefit because they can:
<ul style="list-style-type: none"> ■ establish a greater role for primary care in keeping people at home; ■ develop the commissioning role in a practice way by commissioning for change; and ■ establish the new organisation as a key player, respected by partners.
Primary care practitioners, including GPs and other staff groups benefit because they can:
<ul style="list-style-type: none"> ■ work proactively and constructively with older people; ■ share responsibility with others; ■ manage workload; ■ make appropriate referrals; ■ spend more time preventing older people from becoming ill, rather than responding to crisis; and ■ enhance the role of general practice.
Hospitals benefit because they can:
<ul style="list-style-type: none"> ■ achieve sustainable solutions to pressures on the hospital, particularly on A&E; ■ contribute towards meeting targets on waiting lists, trolley waits and delayed transfers; ■ reduce avoidable admissions; ■ move towards a more managed acute service by shifting the balance between emergency and planned work; ■ focus on what hospitals do best; and ■ dilute the media focus on the hospital through a joint approach.
Hospital staff, including geriatricians, nurses and other staff benefit because they can:
<ul style="list-style-type: none"> ■ reduce pressure from emergencies; ■ strengthen links with community based services; and ■ move older people out of hospital more quickly and more appropriately.

Source: Audit Commission (2002, p13)

However, while several examples of innovative developments can be cited (see Audit Commission 2002), progress towards the widespread implementation of whole system working has been patchy, and there is a recognised need for a long term change programme that requires careful implementation and monitoring.

2.1 Introduction: Family ethics and expectations – the national framework of policies and practices for family care of dependent older people

2.1.1 What are the expectations and ideology about family care? Is this changing? How far are intergenerational support and reciprocity important?

According to Smith et al (2003) there has been relatively little recent work on the effects of changing lifestyles on the attitudes and willingness of people to provide care for relatives and friends. Their own small-scale study conducted in South Wales suggested that women are consistently more willing to provide care than men, and that those aged 40-59 are more willing to provide care than younger age groups. Not surprisingly relationships play a part, with people being more willing to provide care for a spouse than a parent. The nature of the care required also had an influence, with respondents being more willing to care for a person with physical needs than with dementia, and women being more willing than men to provide intimate physical care.

Notwithstanding such differences, recently there has been increasing attention paid to the 'relationality' of care (Jeon and Madjar 1998), and the nature and quality of the interactions between those giving and receiving care (Efrainsson et al 2001), in order better to understand the varying 'interdependencies' that exist (Mintz and Marosy 2000). The following is modified from Nolan et al (2003).

Over the last decade several studies have sought to shed further light on the dynamics of the relationships between family carers and those they help and support, often explaining variation in relationships using concepts such as reciprocity or mutuality.

For example, Martini et al (2001) considered the relationships between daughters and their relatively independent older mothers and examined the reactions of both the giving and receiving of help. They identified two key factors, which they termed 'perspective taking' and 'attribution'. 'Perspective taking' refers to the ability of an individual to recognise and respond to the feelings of the 'other party' about giving or receiving help, whilst 'attribution' is concerned with the perceived motives behind the actions of others. Martini et al (2001) argue that both mothers and daughters want to maintain an element of personal control in their relationships and that if the giving or receiving of 'help' is seen to threaten this perception then feelings of competence and independence are undermined. It is here that perspective taking and attribution are important.

The authors suggest that mothers are often better able to take the perspective of their daughters, as they are likely to have been in a similar situation themselves, whereas daughters have relatively more difficulty in taking the perspective of their mothers. They found that where mothers were able to appreciate

the 'costs' to their daughter of providing help and could understand their motives then daughters were more satisfied with their relationships, but mothers reported no differences. Conversely, in situations where daughters could appreciate the potential difficulties that their mothers had in accepting help and were sensitive to the manner and form of the support they provided, then mothers were more satisfied with their relationships. If difficulties existed in relationships and behaviours were seen as being 'dispositional', that is they were attributed to a deliberate act, then more negative helping relationships emerged.

On the basis of their results the authors promote the need for more open discussion between mothers and daughters about their feelings regarding the giving and receiving help. Martini et al (2001) suggest that there is a need for further studies which explore in greater detail the ways in which help is given and received in relatively independent relationships as this may have important implications when more sustained help is required. They also argue that it should be possible to provide 'attributional training' in order to avoid the development of negative (dispositional) attributions among mothers and daughters, and to develop methods that would help enhance each group to take the perspective of the other.

Adopting a not dissimilar stance, Lee et al (2001) contend that, although the notion of 'empathy' has been extensively studied in formal caregiving contexts, it has received little explicit attention within family (informal) caring relationships. They go on to suggest that helping carers to better empathise with the cared for person is likely to enhance their positive appraisal of their situation. In particular they promote the idea of 'cognitive empathy', whereby carers take a balanced, rather than a purely emotional, view of their situation and thereby set more appropriate expectations of themselves and the cared for person.

In a study exploring a number of differing caregiving situations, such as Alzheimer's disease, stroke, spinal injury, diabetes and cancer, Ayres (2000a) sought to identify the 'meanings' that carers ascribe to their roles and identified three 'types' of relationships, each shaped by the expectations that carers hold and the types of interaction that they experienced.

In the 'ideal life' carers had few expectations of the cared for person and were motivated largely by feelings of love and affection. Negative aspects of care were played down, rewards enhanced, and difficult behaviours understood primarily in terms of the illness itself. Such carers often saw their lives as being better now than previously.

The largest number of relationships were categorised as 'normal / ordinary', where carers had flexible expectations of the cared for person and saw their relationship as reciprocal, with the disabled person making an active contribution. While they recognised that caring had both positive and negative effects they rejected the notion that it was burdensome.

In 'compromised' relationships carers held unrealistically high expectations of the cared for person, and if these were not met then a sense of failure prevailed. Consequently, carers were dogmatic and actively 'policed' the behaviours of the cared for person. These carers tended to dwell on the difficulties they experienced, and saw life as providing few satisfactions. Importantly Ayres (2000a) suggests that they were also likely to reject offers of help either because they believed that no one else could understand their situation or they felt that they were not 'worthy' of receiving support.

A fourth group of 'ambiguous' relationships were also identified where there was a lack of fit between the expectations of carers and the 'explanations' they sought for the behaviour of the cared for person. In many cases carers were often 'new' to their role and Ayres (2000a) believes that intervention at this point could help to proactively shape future relationships so that they were more likely to be seen as 'normal' as opposed to 'compromised'.

In a related paper Ayres (2000b) further elaborated upon the expectations carers bring to their role, the explanations they draw upon to understand their changing relationships, and the strategies they adopt when providing care. She concluded that carers' expectations provide an essential context which frames both the explanations they accept and the caring strategies they adopt. If their expectations are not met then the willingness of carers to seek a flexible explanation is critical to ongoing positive relationships. On this basis Ayres (2000b) suggested that interventions could be targeted at helping carers to reframe their expectations and also to pursue differing forms of explanation where no blame was attributed to the cared for person.

While the terminology used in the above studies may differ the similarities between notions such as 'perspective taking', 'attribution', 'cognitive empathy', 'expectations' and 'explanations' are readily apparent, as is their potential not only to provide a better understanding of the dynamics of caring relationships, but also to offer differing forms of intervention and support.

All of the above studies, either implicitly or explicitly, were underpinned by the idea of 'balance' within relationships, often described in terms of reciprocity, mutuality, and manifest in the congruence between expectations and behaviours.

Whilst there is still considerable conceptual ambiguity concerning the various 'types' of reciprocity or mutuality that exist, with terms often being used in interchangeable ways, there are distinct 'threads of continuity'. Studies attest to the centrality of the relationship between the carer and disabled person, not only to a better understanding of the dynamics of caring interactions, but also to the development of differing and innovative forms of help and support. Small wonder then that there are increasing calls for consideration of such relationships to be a core component of any assessment of the need for help and support (Nunley et al 2000, Snyder 2000). However, carer assessments remain dominated by a stress-burden model and an overt focus on the instru-

mental aspects of care as the primary eligibility criteria for services (Nolan et al 2003).

Most of the above studies have focussed on mainly white populations and less work has been done on the views of differing minority ethnic groups, especially in the UK. However, a recent study completed by the Joseph Rowntree Foundation (2004) suggests that myths about the widespread availability of an extended family support network among minority ethnic groups need to be challenged, and that in fact changing values between generations may well be compounded by considerable cultural differences between younger and older members of the same ethnic groups.

2.1.2 Are there any legal or public institutional definitions of dependency – physical and mental? Are these age-related? Are there legal entitlements to benefits for caring?

There is no legal definition of what is meant by an old person. What is often used is qualifying pension age. Dependency is less easy in terms of long-term care and tends to be clinically or capacity related. The legal definition of capacity in terms of legal decision making may help - Capacity is defined as the ability to make a specific legal decision at a specific time, ie it is a functional test. Capacity is also an issue in terms of consent to treatment. The Mental Capacity Bill currently before Parliament and the Codes of Practice may assist. The current DCA leaflets on Making Decisions Helping People who have difficulty in Making Decisions can be helpful (they are available free from the DCA or on the DCA website – www.dca.gov.uk).

The main form of benefit for caring is called the Carer's Allowance (CA). The CA (formerly called Invalid Care Allowance) is a taxable benefit for carers. The following description of this allowance is adapted from the guidance produced from the Department of Work and Pensions (DWP), and is available from their website (www.dwp.gov.uk). In advising carers about the CA this leaflet explains that:

- your other benefits may increase or decrease;
- certain benefits for the person you look after may sometimes reduce;
- you must spend at least 35 hours a week caring, which need not be every day;
- CA is not affected by any savings you may have;
- the person you care for could be a relative, friend or neighbour;
- CA can be paid to more than one person in a household, such as a couple caring for each other.

Carers are entitled to claim CA if they are:

- aged 16 or over;

- spending at least 35 hours a week looking after someone who is getting or waiting to hear about these benefits:
 - Attendance Allowance,
 - Disability Living Allowance at the middle or highest rate for personal care,
 - Constant Attendance Allowance at or above the normal maximum rate with an Industrial Injuries Disablement Benefit, or basic (full day) rate with a War Disablement Pension.

Further details can be located at www.dwp.gov.uk/lifeevent/benefits/carers.

2.1.3 Who is legally responsible for providing, financing and managing care for older people in need of help in daily living (physical care, financial support, psychosocial support or similar)?

The primary legislation, which plays a part in the provision of care, falls into the following categories:

- Statute Guidance under section 7 the Local Authority Social Services Act 1970 (LASSA). This guidance is mandatory and has the force of statute.
- General guidance to Strategic Health Authorities (SHA) and Social Service Departments (SSD)
- Policy, eg Making Decisions on Mental Incapacity and Valuing People policy on Learning Disability and the National Service Framework for Older People.

Legally identifying the type of care needed requires an understanding of this legal framework. Health and Social care fall under different legal frameworks. Moreover Disability legislation and Human Rights legislation also enter into the entitlement to services issues. The funding of service provision is also controlled by different statutory routes. Health care is free at the point of delivery and social care is not, the National Assistance Act 1948 requires local authorities (LAs) to charge for residential services and to recover unpaid fees. Home care charges are at the discretion of the LA but are subject to the Fairer Charging Guidance issued to SSD under s 7 LASSA.

Social care needs may be met by assessment under section 47 National Health Service and Community Care Act 1990 (DoH 1990) as modified by the Health and Social Care Act 2001. Also as a result of the 2001 Act Primary Care Trusts are involved in commissioning packages or part packages of care. The requirement of the 2001 Act in implementing *R v N E Devon Health Authority ex parte Coughlan* 1999 emphasises that legally the assessment should be multi disciplinary and should also involve housing as well as the health and social care elements.

Assessment of need is totally separate from any assessment to pay for services and services should be needs led (whether in the context of health or social care or both) rather than price driven. The reality does not necessarily comply with this requirement in some local authorities and Primary Care Trusts and Strategic Health Authorities. There is clear evidence that many SHAs are failing to provide full NHS funded care and the Health Ombudsman has awarded many repayments to clients. Currently there are approximately 11,000 cases still to be investigated. There is a reluctance to make these provisions even though they are required by statute where the multi-disciplinary assessment requires the meeting of clinical need by part or full funding by the NHS. This funding has now been established, both through the Courts and the Ombudsman, as being available to people in their own homes as well as hospitals, hospices and nursing homes. Funding is also required to be regularly reviewed to ensure that the right levels of care are being provided. These provisions will be affected by the introduction of the Independent Consultee under the Mental Capacity Bill who will oversee the care of particularly elderly people who are isolated from their family or have few or no relatives or friends who can undertake this role.

Charging policies are governed by the National Assistance Act 1948, which requires LAs to charge for the provision of residential care services and to recover those costs where necessary, the Charging for Residential Accommodation Guidelines currently LAC 2004 (9) (Regularly updated) CRAG, The National Assistance (Assessment of Resources) Regulations 1992 as amended and the Health Social Services and Social Security Act 1983 (HASSASSA). The principles and practice of the financial assessment are set in these Regulations and are followed in all assessments for financial contributions to residential care by Social Services Departments (SSD). They do not apply to health care where the client's resources are irrelevant and care is related to clinical need.

Means testing is of the service user only, not their spouse or their children. The liable relative rules re spousal and parental support are only enforceable through the family courts and this has not so far occurred. Funding is now complicated by the Health and Social Care Act 2001. Some older people will qualify for full NHS funding based on predetermined criteria, or alternatively a banded contribution towards the costs of nursing care provided in nursing homes. The bands are subject to preset criteria and are increased annually. The aim is to provide free health care in care homes (nursing homes) for those who would receive this care free in their own homes or in hospital.

State funding for social care is means tested under the NHSCCA 1990 and applies only when predetermined capital levels are reached regardless of income. The upper capital limit is currently £20,000 and increasing support is given until capital is reduced to £12,250. Contributions according to income will be related to these sums. Those who have more than £20,000 will be deemed

to be self-funding. For those who have assets between the two levels a tapering contribution will be levied.

Use of services may also be affected by the Direct Payments Act 1996 whereby the individual having been assessed as needing services can elect to use this route to buy their home care package to fit their own requirements as well as offering a more flexible package of care rather than have it provided by the local authority. All local authorities are required to advise on this availability but there are specified exclusions as to who can be paid to provide services.

The provision of services by the local authority is also bound into the Chronically Sick and Disabled Persons Act 1970 as where a person is deemed to be disabled then services under s 2 are mandatory upon the Local Authority (see *R v Islington LBC ex parte Rixon* 1998). Services which have to be provided under this section for those who are assessed as being disabled include: home care (practical assistance in the home), day centres, adaptations to property, travel, meals, holidays and recreation, telephones, TV, radios, educational provisions and specialist employment services.

2.1.4 Is there any relevant case law on the rights and obligations of family carers?

We are not aware of any existing case law. However, the law does owe various duties to carers to be assessed and their needs catered for. Statutory provision is found in the Carers (Recognition and Services) Act 1995, The Disabled Persons (Services Consultation and Representation) Act 1986, Carers and Disabled Children Act 2000. This legislation gives rise to support for carers and a duty to assess them and their needs.

2.1.5 What is the national legal definition of old age, which confers rights (eg pensions, benefits, etc)

There is no legal definition of old age. However, it is usually taken to be the age of entitlement to the state pension. This is confirmed by other entitlements – free prescriptions, bus passes, rail cards etc.

2.2 Currently existing national policies

2.2.1 Family carers

The NHS and Community Care Act (1990) was the first piece of legislation to formally acknowledge the need to support family carers, however, it was not until the Carers (Recognition and Services) Act (1995) was introduced that carers had any statutory rights. This Act gave carers the right to an assessment of their needs, but there was no legal requirement for local authorities to provide support. This is also supplemented by an automatic right to assess-

ment under s 8 Disabled Persons (Services, Representation and Consultation) Act 1986 and in the Carers and Disabled Children's Act 2000. The 1995 Act made the following provision:

'Carers who provide or intend to provide a substantial amount of care on a regular basis have been entitled on request (at the time the person they care for is assessed for community care services) to an assessment of their ability to provide care and continue caring. The results of this assessment are taken into account when decisions are made about the type and level of community care services to be provided to the person cared for. The assessment under the 1995 Act is of the carer's ability to provide care and his or her ability to sustain the care that he or she has been providing. However, the assessment does not give local authorities the power to offer services to support them.'

Although the introduction of the Carers Act was an important first step, it provided limited practical support. In 1999 the UK Government therefore announced its National Strategy for Carers, in their document 'Caring for Carers' (DoH 1999).

The aim of the strategy was to enhance the quality of life for carers by trying to ensure that they have:

- freedom to have a life of their own;
- time for themselves;
- the opportunity to continue to work if they want to;
- control over their life and the support they need;
- better health and well-being;
- integration into the community;
- peace of mind.

The strategy advocated a change of culture so that carers were valued and accorded status. Proposals within the strategy called for more flexible employment policies, and especially the need for better information, support and care for carers. A specific focus was placed on the provision of breaks for caring, with the introduction of the carers special grant, which provided resources for local authorities to develop more innovative forms of breaks for carers.

In building on the National Strategy the Government introduced the Carers and Disabled Children Act (2000). This has the following policy aims and objectives:

The Carers National Strategy document 'Caring about Carers', published on 8 February 1999 highlighted the need for legislation to enable local councils with social service responsibilities to provide services direct to carers. The Government's aim is to support carers in their caring roles and to help them maintain their own health and well-being.

To meet these aims the Carers and Disabled Children Act 2000 came into force on 1 April 2001, and gave local councils the power to supply certain services direct to carers following assessment. This power involves a new right to a carer's assessment; even where the person cared for has refused an assessment for, or the provision of, community care services.

The Government has given local councils the power to make direct payments to carers (including 16 and 17 year old carers receiving support under the Act) to meet their own assessed needs.

For the purposes of the Act the term 'carer' includes people (age 16 and over) who may or may not be a relative and who may or may not be living with the person for whom they are caring. The Act excludes from the definition of a carer paid care workers and volunteers from a voluntary organisation. The exclusion extends to anyone who is providing personal assistance for payment, either in cash or kind.

Right to an assessment under the Carers and Disabled Children Act 2000

For carers age 16 or over who provide a substantial amount of care on a regular basis for someone age 18 or over, the Act provides a right to an assessment, even in circumstances where the cared for person has refused a community care assessment.

Status of care for person – Eligibility for a carer assessment, in the first instance, is dependent on the local council being satisfied that the person cared for is someone for whom it may provide or arrange for the provision of community care services.

Substantial and regular – There is no definition in the Act of 'substantial and regular care'. It is a matter of professional practice to identify the impact of the caring role on the carer in light of the carer's age, general health, employment status, interests and other commitments. Key factors relevant in deciding the impact of the caring role on the carer are the sustainability of the caring role and the extent of risk to the sustainability of that role.

Services to carers

Councils have been given a power to provide services directly to carers. Carers' services are not defined in the Act. Councils may provide any service that either:

- supports the carer in their caring role, or
- helps the carer to maintain their own health and well-being.

Councils should listen to carers and be innovative in the type of support they offer.

Charges

Carers may not be charged for Community Care services provided to the people they care for. Cared for people may not be charged for the carers' services provided to their carers. If both user and carer are being assessed for a charge for their respective services (eg if they are spouses or partners), they may choose to be separately or jointly assessed for any charges.

Direct payments for carers

Carers may choose to have direct payments to purchase services that will meet their own assessed needs instead of receiving services provided or arranged by the council. They may not have a direct payment to buy community care services for the adult they care for.

Short term break voucher schemes

Vouchers will enable cared for people to make arrangements for additional support when their carer needs a break. Cared for people may choose to allow the carer to be the named person who will redeem the voucher.

Carers need breaks, but it is the cared for person who needs additional support. Therefore, it is the cared for person who will receive the service and must be the recipient of the voucher in the first instance. Cared for people may, however, elect to have the vouchers issued in their carer's name so that the carer can redeem the vouchers.

Recent developments

A new Act has recently been passed by Parliament that further advances the rights accorded to carers. The Caring (Equal Opportunities) Act (2004) focuses on health, information, employment and life-long learning for carers.

The Act gives carers more choice and opportunities to lead a more fulfilling life by ensuring that they receive information about their rights on training and work opportunities, and it also ensures that carers' own health is given more consideration. It aims to achieve three main things, to:

- ensure that carers are systematically given information, including about their rights, so that they can make informed decisions about their lives.
- ensure that carers' health, in its broadest sense, is positively considered by social services.
- help to give carers more opportunities in education, training and employment.

In order to meet the above aims the Act places:

- a duty on social services to promote equality of opportunity for carers, particularly in relation to their health and well-being. They would have to look at what services they provide (or secured) to ensure that they were

sufficiently flexible to allow carers to work, have a break or enter training or life-long learning opportunities, whilst caring;

- a duty on local authorities to tell carers about their rights to an assessment;
- a duty on local authorities to develop information strategies to ensure that carers know about their rights;
- a duty on health and social services to promote the health and welfare of carers;
- a duty on other parts of the local authority to ensure that they work with social services, if social services asks for their assistance, to deliver information strategies to help carers.

2.2.2 Disabled and / or dependent older people in need of care / support

As noted earlier (see section 2), public services generally have undergone a programme of sustained change and modernisation over the last decade. Services to support older people have often been the drivers of such change, in both health and social care. For example, older people figured prominently in the Government's New NHS Plan (DoH 1997) designed to provide a radical overhaul of the health care system. Furthermore, widespread concerns about the poor standards of acute health care for older people (HAS 2000 1998) precipitated the introduction of the National Service Framework (NSF) For Older People (DoH 2001). At the time of its launch the NSF was described as 'the first ever comprehensive strategy to ensure fair, high quality, integrated health and social care for older people' (Milburn 2001). It was designed as a 10 year programme of reform intended to promote independence and good health for older people and a 'culture change so that all older people and their carers are always treated with respect, dignity and fairness' (Milburn 2001).

Consistent with recent trends, considerable emphasis was placed on the closer integration of health and social care, recognising the complex interplay of physical, mental and social care factors that impinge on independence for older people. The NSF for Older People is seen to lie at the heart of a programme of reforms for health and social services, introducing new 'care standards' and further promoting services such as intermediate care designed to fill traditional gaps in services between health and social care.

The NSF comprised four main themes:

- Respect for the individual by focussing on person-centred care and the elimination of old age discrimination.
- Intermediate care – a new 'layer' of care to prevent unnecessary hospital admission, support early discharge, and reduce / delay long-term residential care.

- Providing evidence-based specialist care, with a particular emphasis on stroke, falls and mental health in older people.
- Promoting an active, healthy life in older age.

Eight standards were identified that addressed these various themes, intended to be nationally applicable. Responsibility for meeting these standards crossed organisations, particularly the NHS and local councils. As noted earlier (see section 2), new structures were created in the form of 'Local Strategic Partnerships', and closer integration of services was achieved by the introduction of more consistent approaches to care such as the 'Single Assessment Process', designed to assess all the relevant needs of older people.

More recently a series of reports by the Audit Commission (Audit Commission 2004a, b, c, d, e) has provided further detail about the future vision for services for older people. Building on standard 8 of the NSF (The Promotion of Healthy and Active Life in Older Age) there is a call for 'a fundamental shift' in the way that older age is viewed with a move away from dependency and deficit towards a focus on well-being and independence in order that services can be designed so as to be 'future proof'. The onus is placed on a 'better informed' public taking greater responsibility for their health and on building a broader view of old age based on citizenship, participation and partnership.

However, while independence is increasingly the watchword of public policy in relation to older people, there is also growing recognition that independence is not simply the avoidance of dependence and the maintenance of physical abilities. Instead the importance of 'interdependence' is extolled (Audit Commission 2004a) recognising that older people both give and receive care in a reciprocal way. Rather than being defined relative to physical ability and the absence of dependence, independence is therefore seen to comprise three main components:

- the ability to make choices;
- to seek personal fulfilment through activity and relationships;
- to exercise control over surroundings.

In terms of service delivery closer integration is again the goal. This is seen to require a change of approach so that 'citizenship and engagement' underpin the way that care is provided (Audit Commission 2004a).

The vision for such change is described in the first of these reports (Audit Commission 2004a), whilst the second provides examples of how a more strategic approach can be fostered (see Audit Commission 2004b). The third report focuses specifically on the needs of frail older people (Audit Commission 2004c). Here emphasis is placed on how services can help to 'sustain' frail older people rather than simply responding 'when things go wrong'. Greater pro-activity and a whole person / whole system approach is seen as the key to success, based on a system of 'Intensive Case Management', defined as:

‘... a pro-active, community based approach that combines the contribution of health, social care and other agencies. The approach identifies and targets people who already have a large amount of support from health and social care services’ (Audit Commission 2004c, p16).

Consistent with the NSF, the Single Assessment Process is viewed as one of the essential elements of care in order to reduce duplication of effort and better understand the complexity of peoples’ needs. Only in such a way will services be able to respond to older people’s personal goals and aspirations. The report provides several examples of initiatives to which interested readers are referred. Taken together these reports provide an overview of recent policy developments for older people (their carers are considered in the next section), and those requiring further details are advised to consult the original documents (DoH 2001, Audit Commission 2004a, b, c).

2.2.3 Working carers: Are there any measures to support employed family carers (rights to leave, rights to job share, part-time work etc)?

See section 1.9.

2.3 Are there local or regional policies, or different legal frameworks for carers and dependent older people?

See 2.4 below.

2.4 Are there differences between local authority areas in policy and / or provision for family carers and / or older people?

The legal framework for both health and social care in England and Wales is complex and is continually shifting and changing. Case law often determines change but changes are also driven by government policy, local policy and availability of funding. An incoming change will be felt when the Mental Capacity Bill is passed and decision making in these areas becomes in many ways more complex but also will enable proxy decision making on care issues to be undertaken and monitored more closely. The introduction of the No Secrets Guidance for vulnerable adults will impact on not only the Bill but also local policy. The issues are blurred by the fact that for the most part each LA and SHA to a degree relies on its own interpretation of legislation, guidance and policy so there is no clear framework which can be applied nationally. Additionally there will always be local variation. This can lead to allocation of services by postcode or if you like a lottery. The problem in part arises because the different pieces of legislation do not necessarily join up and are on occasions contradictory. The supporting regulations also do not always help and so practice has evolved from case law and the Ombudsmen reports. The service user and their advisers are therefore frequently confused. Entitlement to care

is a maze and it is very difficult to ascertain entitlement because of difficulties in accessing information on policies, procedures and service provision. Additionally this issue is complicated by the crisis nature of many decisions and the need to make rapid decisions. The introduction of the Community Care (Delayed Discharges) Act 2003 has added a further pressure on service provision and adversely affected the service user.

3 Services for family carers

Whilst it might be argued that services supporting the cared for person may also be of benefit to the carer, services aimed primarily at the carer themselves have recently become much more prevalent. Askham (1998) provides a very inclusive definition of carer support as any intervention that helps a carer to take up (or not to take up) a caring role, to continue in a caring role, or to end a caring role. However, whilst there has been some evidence of service innovation in recent times (Banks and Roberts 2001), there is little doubt that the primary aim of most carer support is to help the carer to continue in their role. It is not possible to detail the full list of potential services available to carers here, but there is now a far clearer understanding of what carers want from services, especially in a primary care setting, and these include:

- to be fully informed;
- to be recognised and have their own health and well-being taken into account;
- quality services for the person cared for and for carers to have a life of their own;
- opportunities for a break from caring;
- emotional support;
- training and support to care;
- financial security;
- having a voice in service development and delivery. (King's Fund 1998)

As noted previously, the Carers National Strategy (DoH 1999) placed considerable emphasis on carers being fully informed and saw the provision of breaks for carers as being the most important form of support. Provision of such breaks was supported by the Carers Special Grant, but this is now no longer ring-fenced, and there are concerns that the provision of breaks may decline.

More recently, for the purpose of monitoring provision, services for carers have been categorised into four main groups. These are:

- breaks for the carer;
- information and advice;
- other specific carer services;
- other services for the cared for person.

These are further elaborated upon as follows:

Breaks for the carer

As defined in the Carers Grant Guidance: A 'breaks service' is to be construed as one which actually gives the carer a break from direct responsibility of supervising or caring for the relevant person by providing a service to that person. This would include day care at home or elsewhere and / or residential, and there is no requirement for an overnight stay. This category does not include breaks intended for the person needing services.

Information and advice

This is defined as a baseline minimum set of information, for example:

- social service phone number for emergencies and
- national voluntary sector contact information and
- local numbers if available and
- national financial support line number and
- general advice on back care / moving and handling and
- consistent point of contact and
- anything else relevant to the individual circumstances.

Other 'specific' carer services

The Carers and Disabled Children Act 2000 enables local councils to offer direct carers support. Services for carers are not defined in the Act as such, but the local councils may provide any services which, in their view, will support the carer in their caring role and help them to maintain their own health and well-being.

These services may take any form and examples described in the Carers Grant Guidance include provision of information, emotional support, driving lessons, moving and handling classes or access to training opportunities for the carer. This would of course include direct payments for carers' services, which can be given to carers under the 2000 Act.

Other services for the cared for person

This is where the cared for person is in receipt of any services as a result of an assessment of their needs. An example is that the cared for person is in receipt of day care and home care to meet their needs.

Such definitions are concerned primarily with statutory provision, but there are, however, numerous charitable and voluntary organisations that act both as lobbying groups for carers and, in some cases, as direct service providers. In addition a plethora of web-based sites for carers have developed over recent years, some local based, some national. Some of the main carer groups / service providers are briefly described below:

Carers UK

Previously named Carers National Association, Carers UK aims to make people aware of the role of carers and improve recognition of their needs. The organisation is led by carers and involves carers in research, policy development and campaigning.

It has a national office in London and regional offices in Scotland, Northern Ireland and Wales, with branches throughout the UK. The majority of its income comes from grants from the Government and other public bodies. Other sources include donations from trusts and public bodies, from legacies, from corporate donations and sponsorship, and from membership subscriptions.

Carers UK operate a special phone service called Carers Line, for carers who have questions about benefits, services and other matters. They also lobby for improved status for carers by producing briefings and position papers on government policies. Specific problems are also addressed through research and action. They also now have an online Web-based service CARERS online (www.carersonline.org.uk).

Princes Royal Trust for Carers

This national charity was formed in 1991 and aims, mainly at local level, to make it easier for carers to cope by providing information, support and practical help. There are a network of independently managed Carers Centres, which provide such things as advocacy at tribunals, assessments and case reviews and assistance in accessing funds. They can also provide practical help such as shopping befriending, relief breaks for carers, social aspects and training and education.

The trust has set up four specific funds to help carers in practical ways:

- *The Carers Relief Fund* helps out with basics such as washing machines or extra bedding or special flooring.
- *The Educational Bursary Fund* helps with educational projects and non-vocational courses.
- *The Royal Bank of Scotland Return to Work Fund* helps carers to participate in training to enhance future employment prospects.

The Excel Rural Transport Fund forms a lifeline for those carers living in rural or isolated communities where for example transport costs may be very high in order for them to reach the services they require.

Crossroads

Crossroads Caring for Carers is a charity whose main aim is to provide short-term breaks for carers. Practical help is provided in the form of trained, paid care workers who are sent to the home to take over the caring duties to enable the main carer to have a break. There are approximately 200 local schemes employing some 4,000 people across the country and providing 4 million care

hours to 39,000 carers. The scheme must comply with quality assurance, which is checked out by a Quality Audit Team.

The Crossroads schemes are mainly financed by local authorities and the Carers Grant has brought the possibility of expansion as it is specifically for the types of services provided by Crossroads. If the Carers Grant does not continue this may have a negative impact on the scheme.

The Alzheimer's Society

The Alzheimer's Society is the leading care and research charity for people with Alzheimer's disease and other forms of dementia, their families and carers. Founded in 1979, the Society now has over 25,000 members and operates through nearly 300 branches and support groups. It has expertise in information and education for people with dementia and their carers as well as professionals. It also provides help lines and support, runs quality day and home care, funds medical and scientific research and gives financial help to families in need. The Alzheimer's Society campaigns for improved health and social services, and greater public understanding of all aspects of dementia.

Review of services for carers

Despite the far more widespread availability of support services for carers, a recent major review conducted by the Audit Commission (Audit Commission 2004e) suggests that there is still scope for considerable improvement. The study looked at provision in several areas of England in five main domains:

- Identifying carers
- Information available
- Provision of support and services
- Assessment arrangements
- Management arrangements

The authors concluded that despite progress staff in primary care, especially GPs and others, were not routinely identifying carers nor referring them on. Furthermore, whilst social services departments were generally better at identifying situations that involved a carer, routine collation of this information was often absent. In terms of advice, although this was more widely available, the anticipated comprehensive review of information for carers recommended in the NSF was generally not being conducted and there was a need for information to be more user friendly. Although there has been a growth in the numbers of call centres / websites for carers, these could be further developed and better access encouraged. Despite technology the most frequent way that carers received information was by word of mouth, highlighting the need for service staff to be as up-to-date as possible. Only half of carers surveyed had been given an emergency contact number.

Advice and training for carers was usually given in the form of verbal or written information and the number of carers receiving specific training was 'very small'.

In terms of specific services, it was usually the cared for person who was in receipt of support, especially home care, which was seen by carers as the most important form of help, especially cooking / dressing, getting in and out of bed, and help with meals. Carers routinely requested more home and personal care, better quality and reliable services, more day care, and better transport.

Reflecting government policy, the most frequently provided service for carers was some form of break, as either day care, residential / nursing home, sitting service or other, such as at a hotel. The provision of more breaks that could be seen as a form of holiday, say in a hotel, was the most frequently requested type of break by carers. Other services carers requested included house cleaning, financial help, someone to listen to them, and help with the garden. Support could have been better targeted, eg at the time of hospital discharge, and more provision geared outside traditional hours.

The report also identified several problems with carer assessments, which were generally not widely promoted, with many carers not being aware of their right to an assessment. Even when assessments had been conducted, it was not clear whether good practice had been followed, and very few carers appeared to have received written information about the results of their assessment, with even fewer having a copy of their care plan. To compound matters the evidence suggested that assessors had often adopted a 'gatekeeper approach' that was based on the availability of existing services rather than viewing the assessment as an opportunity to be more creative, or to offer a 'sympathetic ear'. The report concluded that:

'Those conducting carer assessments need to move away from a 'gatekeeper' approach and instead see assessments as an opportunity to engage with carers as real partners in the provision of care – mostly exploring with them what help and support they might access at little or no cost.' (Audit Commission 2004e, p50)

The latter part of this statement highlights existing tensions between the desire to help carers and the limitations on resources to do so. Overall the report concluded that the Government's aspirations for carers are not currently being met for the majority of them. It called for a 'clearly articulated and coordinated approach' in order to improve the situation. Recommendations included:

- Training in the identification of carers, especially for GPs and primary care staff.
- Imaginative ways for carers to identify themselves.
- A clear information strategy, available in a variety of forms – especially information on who to contact in an emergency, and benefits available.

- The need for all staff to be up-to-date.
- Local registers for carers.
- Need to embed services for carers into local practice, especially as ring fencing has now been removed.
- A need to recognise what carers want, especially more help and better equipment.
- More of a focus on delayed discharges and assessment of carers at this time.
- Better support for employed carers.
- Services that are varied, and of high quality.
- Need for better assessment practice on a range of fronts.

In particular the authors stressed the importance of a clearly articulated, multi-agency strategy building on partnerships between and within organisations.

Services for family carers	Availability			Statutory	Public, Non statutory	Voluntary		Private
	Not	Partially	Totally			Public funding	No public funding	
Needs assessment (formal – standardised assessment of the caring situation)			X	Yes ¹				
Counselling and Advice (e.g. in filling in forms for help)			X	Yes ²		Yes ³		Yes
Self-help support groups		X		Yes		Yes		
“Granny-sitting”		X		Yes		Yes		Yes
Practical training in caring, protecting their own physical and mental health, relaxation etc.		X		Yes ⁴		Yes		
Weekend breaks			X	Yes		Yes		Yes
Respite care services			X	Yes ⁵				
Monetary transfers								
Management of crises		X		Yes ⁶		Yes		
Integrated planning of care for elderly and families (in hospital or at home)			X	Yes ⁷				
Special services for family carers of different ethnic groups		X		Yes ⁸		Yes ⁹		
Other								

¹ Available to carers providing ‘regular and established care’. But, as noted above, implementation is patchy and piecemeal.

² Again, widely available in principle but delivery is not consistent.

³ Several carer organisations provide a variety of advice services either by telephone, email, or web-based. Formal counselling is less widely available.

⁴ Not as widely available as is desirable.

⁵ Breaks of various forms are the bedrock of the governments support for carers. Support by the provision of the Carers Special Grant. This has now lost its ring-fenced status and the impact of this on future provision is uncertain.

⁶ The need for better support at times of crisis, and a more proactive approach to preventive work with carers is a top priority.

⁷ This is another area where there is need for more proactive work. Recent legislation enacted in the Community Care (Delayed Discharges) Act 2003 places special onus on the needs of carers.

⁸ These are not as well developed as they might be, many of the services are provided by specialist voluntary groups.

⁹ See footnote number 8.

3.1 Examples

3.1.1 Good practices

Good practice for carer assessments and support is provided in the guidance that accompanied the Carers and Disabled Children Act 2000.

Quality standards for carer services were defined following the Carers National Strategy as follows (the following is a verbatim account of the Executive Summary, obtained from www.carers.gov.uk/qualitystan.htm):

- The following standards are based on carers' views of quality¹ and are broadly supported by carers and managers and practitioners from voluntary, health and local authority services who took part in a wide consultation process.
- Many respondents stressed that above all else action is needed by mainstream health, community and social services to deliver good quality support to disabled, ill and frail people. These services also need to better recognise and respond to carers and ensure carers can get help and substitute care in an emergency, a break from caring and night cover.
- The standards are primarily designed for services exclusively aimed at supporting carers, for example: carer centres, carer support projects, carer groups and services designed to offer carers a break, special help or advice.
- However, these standards are equally relevant to mainstream health, housing, education, community and social services who will need to address these carer quality standards as well as other quality standards related to the modernisation of health and social services and local government.
- It is recommended that as a pre-requisite for providing a quality service, **all** carer support services should demonstrate they meet four essential requirements:
 - carers from all local communities are effectively involved in the organisation;
 - the service works in partnership with all local agencies;
 - the service is clear about its principles, aims and how these will be delivered and monitored;
 - all staff, including volunteers and trustees, are appropriately trained and supported.
- It is proposed that any service aiming to provide carers with information, a break, emotional support, support to care and maintain carer's own health

or support to have a voice will need to meet the relevant standard and accompanying list of conditions.

- The five key standards are:
 - *Information:* Any service providing information to carers provides information which is comprehensive, accurate and appropriate, accessible and responsive to individual needs.
 - *Providing a break:* Any service offering a break to carers works in partnership with the carer and person being supported, is flexible and gives confidence and can be trusted.
 - *Emotional support:* Any service offering emotional support to carers, either on a one-to-one basis or in a group, is sensitive to individual needs, confidential, offers continuity and is accessible to all carers.
 - *Support to care and maintain carer's own health:* Any service which supports carers to care and to maintain their own health and well-being by offering training, health promotion and personal development opportunities is responsive to individual needs.
 - *Having a voice:* Any service which supports carers to have a voice as an individual and / or collectively is accessible to all carers and is able to act in an independent way.
- It is proposed these standards for services directed exclusively at carers are monitored through contracting processes. Contracts between the funding organisation and the carer support service should include these standards and evidence for meeting each condition obtained systematically as part of the agreement.
- Organisations providing local carer support services should be encouraged to carry out self-audits and continue to develop their own quality assurance schemes in order to deliver these standards.
- Recommendations from the consultation for action centrally and locally to put these standards into practice include:
 - Support local partnerships between carers, statutory and voluntary organisations to address these standards constructively, ensuring no small voluntary or community organisation is disadvantaged.
 - Ensure mainstream services meet these quality standards as well as standards for services to the person being supported.
 - Support carers to have a key role in monitoring the quality of services.
 - Give priority to ensuring carers from all communities are included.

3.2 Innovative practices

There are now several innovative schemes for carer support. The previously cited Audit Commission report on services for carers (Audit Commission 2004e) provides details of a number, including:

- A primary care booklet to identify carers.
- A recognition and discount scheme to aid in the identification of carers.

An Internet site for carers (www.carersnet.org.uk) linked to Carers UK national website (www.carersonline.org.uk).

- GP attached carer support worker service.
- Voluntary organisation carer database, information and support centres.
- Initiatives to encourage carers to take up services / benefits.
- Intensive carer support schemes.

More detailed descriptions of these and other schemes can be found in the report.

4 Supporting family carers through health and social services for older people

As noted in section 3, in addition to services designed to support family carers there are a range of services, both specific and generic, to support older people which may also have benefits for family carers. A brief overview of those used by older people follows. Based on the GHS 2000 Maher and Green (2002) report that amongst the 65-74 year age group, 32 % of cared for people attend some form of daily club or day care / hospital, with the figure being 29 % in those aged 85 and over. Attendance at such facilities potentially offers the carer some form of respite from caring. In terms of other services two fifths (41 %) of cared for people (of all age groups) receive visits from health, social or voluntary services. Visits were significantly lower amongst those living with a carer (23 %) than those living in another household (50 %). People living in the same household as the carer are less likely to receive visits from health practitioners (15 % / 30 %) and home help / meals on wheels (9 % / 31 %). The use of such services by carers also varies considerably.

4.1 Health and social services

4.1.1 Health services

4.1.1.1 Primary health care

The health care system in the UK has seen a marked shift towards primary care, with the formation of Primary Care Trusts (PCTs) with increased responsibility to commission as well as provide care. The General Practitioner (GP) is often the first port of call for both older people and their carers. As noted in the recent Audit Commission report (Audit Commission 2004e), there is scope for improvement in the way that carers are identified and referred on to other agencies by members of the primary health care team.

GP's, practice nurses and district nurses provide the majority of the health services for elderly people within the community with the assistance of other professionals. Over 90 % of older people are registered with their GP and it is reported that GPs have the highest professional contact rate with elderly people in the community (Kennie 1993). In recent years this may be in part due to the GP contract that came into force in 1990. This requires GPs to conduct an annual assessment of patient's on their list who are 75 and over. In return they receive a monetary reward for each patient that they screen. GPs also rely on the expertise and support of a multidisciplinary team when caring for elderly people in the community. This multidisciplinary team includes geriatricians, occupational therapists, physiotherapists, clinical psychologists and psychia-

trists. Most of these specialists will be based in the hospital setting. Much of the face-to-face contact with elderly people is provided by practice nurses.

Community nurses and psychiatric nurses

It has been estimated that elderly people represent about 80 % of community nurse's workload (Conti and Webster 1998); with district nurses providing 2.75 million visits every year. The majority of the contacts are with frail older people (85+), as community nurses work on the boundaries between health and social care. The community psychiatric nurse plays a similar role to the community nurse, monitoring the individual, liaising with the other services, and supporting older people and their carers.

Health visitor

Conti and Webster (1998) estimate that of the health visitor's time, only 15 % is spent with elderly people and this percentage is decreasing, despite the considerable potential for a greater input.

Hirst and Arksey (2000) argue that members of the primary health care team, and nurses in particular, have a potentially key role to play in identifying carers and responding to their health needs. In particular they suggest the following:

Health promotion

- Enabling carers to maintain their own health and well-being.
- Encouraging stress management and time off from caregiving.
- Working in partnership with carers to maintain / improve the health of the care recipient.

Practical support

- Counselling and listening to carers, helping them to acknowledge and deal with their feelings about caregiving.
- Enabling carers to adjust when caregiving ends, especially following admission to long-term care or bereavement.

Information and advice

- Providing information, advice and advocacy, help with claiming welfare benefits, and signposting sources of information.
- Ensure carers know of their rights to an assessment, of their own needs under the Carers Act, and the Carers and Disabled Children Act.
- Advising carers on what to do in case of an emergency and ensuring they know how to access NHS Direct.
- Providing information, with permission, about the illness or impairment of the person cared for, and about their treatment and medication, including possible side effects and changes in treatment.

Referral to other agencies

- Enabling carers to access other health, housing and social care services, including carer support groups, services providing short breaks or long-term care, and local voluntary organisation.

However, as the Audit Commission report (Audit Commission 2004e) suggests, there is some way to go before such potential can be realised. Notwithstanding such limitations, primary care staff are valued by carers, with studies suggesting that GPs often provide the best information, help and practical support (Henwood 1998), and having a better understanding of their role and needs than NHS consultants and other specialists (Keeley 2002). Furthermore, the attitudes of primary care staff, particularly district nurses, towards carers is often much more positive than those of care managers within social services departments (Audit Commission 2004e).

Other services based in the community that are used by older people and may benefit carers include the following:

Physiotherapists

Physiotherapists have special skills for physical treatment of rehabilitation in older people. They work widely in hospitals and in the community as part of the multidisciplinary rehabilitation team.

Occupational therapists

Occupational therapists work with physical and mental health problems to promote the independence of people caring for themselves, or who have a carer helping to support them. They are part of the multidisciplinary rehabilitation team enabling people to return home from hospital. In the community they work with families and carers to resolve practical problems. They have particular expertise in the area of aids, housing adaptations and equipment.

Chiropodists

NHS chiropody services may be provided free of charge at a variety of settings such as health centres, day centres and GP surgeries, although this may be limited to medical problems rather than routine care. There is a consensus in the literature that the level of community chiropody / podiatry services for elderly people are not sufficient (Sandifer et al 1998).

There are regional variations in the availability of community resources and personnel, especially between those living in rural and urban locations. It is estimated that over 80 % of rural parishes are without community health services within their boundaries (Brown 1999). The problem is further compounded by the fact that in these areas public transport is more scarce and of the older households only 51 % own a car (Harding 1997).

Day hospitals

Day hospitals are usually based at district hospital sites and offer hospital-based services to patients who are living in the community. Although rehabilitative care is still the main focus many contemporary day hospitals have developed to provide a wide variety of specialist clinics such as Parkinson's disease. Day hospitals can be tailored to meet local needs dependent on the flexibility of the multidisciplinary team, which can include medical and nursing staff, physiotherapists, occupational therapists, social workers and input from speech therapists, dieticians, dentists, continence advisers and chiropodists mean that the day hospital can provide great flexibility.

4.1.1.2 Acute hospital and Tertiary care

Hospital care

The vast majority of acute hospital care for older people is provided free of charge by the NHS. Recent years have seen a move away from specialist or dedicated geriatric units towards more generic facilities. The provision of specialist units, for example, stroke care, also varies throughout the country. As noted in section 2.2.2, concerns over the quality of acute hospital care for older people, particularly a lack of attention to basic care needs and evidence of age discrimination in service access resulted in the Government launching the National Service Framework (NSF) (DoH 2001) for older people with the intention of providing national minimum standards of care. One of the key developments arising from the NSF has been the widespread introduction of a new layer of care, 'intermediate care'.

Intermediate care

Recent policy has emphasised the development of intermediate care defined as 'a range of services designed to facilitate the transition from hospital to home and from medical dependence to functional independence' (Enderby and Stevenson 2000, p36).

This is part of a major initiative to promote independence for older people, which included the investment of an extra £900 million by 2003 / 2004 for intermediate care and related services. Targets include an extra 5000 intermediate care beds and a further 1,700 supported intermediate care places by 2004. While progress towards these goals has been made, problems remain in the lack of a standardised approach to, and definition of intermediate care.

Rehabilitation

Specialist rehabilitation centres are available regionally, and are often condition specific (for example, stroke). The Department of Health claims that over the last four years the proportion of hospitals with specialist stroke units has increased significantly (DoH 2001). However, as with intermediate care, issues remain about the purpose and focus of rehabilitation and the extent to which current services address the needs of older people. The continued emphasis

on the promotion of independence (Hanford et al 1999) runs the risk of marginalising the most frail and disabled section of the population who are most at need (see, for example, Dalley 2001).

4.1.1.3 Long-term health care facilities

Long-term hospital care in the UK has all but disappeared, and most formal support is provided by the care home sector.

4.1.1.4 Hospice / palliative / terminal care facilities

There are very limited hospice / palliative / terminal care facilities for older people and those available have historically been associated with cancer care, often provided in hospices. Individuals with non-cancer disease continue to be disadvantaged in terms of accessing palliative health care (Seymour and Hanson 2001), despite the fact that it is recognised that palliative care is essential to all those affected by life-threatening illness (Clark and Seymour 1999).

The Royal Commission for Long Term Care (1999) reported significant shortfalls in the provision and funding of palliative care for older people. Many of the deficiencies relate to care home provision. Fifteen percent of all deaths now occur in nursing or residential homes (Clark and Seymour 1999), but there are often not enough staff or the specialist resources to provide appropriate palliative care (Siddell et al 1998). Recently commissioned research studies are exploring the provision of palliative care, especially in care homes. In December 2002 the Government announced an extra £50 million investment in palliative care services from 2003 / 2004.

4.1.1.5 Are family carers expected to play an active role in any form of in-patient health care?

Family carers are not expected to play a major role while the older person has a hospital stay. However, several studies highlight the fact that most carers would like to play a larger role than they currently do, but that this desire can often meet resistance from professional staff (see, for example, Allen 2000, Brereton and Nolan 2003).

4.1.2 Social Services

Within the public sector Social Services Departments provide the majority of social support to elderly people in the UK. Such departments are run by the local council but there is variation in provision across the four countries. Social services provide a range of care and, while the percentage of money spent on older people is falling (Palmer et al 2002), nearly half the annual expenditure is still on this client group (DoH 1998).

4.1.2.1 Residential care (long-term, respite)

In recent years residential and nursing care has increasingly been provided by the private sector but a large percentage of the funding still comes from the statutory sector. In 1999 The Royal Commission on Long term Care estimated that around 205,000 elderly people in the UK receive publicly financed residential care. In England in 2001 there were 431,200 residential places in 24,100 residential care homes and 186,800 registered beds in 5,700 nursing homes and private hospitals and clinics. Between 2000 and 2001 there has been a 3 % decrease in residential care homes and a decrease of 3 % in nursing homes and private hospitals and clinics. Over half (54 %) of supported residents were in independent residential care homes, 27 % were in independent nursing homes and 16 % were in local authority staffed homes (DoH 2003a).

In 1997 the Labour Government set up a Royal Commission on long-term care. Its aim was to examine the long and short-term options for funding the long-term care of elderly people. Their main recommendations were that nursing care and personal care should be centrally funded for long-term care but means testing should remain for the residential element (Royal Commission on Long-Term Care 1999). In October 2001 free nursing care was introduced to care homes but the Government rejected the idea of funding personal care. In Scotland, however, the Parliament decided that they would fund personal and nursing care. This has led to heated debates about what constitutes personal care and how it can be differentiated from nursing care.

4.1.2.1.1 Basic data on % of > 65s in residential care by age group and type of residential care (sheltered housing, residential homes)

Around four fifths of all supported residents are aged sixty-five or over and on average residents are in their mid-eighties (DoH 2003a).

Table 9: To show local authority supported residents in permanent residential and nursing care by age group in 2001 (DoH 2003a)

Age	Residential	Nursing
65-74	13,384	8,279
75-84	43,575	24,541
85+	74,420	31,494

In 2001, 5 % of all elderly people lived in sheltered accommodation with a resident warden and 3 % without a resident warden. The proportion living in all forms of sheltered accommodation increases with age from 3 % of people aged 65 to 69 to 19 % aged 85 and over (ONS 2003).

4.1.2.1.2 Criteria for admission (degree of dependency, income etc)

Anyone who can afford to pay for care themselves can go into residential care if they wish. If assistance is needed to pay for the costs of residential care then an assessment of need is required before financial assistance can be provided.

4.1.2.1.3 Public / private / NGO status

Where the Social Services Department agrees that there is a need for residential or nursing care, it will consider eligibility for assistance with paying for care home fees. This is essentially based on the capital that an older person has.

The term "capital" includes savings, investments and property. Capital below £12,500 is not included in calculating the personal contribution. If individuals have capital between £12,500 and £20,000 then they will be required to make a weekly contribution, called a tariff. This charge will reduce as the capital reduces, until the capital falls below £12,500 when it will no longer apply.

If individuals have more than £20,000 in capital then they have to pay the full cost of residential or nursing home care. However, if the capital falls below £20,000 while living in a home then the individual can be reassessed. Capital that is disposed of or property that is transferred will be investigated as part of the assessment and may be included in the financial contribution.

Any client admitted to permanent residential care after 9 April 2001 is entitled to apply for a 12-week disregard of their property. If the property is sold within the 12-week period, the disregard will cease to apply from the date of sale. If the property has not been sold at the end of the 12-week disregard period, it will be included in the financial assessment. However section 53 and 55 of the Health and Social Care Act (2001) extend the powers of local authorities to place a charge on an interest in land as an alternative method of a person financing their long-term care.

4.1.2.1.4 Does residential care involve the participation of carers?

There is no systematically developed approach for formalising relationships between family carers and staff in residential care. The extent to which family carers are involved will vary on a home-by-home basis.

4.1.2.2 Community care services (statutory coverage and whether aimed primarily at older people living alone or including support to family carers)

4.1.2.2.1 Home help / Personal care

As noted in section 3, the provision of more home care is one of the most frequently requested forms of support by family carers. Figures on the provision of such services indicate that in the year 1 April 2001 to 31 March 2002,

600,000 people were in receipt of home help / home care, of whom 500,000 were over the age of 65, the vast majority of whom (432,000) suffered from physical and sensory disability or frailty (DoH Community Care Statistics 2001-02). A survey conducted during one week in September 2002 (DoH 2003b) suggested that 2.98 million contact hours were provided to 366,800 households (or 381,900 clients), an increase in contact hours of 3 % but a fall in the number of households by 4 % since 2001. These figures suggest that councils are providing more intensive services for a small number of consumers, a trend seen over the last decade. Of those households receiving care, about 81,500 (22 %) were provided with intensive home care (more than 10 hours or 6 visits per week), an increase of 5 % since 2001. Sixty-four percent of contact hours (to 216,200 households) were provided by the private sector, reflecting an increase in commissioning from the private sector by councils.

With regard to longer-term trends between September 1999 and September 2002 contact hours increased by 14 % whilst numbers of households decreased by 23 %. Provision by the independent sector increased from 42 % to 64 %.

4.1.2.2.2 Meals services

Figures for the period 1 April 2001 to 31 March 2002 indicate that approximately 212,000 clients were in receipt of meals services of whom 195,000 were over the age of 65 (DoH 2003b).

4.1.2.2.3 Other home care services (transport, laundry, shopping etc)

Transport is a major issue for frail older people, with 14 % of people aged 65 and over being unable to walk down the road on their own, and 10 % being unable to manage stairs and steps (ONS 2003). Disabled people (whether older or not) are entitled to tax exemptions on road licence duty, may be eligible for help with the purchase of an adapted car, and can get parking exemptions.

Regulations under the Disability Discrimination Act (1995) require buses, coaches, trains and trams to be accessible to disabled people including wheelchair users, although some of the new regulations have until 2020 to come into force. The Disabled Person Railcard is valid for 12 months and allows reductions of up to a third for disabled travellers.

Some local authorities provide a dial-a-ride service, which may be partially funded or means tested, but there are wide variations across the regions.

4.1.2.2.4 Community care centres / Day care ("protective" care)

A range of care centres are potentially available in the community, but again regional variations exist. Recent initiatives have promoted the development of resource centres which bring together a range of services in one location. More traditional day centres also exist, which are provided by several organisations, often charitable but with grant aid from the local authority. Such cen-

tres may provide both social and therapeutic activity, with access, for example, to chiropody. If services are provided or aided by Social Services then a small means tested payment may be required. Figures suggest that for the period 1 April 2001 to 31 March 2002, 261,000 clients used day care, of whom 141,000 were over the age of 65.

4.1.2.3 Other social care services

Counselling and Training

The National Strategy for Carers (DoH 1999) acknowledged that emotional support through counselling was an important service. Local carers centres can provide counselling to meet the emotional needs of carers but, despite the value of counselling, funding for dedicated staff to run the service is unusual.

There are many charitable organisations that provide training for carers throughout the country. An example is the St John Ambulance. They provide First aid and Care training for carers working in residential settings and as family carers. Some of the courses, such as the 30 hour Fundamental Care Course, offer a certificate and can link to national qualifications if required.

Given the recent enactment of the Carers (Equal Opportunities) Act, training for carers is now likely to figure far more prominently (see section 2.2.1). Moreover, carers' organisations such as Carers UK, in conjunction with approved training organisations, are also actively promoting training and developing opportunities for carers to gain some formal recognition for training (see www.city-and-guilds.co.uk).

Equipment

Equipment to make life easier for older or disabled people is usually provided through Social Services after an assessment from an occupational therapist. Social Services may be able to give access to a range of equipment such as text phones, flashing or vibrating alarm clocks or doorbells and loop systems for listening to the television. They can also provide simple items such as kettle tippers or tap turners and raised toilet seats, and more complex equipment such as hoists for getting people in and out of the bath. Items such as wheelchairs and walking aids can often be loaned from the local hospital or community health service. A small deposit is usually required.

Environmental control systems enable people with severe disabilities to operate appliances and equipment in the home from a central control they can be linked with alarms, door locks, intercoms, telephones, lights, heaters, communication aids and computers. Disabled living centres are located around the UK and offer disabled people the chance to see and try a wide range of services to meet their needs. They also offer a free and independent advice service about what is available, where to get it and how much it costs. Many centres also arrange training on a variety of topics of interest to disabled people, carers and professionals.

Social Services and housing authorities can assess whether improvements or adaptations are needed to the home to enable people to live more independently.

House Restoration Grants are means tested grants for getting a house into a fit state to live in. Disabled Families Grants may be awarded after an occupational therapist has assessed whether adaptations proposed are necessary and appropriate. These grants could be used for kitchens or bathroom facilities or to help people get round their homes easier. They are limited to £25,000 but local authorities can give more if they think it is necessary. Home Repair Assistance is a discretionary grant, which is not means tested, that may be given through the Department of Health to meet the costs of minor repairs, improvements or adaptations with a limit of £2,000 to £4,000 over a three year period. There are agencies throughout England, Wales and Scotland to help people decide what work needs doing and to organise it. This is usually free, but where it is not this cost can be covered by grants.

In recent years information technology such as personal computers, CD-Roms and ISDN lines have provided older people and their carers with various ways of accessing information and support (Hanson and Clarke 2000) (also see section 6.6).

4.2 Quality of formal care services and its impact on family caregivers: systems of evaluation and supervision, implementation and modelling of both home and other support care services

There have been a number of recent developments in this field. Standards for services specifically for carers were discussed in section 3.1.1.

4.2.1 Who manages and supervises home care services?

In-home support provided by Social Service Departments is managed within Directorates with line management and reporting systems back through to an Executive Director.

External providers such as voluntary organisations or commercial sectors are managed by their own managers / owners / committee / board.

All purchased home care services are delivered under contract with a legal Form of Agreement and a detailed Service Specification. These are subject to quarterly monitoring, Annual Services Reviews and independent service user surveys run by SSD Contracts Unit.

4.2.2 Is there a regular quality control of these services and a legal basis for this quality control? Who is authorised to run these quality controls?

A major new body, the Commission for Social Care Inspection (CSCI) has recently been established to monitor and assess performance across a range of service provision.

The following information is adapted from the CSCI website (www.csci.org.uk/about-csci):

Launched in April 2004, The Commission for Social Care Inspection is the single, independent inspectorate for social care in England. The Commission was created by the Health and Social Care (Community Health and Standards) Act 2003.

CSCI incorporates the work formerly done by:

- The Social Services Inspectorate (SSI)
- SSI / Audit Commission Joint Review Team
- The National Care Standards Commission (NCSC)

The Commission has a much wider remit than its predecessor organisations. And its creation is a significant milestone for social care. Brining together the inspection, regulation and review of all social care services into one organisation allows for a more rational and integrated system.

For the first time, one single organisation has a total overview of the whole social care industry. The Commission will be able to provide a complete picture of social care in England:

- locally and nationally;
- in adult services and children's services;
- for people who use social services;
- for local councils, voluntary and private providers;
- for government.

The Commission for Social Care Inspection's primary function is to promote improvements in social care by putting the people who use social care services firmly at the centre of its work.

The remit of CSCI is greater than anything seen before in social care. It works on a local level, at a national level, and across all sectors.

In each local council area CSCI:

- registers the private and voluntary care services that are required to meet national standards;

- inspects, assesses and reviews all care services in that area. This includes private and voluntary care services and local council social service departments;
- inspects boarding schools, residential special schools and further education colleges with residential students aged under 18;
- publishes an inspection report detailing its findings after each inspection;
- provides the local council with details of the number and quality of private and voluntary care services in their local area;
- deals with complaints about care service providers;
- from 2005 CSCI will review complaints about council social services departments.

In order to carry out its national role, CSCI:

- draws together all the information it has about the state of social care services nationally;
- uses the information to inform policy makers of the impact of national and local policies on people who use social care;
- reports annually to parliament on the state of social care in England, how resources are being used and how the reform of social care is progressing;
- carries out research and studies into social care;
- comments on social care research by other organisations.

The Commission provides a complete picture of social care in England – from the national policy level right down to the experience of individual social care users.

Using the national minimum standards, CSCI assesses the extent to which registered services meet the needs of service users.

The following services for adults fall under the Commission's remit:

- care homes
- care homes providing nursing care
- care homes providing adult placement
- domiciliary care agencies
- nurses agencies

These services care for:

- older people
- people with dementia

- learning disability
- physical disability
- sensory impairment
- mental health problems
- alcohol dependency
- drug dependency
- autistic spectrum disorder
- terminal illness
- HIV and AIDS
- people who are, or have been ill

For further details of the work of CSCI visit their website.

4.2.3 Is there any professional certification for professional (home and residential) care workers? Average length of training?

Professional care workers such as nurses, social workers and professions allied to medicine are professionally trained and regulated. There is also a range of non-professional care qualifications for care workers, often linked to national awards, such as the National Vocational Qualification (NVQ), or other vocationally orientated accreditation systems. Several different types of provider may offer training from in-house arrangements, work-based study, or external organisations. Recent work (Henwood 2001) has highlighted considerable disparities across the country, and the generally low level of training for non-professional care workers, especially in care homes. Such training has tended to focus on the minimal health and safety requirements, with little attention to the philosophy of care and the development of interpersonal skills.

There is now a requirement for 50 % of care assistants to have NVQ Level 2 by 2005, providing a significant challenge for care homes.

4.2.4 Is training compulsory?

As noted, training is not currently compulsory for every member of staff, although most organisations provide some form of minimum induction programme. But minimum requirements for a proportion of staff to be qualified have now been set. Professional qualification is of course mandatory for the established disciplines.

4.2.5 Are there problems in the recruitment and retention of care workers?

Recruitment and retention is a major issue and a growing concern. Problems are apparent with respect to both qualified and unqualified staff. In the former area work with older people is not accorded the value and status of acute care. With respect to unqualified staff, turnover is high and wages low, further exacerbating an already difficult situation.

4.3 Case management and integrated care (integration of health and social care at both the sectoral and professional levels)

See sections 2 and 2.2.2.

4.3.1 Are family carers' opinions actively sought by health and social care professionals usually?

See section 3 and Audit Commission (2004e).

5 The cost - benefits of caring

5.1 What percentage of public spending is given to pensions, social welfare and health?

From government statistics for the year ending 31 March 2001, the total Government benefit expenditure was 9.98 % of the GDP. Retirement pensions accounted for 4.1 % of the GDP.

Total Government spending on the NHS stood at 5.51 % of the GDP and for welfare services 1.35 % of the GDP (Government Statistics 2003).

With regards to NHS expenditure in the period 1996-1999 expenditure for people aged 65 and over made up 35.6 % of total health services (Seshamani and Gray 2002).

5.2 How much, private and public, is spent on long-term care (LTC)?

The total value of the care home market for older and physically disabled people for the year up to April 2001 is estimated at £9.1 billion, of which private sector provision accounted for £7.2 billion (Laing and Buisson 2003). However, most of the residents of LTC facilities are supported by the local authority.

5.3 Are there additional costs to users associated with using any public health and social services?

The National Health Service is free and there are no additional costs associated with using such services. Charges can be made for dental services, eye sight tests and prescriptions but these are free to those on benefits or people aged 65 and over. Social services are means tested and a small fee is usually payable.

5.4 What is the estimated public / private mix in health and social care?

With regards to provision for elderly people, private sector provision of long-term care is extensive, but most residents in private care homes are supported by social security payments. There have been increases in the number of older people who possess private insurance to cover their care needs. An increasing number of companies offer long-term care insurance and it has been estimated that there are 23,000 long-term care insurance policies in force across the UK (RCOLTC 1999), with this number growing.

In relation to the overall balance of expenditure, the following figures are the most recently available.

Table 10: Scale of UK health and care markets

Sector	Billions £ / annum
NHS	65
Independent sector hospitals	2.2
Independent sector care homes	9.6
Public sector care homes	2
Independent sector domiciliary care	1.2
Public sector domiciliary care	0.7

Source: Laing and Buisson 2003

5.5 What are the minimum, maximum and average costs of using residential care, in relation to average wages?

There are no minimum and maximum costs of residential care. In the public sector the local authority sets the costs and in the private sector independent residential homes can decide what they want to charge themselves. A recent survey found the average cost for private residential care was £302 per week and the average cost for private nursing care was £422 per week (Laing and Buisson 2003).

5.6 To what extent is the funding of care for older people undertaken by the public sector (state, local authorities)?

As outlined earlier, people needing residential care or services in the community are means tested on their ability to contribute to their care but the majority of the funding for the care of older people is provided by the public sector. NHS funds derive mainly from taxation collected and allocated by Central Government, with increasing local decision making on how it is spent. There is line of accountability from local health commissioners to the relevant Secretary of State responsible for Health in England, Scotland, Wales and Northern Ireland. Services are commissioned locally from providers primarily in the public sector, with some private sector involvement. In England, Scotland and Wales, local authorities deliver Social Services. Their expenditure derives from an allocation of general taxation via a government grant and money raised locally through council tax and fees and charges. There is far less direct central Government control over the detailed allocation of local authority expenditure than with the NHS, reflecting local authority autonomy. Funding consists of a grant covering a number of service blocks, but the individual local authority has discretion on how much to spend on each service.

After consultations with local authority associations the Government determines annually the amount of grant which goes to local authorities overall. This is then divided between authorities according to a formula. Standard Spending Assessments (SSAs) are produced, which show approximately how much the Government expects local authorities to spend on Social Services overall - not specifically on older people - to deliver a standard level of service. Most authorities spend more than SSA for Social Services as a whole (on average of 9 % above). In England in 1996, according to figures supplied by the Department of Health, authorities spent 16 % less than the SSA on services for older people (a sum of £0.7bn) while spending more on younger disabled people and on children (The Royal Commission on Long Term Care 1999).

5.7 Funding of family carers

5.7.1 Are family carers given any care benefits (cash, pension, credits / night allowance etc) for their care. Are these means tested?

See section 2.1.2 for Carers Allowance.

There are benefits that can be claimed by carers who work. Their availability may depend on the income and savings of the carer, that is they are means tested. Other than Carers Allowance main benefits are:

Income Support – for people on a low income who work less than 16 hours a week. It is means tested and people with more than £8,000 in savings do not qualify. Carers who qualify for Carers Allowance get an extra allowance called Carer premium.

Family Credit – a tax-free benefit for families with children where at least one partner works for 16 hours a week or more. It is means tested and there are no special rules for carers.

Housing Benefit and Council Tax Benefit (Rate Rebate in Northern Ireland) – these are benefits to help to pay the rent and the Council Tax or rates if on low income. They are means tested and the carer Premium is again used in the calculation, making the scheme more generous to carers. They are administered by the local council (Housing Executive or Rate Collection agency in Northern Ireland).

Welfare benefits for carers who are NOT in paid work – the only benefit especially for a carer who is not in paid work is the Carers Allowance. However, they may also be entitled to Income Support, Housing Benefit and Council Tax Benefit or Rate rebate.

Carers now may also be entitled to direct payment (see section 2.2.1).

Direct Payment is money that can be given to the carer by their social services department to buy the support needed to care for the person being looked after.

It can be requested by contacting social services and asking for a carer's assessment. A social worker will then visit to discuss the support needed. Social Services can provide some or all the support that has been assessed as needed. But if the support available does not meet carers' needs carers can ask for Direct Payments so that they can buy it themselves. Direct Payments can only be spent on getting the support the carer has been assessed as needing.

In April 2002 the Department of Health published documents to make provision in the regulations for local authorities to issue vouchers for short-term breaks. The aim is to help disabled people who have been assessed as needing services and their carers by providing flexibility of the timing of breaks and how they are supported. An assessment of the needs of the disabled person and the carer is required. Councils can offer time value vouchers, which correspond to the amount of time the cared for will need while the carer is taking a break. They can also provide money value vouchers based on the cost to purchase the support or they can provide time and money value vouchers. The vouchers can be used to arrange residential accommodation but no single placement can exceed 28 days and the total duration of placements must not exceed 120 in one year.

There is a distinction between the direct payments and voucher payments. With direct payments there is a contractual relationship between the provider and the council and the receiver takes full responsibility for all aspects of the contract. With vouchers there is a shared responsibility between the recipient and the council and they cannot be used to purchase services from individual self-employed care workers.

National insurance contributions

People who leave work and claim Carers Allowance have a basic retirement pension that is secure. This is because a National Insurance Credit will be paid for every week they receive Carers Allowance (unless they elected to pay the lower 'married woman's stamp' some years ago). There is however no help towards occupational pension or any additional pension.

If people cannot claim Carers Allowance, they may be able to claim Home Responsibilities Protection for every complete year that they cared for someone provided they are getting Attendance Allowance or Disability Living Allowance care component at the middle or higher rate. This protects the state pension.

5.7.2 Is there any information on the take-up of benefits and services?

As has been noted at several points throughout this report, although carers are in principle entitled to an assessment, and if deemed eligible, certain services, such assessment is not as widely promoted as it might be. Carers are often not aware that they are entitled to an assessment, and even if they secure an assessment, care managers often adopt a 'gate-keeping' approach to limit

demand on available resources (Audit Commission 2004e). On this basis it can be assumed that substantial numbers of carers eligible for benefits and services do not receive them. Although precise figures are not available, Carers UK estimate that 300,000 carers fail to claim their entitlement to Carers Allowance, and that carers are missing out on benefits worth £660 million annually (Carers UK 2004). Only 30 % of carers have had a carers' assessment, and the majority of carers are unsure of their rights to one (Carers UK 2003b). Whilst the new Carers (Equal Opportunities) Act (2004) should ensure that carers are better informed of their rights, improvements will still require a transformation of practice away from a 'gate-keeping' model of assessment, to a partnership approach (Audit Commission 2004e).

5.7.3 Are there tax benefits and allowances for family carers?

The only special income tax allowance for carers is the Additional Personal Tax Allowance. This is only available to married men who have dependant children and whose wives are severely physically or mentally disabled throughout the tax year. You can apply for the allowance for the last six years, as long as you have met all the conditions for the years you claim. This could mean that you are due a rebate and will pay less tax in future.

5.7.4 Does inheritance or transfers of property play a role in caregiving situation?

When someone goes into a residential home they may be required to sell their home, so individuals who are likely to benefit from the inheritance of property may be influenced in their decision to care for their elderly relative.

5.7.5 Carers' or Users' contribution to elderly care costs

a. Medical, nursing and rehabilitation services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
General practitioner	Yes					
Specialist doctor	Yes ¹⁰		Yes ¹¹			
Psychologist	Yes ¹²					
Acute Hospital	Yes					
Long-term medical residential care (for terminal patients, rehabilitation, RSA, etc.)	Yes					
Day hospital	Yes					
Home care for terminal patients	Yes					
Rehabilitation at home	Yes					
Nursing care at home (Day / Night)	Yes		Yes			
Laboratory tests or other diagnostic tests at home	Yes ¹³					
Telemedicine for monitoring	Yes ¹⁴					
Other, specify: "home care"						

¹⁰ Referral required from GP.

¹¹ May be provided privately if desired.

¹² See footnote number 10.

¹³ Via GP or Primary Care Team.

¹⁴ Not in widespread use.

b. Social-care services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Permanent admission into residential care / old people's home			Yes ¹⁵	Yes ¹⁶	Yes	Yes
Temporary admission into residential care / old people's home in order to relieve the family carer				Yes	Yes	Yes
Protected accommodation / sheltered housing (house-hotel, apartments with common facilities, etc.)			Yes	Yes	Yes	Yes
Laundry service				Yes	Yes	Yes
Special transport services				Yes	Yes	Yes
Hairdresser at home				Yes	Yes	Yes
Meals at home						
Chiropract / Podologist	Yes		Yes			
Telerecue / Tele-alarm (connection with the central first-aid station)				Yes	Yes	Yes
Care aids				Yes	Yes	Yes
Home modifications				Yes	Yes	Yes
Company for the elderly						
Social worker	Yes					
Day care (public or private) in community center or old people's home				Yes	Yes	Yes
Night care (public or private) at home or old people's home			Yes	Yes	Yes	Yes
Private cohabitant assistant ("paid carer")						
Daily private home care for hygiene and personal care			Yes			
Social home care for help and cleaning services / "Home help"				Yes	Yes	Yes
Social home care for hygiene and personal care				Yes	Yes	Yes
Telephone service offered by associations for the elderly (friend-phone, etc.)	Yes ¹⁷					

¹⁵ The vast majority of social care services are provided by social services. They are usually based on both being defined as being in need (severity based), and on ability to pay (means tested). Most services may also be purchased privately, including permanent care, if individuals have the private resources to do so. Carers are eligible for services if providing 'regular and substantial' care as assessed under the carers' legislation (see section 2.2.1).

¹⁶ See footnote number 15.

¹⁷ Often provided by the voluntary sector, as purchased by Social Services Department. May be a small charge levied.

b. Social-care services	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Counselling and advice services for the elderly	Yes ¹⁸					
Social recreational centre						
Other, specify						

¹⁸ See footnote number 17.

c. Special services for family carers	General access:			Access based on:		
	Free at point of use / wholly reimbursed	Partly privately paid / partly reimbursed	Completely privately paid	Means-tested		Based on severity
				Partly reimbursed	wholly reimbursed	
Training courses on caring	Yes ¹⁹					
Telephone service offered by associations for family members	Yes ²⁰					
Internet Services	Yes ²¹					
Support or self-help groups for family members	Yes ²²					
Counselling services for family carers	Yes ²³					
Regular relief home service (supervision of the elderly for a few hours a day during the week)				Yes ²⁴	Yes	Yes
Temporary relief home service (substitution of the family carer for brief periods of time, for example, a week)				Yes ²⁵	Yes	Yes
Assessment of the needs	Yes ²⁶					
Monetary transfers						
Management of crises						
Integrated planning of care for the elderly and families at home or in hospital	Yes ²⁷					
Services for family carers of different ethnic groups	Yes ²⁸					
Other, specify						

¹⁹ Many of these services are provided by the voluntary or charitable sector. Their availability varies widely. Carers UK are currently promoting the use of on-line training opportunities for carers, and are actively lobbying local councils to provide a wider range of on-line activities to help end carer isolation and also to develop other skills that may help in seeking employment (see: www.city-and-guilds.co.uk).

²⁰ See footnote number 19.

²¹ See footnote number 19.

²² See footnote number 19.

²³ See footnote number 19.

²⁴ See section 2.1.2 on carers' rights to assessment and services.

²⁵ See section 2.1.2 on carers' rights to assessment and services.

²⁶ See section 2.1.2 on carers' rights to assessment and services.

²⁷ Not as well developed or coordinated as it might be. See section 2.1.

²⁸ Availability is limited and patchy.

6 Current trends and future perspectives

An overview of the current trends with regard to care of older people, and specifically the support for family carers, was presented in section 2, specifically sections 2.1, 2.1.1, 2.1.2 and 2.2 / 2.2.1. Specific questions are considered below.

6.1 What are the major policy and practice issues debated in family care of older people from the carers' point of view? Are older people and / or carer abuse among these issues?

As noted in section 3, there are several major groups who are working to address carers' needs, these include Carers UK, The Princes Royal Trust, Crossroads Care for Carers, and the Alzheimer's Society. These organisations have identified a range of issues relating to the needs of carers that they suggest require further attention. These may be said to represent the 'carers' point of view'. These organisations run a series of campaigns, for example, limiting the use of the term 'carer' to a family carer as defined in statute, and restricting its use for paid workers, whether a professional or not (Carers – What's in a name? – CARERSONLINE). Carers UK also have their own newsletter, CAMPAIGN, that provides an overview of the latest and most topical issues (visit: www.carersonline.org.uk for a range of campaign materials and fact sheets).

Similarly, The Princes Royal Trust for Carers currently has a campaign in conjunction with the Royal College of Psychiatrists, 'Partners in Care', specifically designed to help carers of people with mental health problems (www.carers.org/home/).

Based on a major study conducted last year, Carers UK made a series of recommendations to government, local authorities, NHS and Primary Care Trusts, and carers groups and organisations (Carers UK 2003a). These were as follows:

- For Government
 - Review progress to date of the National Strategy for Carers, respond to the findings and recommendations in this survey and propose action for the next phase of the National Strategy, including delivering mainstream support for carers.
 - Introduce legislation to place a duty on local authorities and the NHS to inform carers of their right to an assessment, bringing England and Wales into line with Scotland and Northern Ireland.
 - Substantially increase funding for social care services.
 - Continue ring fenced funding for carers' breaks and services and continue funding beyond 2006. Monitor the impact of the Carers Grant

through the Delivery and Improvement Statement, including the effect of 'lighter touch' performance management for high performing authorities and social service departments.

- Clarify policy and ensure local authorities have constructed their eligibility criteria for supporting carers in line with Fair Access to Care and CDCA guidance.
- Urgently review the policy on lifting and handling to ensure carers are not exposed to unacceptable risks.
- Develop the performance management agenda to address not just the number of carers' assessments but the outcomes of those assessments. Develop and publicise workable models that measure outcomes.
- For local authorities
 - Develop a clear strategy for delivering, where needed, changes in organisational culture and practice in relation to carers.
 - Ensure that their care management process is being used to measure outcomes for carers, backed up by quality assurance and inspection.
 - Introduce procedures to systematically offer carers' assessments, particularly where the user has refused an assessment or services. Find ways of monitoring the effectiveness of this change.
 - Canvass staff attitudes towards carers' assessments and develop new ways of working to tackle unhelpful attitudes, whilst building more constructive ways of linking carers into statutory or non-statutory support.
 - Implement training for staff on the CDCA.
 - Set clear eligibility criteria for supporting carers to ensure no assumptions are made about the presence of a carer and that no individual is at risk as set out in Fair Access to Care and CDCA guidance.
 - Set out their programme for delivering direct payments to service users and carers, including putting in place the necessary support infrastructure.
 - Audit assessments to ensure they are needs led and that blanket policies on not providing certain services such as cleaning and counselling have been lifted.
 - Urgently review policy and practice on lifting and handling to ensure carers are not exposed to unacceptable risks.
 - Abolish charging for social care services, including carers' services.
 - Consider ring fencing part of the allocation of the Carers Grant to set up a fund to encourage innovation in providing new carers' services. Pro-

mote examples of carers' services which have led to good outcomes for carers.

- Ensure contract compliance and that new domiciliary care standards are maintained. Involve carers and users in monitoring services.
- Ensure carers have equal opportunities to employment and consider the role for local strategic partnerships.
- Develop, fund and monitor high quality independent advocacy services for carers and disabled people.
- Local implementation teams of National Service Frameworks and Valuing People should review how they are involving and supporting carers.
- NHS and Primary Care Trusts
 - Have regard to Carers UK's good practice guide on hospital discharge when reviewing hospital discharge procedures in line with "Discharge from Hospital: Practice, process and pathways".
 - Primary Care Trusts should examine referral and signposting mechanisms for carers within primary care, for example to the benefits agencies, voluntary sector and other statutory support for carers.
- For carers groups and organisations
 - Regularly inform carers of their right to an assessment. Carry out take up campaigns, including participating in Carers Rights Day.
 - Audit local authority support services to ensure they are needs led rather than service led.
 - Audit local authority handling and lifting policy and its impact on carers and pass on findings to Carers UK for campaign purposes.
 - Seek written assurance from your director of Social Services that the local authority does not operate any type of blanket ban on types of services such as cleaning, counselling, or lifting and handling services.
 - Ensure local hospital trusts are implementing the new guidance on hospital discharge, including informing carers of their right to an assessment. (Taken from: Missed Opportunities: Executive Summary Carers UK 2003a, www.carersonline.org.uk)

The issues of elder abuse were considered in section 1.11.

6.2 Do you expect there to be any changing trends in services to support family carers, eg more state or more family support, more services or more cash?

The passage of the Carers (Equal Opportunities) Act into statute in the UK clearly suggests that a number of initiatives will follow, with there now being a duty on social services to promote equality of opportunity for carers, especially in relation to health, well-being, and the flexibility of services in order to promote a break or entry to training and life-long learning opportunities. There is also a duty to inform carers of their rights, and for health and social services to promote the health and welfare of carers.

However, just what this will mean in terms of real change is more difficult to determine. As the recent Audit Commission survey on carers' services (Audit Commission 2004e) found, the implementation of existing legislation is extremely patchy and variable, particularly with respect to carers' assessments and their rights to services. This report made a far ranging series of recommendations (see section 3), which if acted upon should see greater emphasis placed on, and success in, identifying carers, ensuring more coherent information strategy, the embedding of services for carers into mainstream practice, greater focus on employed carers, better assessment at time of discharge from hospital, and better and more varied services.

Consequently, there is a recognised need to abandon a 'gate-keeping' approach to services and to develop a more clearly articulated multi-agency model for addressing carers needs. However, the removal of the 'ring-fence' around the carers grant, and the suggestion by the Audit Commission that assessments should be about exploring with carers 'what help and support they might access at little or not cost' provides little in the way of optimism that more resources will be made available.

6.3 What is the role played by carer groups / organisations, 'pressure groups'?

See section 6.1.

6.4 Are there any tensions between carers' interests and those of older people?

Inevitably, within individual caring relationships, tensions may arise in a variety of forms. These are eloquently captured in instruments such as CADI, CASI and CAMI (see section 1.11). Caring engenders a variety of often conflicting emotions from love to duty, to anger and frustration. These may of course cause difficulties within dyadic and wider family relationships. Generally, however, the majority of carers wish to care, but also wish to be more widely recognised and supported in what they do.

Beyond the immediate relationship it could also be argued that wider policies, with their emphasis on maintaining older people at home and promoting independence, also raise several tensions. Certainly, when alternatives to care, such as placement in a residential or care home, might be considered this is often viewed as an unacceptable alternative, even if a carer's health is being jeopardised.

6.5 State of research and future research needs (neglected issues and innovations)

Future research into the needs of family carers, and service responses to the needs, can be identified in several areas. Broadly speaking, such work needs to be both theoretical / conceptual in order to gain further insights into the experiences and circumstances of family carers and policy / practice, in order to explore the interface between formal and family caregiving systems.

From a theoretical / conceptual basis there has, as Fortinski (2001) has noted, been an 'explosion' of research into family care over the last 20 years. Notwithstanding this, there remain 'several unresolved issues' (Pearlin et al 2001) which require further study. In particular there is a greater need to extend our gaze beyond the caregiving dyad to include triadic and other forms of relationship, and to consider the dynamic and temporal nature of such interactions throughout the caring career. This will challenge the conceptual basis for interventions designed to support family carers, which remain rooted largely in a 'stress-coping' paradigm. There is a clear need to develop forms of intervention beyond the current instrumental orientation. This will require new thinking about the purpose of carer support, with a concomitant development of more sensitive and appropriate outcome indicators used to gauge the 'success' of interventions.

While the above debate concerns broad theoretical and conceptual concerns, there is also a need for further empirical work in several areas, and the experiences and needs of carers from minority ethnic groups must figure prominently here.

With regard to research focussing on policy and practice issues there needs to be a clearer link between the emergence of new theoretical insights and the development of new forms of working 'with' family carers as partners and experts in their own right. Despite recent developments the Audit Commission Review (Audit Commission 2004a) on support for family carers identifies several areas where improvements are needed, and reaches the stark conclusion that the governments aspirations in respect of carers are not in large being met. Several recommendations for change are suggested (see section 3). Furthermore, reports produced by carer groups such as the 'Missed Opportunities' report provided by Carers UK (2003a) also identified an extensive list of areas for action (see section 6.1) that have clear implications for further research and

development. Fundamentally, however, there is a need to address several key questions. These include:

- **Why** support family carers? Services need to do more than simply enable carers to 'carry on caring' at the 'least possible cost' and recognise that for some family members caring is not necessarily the most appropriate course of action, and that for others help to give up caring in a timely fashion is also appropriate. For those majority of family members who wish to care, relevant support must be provided throughout the caring career, from the pre-caring stage to sensitive on-going help post-caring.

Several other questions also require attention, including:

- **When** is the most appropriate time to support carers, and how do support needs change, for example, for new and experienced carers?
- **How** is support best delivered, for instance, on a one-to-one basis, or in groups, by the use of technology, or more direct human contact?
- **Who** is the intended beneficiary, and how are potential tensions between the needs of carers and those they support be addressed?
- **Where** does formal support best fit in, and how can professionals be trained in order to provide the most appropriate and relevant form of help that merges professional and family expertise in building a true partnership.

It has recently been suggested that there needs to be symmetry and synchronicity between the views of service providers and family carers and the delivery of services (Nolan et al 2003). With regard to symmetry there should be agreement and congruence, or at least transparency, about the goals and aspirations of both parties. Without this services are likely to be rejected. Synchronicity concerns the timing of support so that it is optimally effective and coincides with major transitions in the caring trajectory. All too often support has either been 'allocated' on the basis of largely instrumental eligibility criteria, or 'imparted' from the 'expert' to the 'lay' individual, rather than negotiated and 'relational' (Nolan et al 2003). Addressing this imbalance is one of the major challenges for the future.

6.6 New technologies – are there developments which can help in the care of older people and support of family carers?

One of the recent Audit Commission reports (Audit Commission 2004d) specifically focused on the role of technology in supporting older people. This recognised the considerable potential for Assistive Technology (AT) as follows:

'Assistive technology has huge potential to help people remain independent'

- It provides choice to users, for example, by enabling them to remain in their own homes.
- It supports both formal and informal carers.
- It can be used to deliver health and social care more conveniently.

Assistive technology is an important way of delivering many public policy initiatives

- Many of the targets in the Priorities and Planning Framework can be underpinned by the use of assistive technology.
- Assistive technology will play a major part in delivering several of the National Service Frameworks.
- Assistive technology has a vital part to play in keeping hospital services local and in supporting the transfer of services from secondary to primary care.
- Assistive technology offers the opportunity to provide better and less expensive care for many of the country's 18 million people who have chronic health conditions.

The evidence to prove its success is strong, but the take-up is slower than the weight of evidence would merit

- The organisation expected to invest in AT (typically local authorities) is usually not the beneficiary, making some reluctant to invest.
- Assistive technology often requires significant changes to the way that people work – implementation often needs well-planned programmes of organisational development.
- There is a crowded change management agenda, which can marginalise assistive technology service developments.
- Suppliers could ease the implementation of assistive technology by offering whole packages of care, not just the technology.

Public services need to use the potential of assistive technology to keep people independent and ease the pressure on existing services

- Health and social care organisations need to take maximum advantage of funding flexibilities available under the 2000 Health Act to pool budgets and support developments across agencies.
- Local authorities need to channel energy into providing information that empowers users and enables them to make informed choices about assistive technology.

- Wherever possible, suppliers need to market assistive technology products to individuals rather than content themselves with selling to public agencies.’ (Audit Commission 2004e, p2)

6.7 Comments and recommendations from the authors

As will be apparent, the last decade has witnessed numerous developments with respect to both family carers and older people, and change is on-going and rapid. Whilst this report cannot include all recent developments it is hoped nevertheless that it has highlighted the most significant issues and provides an insight into current debates within the UK. These may be of interest to those concerned with ensuring that the contribution of family carers is fully recognised and that such individuals receive the help and support they need in a sensitive and timely fashion. Ultimately only by developing genuine partnerships between family and more formal caring systems genuine progress will be made.

7 Appendix for the National Background Report for the United Kingdom

7.1 Socio-demographic data

7.1.1 Profile of the elderly population – past trends and future projections

As with many other countries across Europe, the United Kingdom’s population is gradually becoming older, particularly the numbers of people in advanced old age. Implications of this increase in the oldest age group, with regards to rising health care costs have been debated, and there is much discussion in relation to the global ageing population. Results of the 2001 census show that over 12 million people are aged 60 and over, which is 21 % of the total population. 9.4 million people are aged 65 and over, with 1.1 million of these aged 85 and over, which is over three times as many as there was in 1961 (CSO 2003). Past and future trends are shown in Table 11.

Table 11: Population of older people by age and sex in the United Kingdom

Sex and year	Percentage of total population		
	55-64	65-74	75 and over
Males			
1961	11	6	3
1991	10	8	5
2001	11	8	6
2011	12	9	7
2021	13	10	8
2026	13	10	9
Females			
1961	12	9	5
1991	10	9	9
2001	11	9	9
2011	12	9	9
2021	13	11	10
2026	14	11	11

Adapted from Office for National Statistics, General Register Office for Scotland, Government Actuary’s Department, Northern Ireland Statistics and Research Agency

7.1.1.1 Life expectancy at birth (male / female) and at age 65 years

Table 12: Life expectancy at birth and at selected ages until the age of 80

Age	Men	Women
Birth	75.7	80.4
5	71.2	75.9
20	56.5	61.0
30	46.9	51.2
50	28.3	32.1
60	19.8	23.2
70	12.5	15.1
80	7.1	8.7

NB: Figures are for 2001

Source: Health Statistics Quarterly, No. 22 Summer 2004-07-22

7.1.1.2 Percentage of > 65 years old in total population by 5 or 10 year age groups

Table 13: Percentage of > 65 years old in total population by 5 year age groups

Age range	Total	Males	Females
65-69	2596843	1241382	1355461
70-74	2339231	1059151	1280080
75-79	1966929	817711	1149218
80-85	1313547	482697	830850
85+	1124056	310035	814021

Based on 2001 census data

7.1.1.3 Marital status of > 65 years old (by gender and age group)

Table 14: Marital status of > 65 years old (by gender and age group)

Age group	Married		Single		Widowed		Divorced	
	Men (%)	Women (%)	Men (%)	Women (%)	Men (%)	Women (%)	Men (%)	Women (%)
65-69	78	63	7	5	7	22	8	9
70-74	75	51	8	6	11	36	6	7
75-79	69	38	7	6	20	51	4	5
80-84	62	25	7	7	29	65	3	3
85-89	50	12	5	8	43	78	2	2
90+	34	6	8	10	56	82	2	1

Source: Office of National Statistics

7.1.1.4 Living alone and co-residence of > 65 year olds by gender and 5 year age groups

Older women are more likely to be living alone than older men, and the proportion increases with advancing age. For example, among women aged 85 and over living in private households 71 % live alone compared to 42 % of men of the same age. Men, more than women, live in a married couple family.

Table 15: Percentage living alone by age and sex

Age group	Men (%)	Women (%)
16-24	6	4
25-44	17	7
45-64	16	15
65-74	19	37
75+	33	60

Source: www.statistics.gov.uk

7.1.1.5 Urban / rural distribution by age

no information provided

7.1.1.6 Disability rates amongst > 65 year olds – estimates of dependency and need for care

The proportion of people with a long-term illness or disability which restricts their daily activities increases with age. For women aged 50-64, 26 % report such a disability compared to 74 % of women at age 85. The proportions for men are 27 % at age 50-64 and 67 % at age 85.

The most common types of chronic sickness suffered by those aged 65+ in 2001/2 were heart and circulatory diseases and musculo-skeletal. Women, more than men, suffer from arthritis and rheumatism, whereas men are more likely to report respiratory disorders such as bronchitis and emphysema.

Despite having a long-term illness that restricts their daily activity many older people still consider themselves to be in good health. For example, 37 % of men and 40 % over the age of 85 with a long-term illness still consider their health to be good. Source: Office of National Statistics (2004a).

Of people aged 65-79 living at home 35 % of both men and women report at least one of five types of disability (locomotor, personal care, hearing, sight and communication). The figures for those aged 80+ are 62 % of men and 64 % of women. The proportion of both men and women over the age of 65 who report personal care disability is 14 %, with this figure rising at age 80+ to 24 % for men and 23 % for women. The most prevalent form of disability for both sexes is locomotor, with 30 % of men and 33 % of women over 65 report-

ing such difficulties, especially with walking or climbing stairs. Source: www.official-documents.co.uk – Disability Among Older People.

Among people aged 65+, 14 % are unable to walk down the road and 10 % unable to manage stairs and steps. In terms of self-care the greatest reported difficulty is cutting toenails (36 % of women and 23 % of men). With regard to domestic tasks, those that involve some sort of climbing cause the most difficulty (31 % of older people). One in 20 older people are unable to cook a main meal by themselves. Source: Office of National Statistics (2003).

7.1.1.7 Income distribution for top and bottom deciles

In the last 8 years average net incomes of pensioner units (pensioner couples and single pensions) rose by 25 % after taking into account inflation. The average pensioner unit received £237 per week net income in 2002/3 (£327 for couples and £177 for single pensioners).

In 2002/3 26 % of pensioners were in the bottom fifth of the net equivalent income. Fewer pensioners are in the bottom quintile once housing costs are taken into account. Single female pensioners are more likely to be in the bottom fifth (22 %), single males are more likely to be in the top fifth (24 %) than the bottom fifth (15 %). Older pensioners are more likely to be in the bottom fifth (24 % of couples where the head of household was aged 75, and 24 % of single pensioners). Source: Office of National Statistics (2004b).

Table 16: Distribution of income for pensioners by family type and pension scheme

Family type and pension scheme	Income quintile group (percentage)					All Pensioners (millions)
	Bottom quintile	Second quintile	Third quintile	Fourth quintile	Top quintile	
Before housing costs*						
Couples – of which (see below)	26	27	21	14	12	5.2
No pension scheme	52	28	13	5	3	1.1
Only one pension scheme	22	30	21	16	11	2.8
Both with pension scheme	10	20	29	20	22	1.3
Single – of which (see below)	25	33	21	14	7	4.1
No pension scheme	34	34	17	11	4	1.9
With pension scheme	18	32	23	16	10	2.2
After housing costs*						
Couples – of which (see below)	19	27	22	17	15	5.2
No pension scheme	45	34	12	6	3	1.1
Only one with pension scheme	15	30	23	18	14	2.8
Both with pension scheme	6	16	29	24	25	1.3
Single – of which (see below)	21	31	21	15	11	4.1
No pension scheme	33	35	15	12	5	1.9
With pension scheme	12	29	25	18	16	2.2

Net equivalised disposable income. Occupational or personal pension. Excludes self-employed.

* Figures are presented on both a before and after housing costs basis to take into account variations in housing costs between groups. Both measures have imperfections, so it is not advisable to unduly favour one above another. See Appendix 5: Housing Costs.

Source: Households Below Average Income, Department for Work and Pensions

7.1.1.8 Percentage of > 65 year olds in different ethnic groups

First detailed results of the 2001 census indicate that seven out of eight people in England and Wales give their ethnic group as White British. Eighty-seven percent of the population of England and 96 % of the population of Wales give their ethnic as White British. White Irish made up 1.2 % of the population of England and Wales. Two percent of the population of England and Wales are Indian, Bangladeshi formed 0.5 %, Black Caribbean 1.1 %, 0.9 % Black African, and 0.2 % other black groups, 0.4 % are Chinese. Source: www.statistics.gov.uk – Census 2001 Ethnicity and Religion in England and Wales.

7.1.1.9 Percentage of home ownership (urban / rural areas) by age group

The majority of older people are owner-occupiers, but the proportion decreases with age. In 2001 80 % of people aged 50-64 living in private house-

holds were owner-occupiers, compared to 72 % aged 65-84 and 61 % 85+. The proportion of those living in rented accommodation increases with age, the figures being 50-64 20 %, 65-84 28 % and 85+ 40 %. Source: Office of National Statistics (2004c).

7.1.1.10 Housing standards / conditions if available by age group, eg percentage without indoor plumbing, electricity, TV, telephone, lift (if above ground floor), etc

Few older people live in over-crowded conditions, just 1 % of people aged 50 and over. Just over half of all people aged 50+ in England lived in a property that was under-occupied in 2002/3, but this fell to 32 % at age 85+.

Only a minority of people over 50 report a problem with their house. One in ten older people complained of damp in floors and walls, of difficulties with insects, mice or rats, or the house being too dark. About 12 % said their house was too cold in the winter. For people 50-64 93 % lived in houses with central heating, the proportion decreasing with age to 86 % at 85+. Source: Office of National Statistics (2004c).

The results of the 2001 General Household Survey indicate that elderly households were less likely to have access to most types of consumer durables (accepting televisions and fixed telephones). For instance, 18 % of elderly households had a computer, compared to 61 % of other households, and 55 % of elderly households had a car, compared to 80 % of other households. However, consumer durables in elderly households are on the increase, with 18 % of such households having a home computer in 2001, compared to 10 % in 1998. Source: Office of National Statistics (2003).

7.2 Examples of good or innovative practices in support services

In their series of reports both mapping a vision for integrated services for older people and further developing that vision with respect to the promotion of independence and well-being, the Audit Commission (2002, 2004a, b, c) provide numerous case examples of innovative practice. These include, for example, initiatives aimed at:

- Identifying vulnerable older people / screening and case finding
- Mapping and redesigning service provision
- Neighbourhood community care schemes
- Keep well at home / active ageing / health mentor schemes
- Joint case management arrangements / case management models
- Services to promote intermediate care, hospital discharge and rehabilitation

- Better assessment practice
- Housing strategies for older people
- Care direct (telephone advice) schemes
- Senior surfer projects
- The role of champions in sustaining political support
- Involving older people
- Medicines management

Fuller accounts of these schemes can be obtained from the above reports available on the Audit Commission Web-site (www.audit-commission.gov.uk).

8 References to the National Background Report for the UK

- Allen D. 2000. 'I'll tell you what suits me best if you don't mind me saying': 'lay participation' in health care. *Nursing Inquiry*, 7: 182-190.
- Askham J. 1998. Supporting Caregivers of Older People: An Overview of Problems and Priorities. In *World Congress of Gerontology Adelaide*, pp 5-7.
- Audit Commission. 2002. *Integrated Services for Older People: Building a Whole System Approach in England*. Audit Commission (www.audit-commission.gov.uk).
- Audit Commission. 2004a. *Older people - A Changing Approach: Independence and Well-being*. Audit Commission (www.audit-commission.gov.uk).
- Audit Commission. 2004b. *Older People – Building a Strategic Approach: Independence and Well-being 2*. Audit Commission (www.audit-commission.gov.uk).
- Audit Commission. 2004c. *Supporting Frail Older People: Independence and Well-being 3*. Audit Commission (www.audit-commission.gov.uk).
- Audit Commission. 2004d. *Assistive Technology: Independence and Well-being 4*. Audit Commission (www.audit-commission.gov.uk).
- Audit Commission. 2004e. *Support for Carers of Older People*. Audit Commission (www.audit-commission.gov.uk).
- Ayres L. 2000a. Narratives of family caregiving: four story types. *Research in Nursing and Health*, 23: 359-71.
- Ayres L. 2000b. Narratives of family caregiving: the process of making meaning. *Research in Nursing and Health*, 23: 424-34.
- Banks P and Roberts E. 2001. *A break for carers: An analysis of the local authority plans to use the carers special grant*. King's Fund, London.
- Brereton L and Nolan MR. 2003. Seeking partnerships between family and professional carers: stroke as a case in point. In Nolan MR, Lundh U, Grant G and Keady J. eds. *Partnerships in Family Care: understanding the caregiving career*. Open University Press, Maidenhead, pp 50-68.
- Brown D. 1999. *Care in the country – Inspection of community care in rural communities*. Social Services Inspectorate.
- Carers and Disabled Children's Act. 2000. HMSO, London.
- Carers (Equal Opportunities) Act. 2004. HMSO, London.
- Carers UK. 2003a. Missed Opportunities: The impact of new rights for carers, Executive Summary (www.carersonline.org.uk).

- Carers UK. 2003b. Campaign, June 2003 Issue One (www.carersonline.org.uk).
- Carers UK. 2004. Campaign, February 2004, Issue Three (www.carersonline.org.uk).
- Clark D and Seymour J. 1999. *Reflections on Palliative Care*. Open University press, Buckingham.
- Community Care (Delayed Discharges) Act. 2003. HMSO, London.
- Community Health and Standards Act. 2003. HMSO, London.
- Conti N and Webster S. 1998. *Lecture notes on geriatrics* (Fith ed). Blackwell Science, Oxford.
- Dalley G. 2001. Defining difference: health and social care for older people. In A Warnes, L Warren and MR Nolan. eds. *Care Services for Later Life: Transformations and Critiques*. Jessica Kingsley, London.
- Department of Health. 1990. *National Health Service and Community Care Act*. HMSO, London.
- Department of Health. 1995. *Carers Recognition and Services Act*. HMSO, London.
- Department of Health. 1997. *The New NHS, Modern, Dependable*. HMSO, London.
- Department of Health. 1998. *Health and Personal Social Statistics for England*. HMSO, London.
- Department of Health. 1999. *Caring About Carers: The Carers National Strategy*. HMSO, London.
- Department of Health. 2001. *National Service Framework for Older People*. London: HMSO.
- Department of Health. 2003a. Community Care Statistics 2001, Residential Personal Social Services for Adults, England (www.doh.gov.uk).
- Department of Health. 2003b. Community Care Statistics 2002, Home Care Services for Adults, England (www.doh.gov.uk).
- Disability Discrimination Act. 1995. HMSO, London.
- Efrainsson E, Höglund I and Sandman P. 2001. 'The everlasting trial of strength and patience': transition in home care nursing as narrated by patients and family members. *Journal of Clinical Nursing*, 10(6): 813-19.
- Enderby P and Stevenson J. 2000. What is Intermediate Care? Looking at Needs. *Managing Community Care*, 8(6): 35-40.

- Fortinsky RH. 2001. Health care triads and dementia care: integrative framework and future directions. *Aging and Mental Health*, 5(Supplement 1): S35-S48.
- Government statistics. 2003. www.statistics.gov.uk.
- Hanford L, Easterbrook L and Stevenson J. 1999. *Rehabilitation for Older People: The emerging policy agenda*. King's Fund, London.
- Hanson E and Clarke A. 2000. The role of telematics in assisting family carers and frail older people at home. *Health and Social Care in the Community*, 8: 232-41.
- Harding T. 1997. *A life worth living: The independence and inclusion of older people*. Help the Aged, London.
- Health Advisory Service (HAS) 2000. 1998. "Not because they are old": An independent inquiry into the care of older people on acute wards in general hospitals. Health Advisory Service 2000, London.
- Health and Social Care Act. 2001. HMSO, London.
- Health Statistics Quarterly No 22. 2004. Expectations of Life at Birth and Selected Age (Table 5.1). Office of National Statistics.
- Henwood M. 1998. *Ignored and invisible? Carers' experience of the NHS*. Report of a UK research survey commissioned by Carers National Association, London.
- Henwood M. 2001. *Future Imperfect: Report of the King's Fund Care and Support Inquiry*. King's Fund, London.
- Hirst M and Arksey H. 2000. Informal Carers Court. *Nursing Standard*, 14(42): 33-34.
- House of Commons Health Committee. 2004. Elder Abuse, Volume 1. HMSO, London.
- Hutton S and Hirst M. 2001. *Relationships Over Time: End of Project Report*. Social Policy Research Unit, University of York.
- Jeon YH and Madjar I. 1998. Caring for a family member with chronic mental illness. *Qualitative Health Research*, 8(5): 694-706.
- Joseph Rowntree Foundation. 2004. Black and minority ethnic older peoples' views on research findings. Findings May 2004 (www.jrf.org.uk/knowledge/findings/social_care/564.asp).
- Keeley B. 2002. *Barclays Carers Speak Out Project*. The Princes Royal Trust for Caring, London.
- Kennie DC. 1993. *Preventative care for elderly people*. Cambridge University Press, Cambridge.

- King's Fund. 1998. *The Carers' Compass: New Directions for Improving Support for Carers*. King's Fund, London.
- Laing and Buisson. 2003. Long Term Care (www.laingbuisson.co.uk/longtermcare.htm).
- Lee HS, Brennan PF and Daly BJ. 2001. Relationships between empathy to appraisal, depression, life satisfactions and physical health of informal caregivers. *Research in Nursing and Health*, 24: 44-56.
- Nolan MR and Grant G. 1992. *Regular Respite: an Evaluation of a Hospital Rota Bed Scheme for Elderly People*. Ace Books, Age Concern Institute of Gerontology Research Papers Series No 6, London.
- Nolan MR, Keady J and Grant G. 1995. CAMI: a basis for assessment and support with family carers. *British Journal of Adult / Elderly Care Nursing*, 1(3): 822-6.
- Nolan MR, Grant G and Keady J. 1996. *Understanding Family Care: a multi-dimensional model of caring and coping*. Open University Press, Buckingham.
- Nolan MR, Grant G and Keady J. 1998. *Assessing Carer's Needs: A Practitioner's Guide*. Pavilion Publications, Brighton.
- Nolan MR, Lundh U, Grant G and Keady J. 2003. eds. *Partnerships in Family Care: understanding the caregiving career*. Open University Press, Maidenhead.
- Nunley BL, Hall LA and Rowles GD. 2000. Effects of the quality of dyadic relationships on the psychological well-being of elderly care recipients. *Journal of Gerontological Nursing*, (Dec): 23-31.
- Maher J and Green H. 2002. *Carers 2000*. Office of National Statistics. HMSO, London.
- Martini TS, Grusec JE and Bernardine SC. 2001. Effects of interpersonal control, perspective taking and attributions on older mothers and adult daughters' satisfaction with their helping relationships. *Journal of Family Psychology*, 15(4): 688-705.
- Milburn A. 2001. Foreword. In Department of Health 2001, *National Service Framework for Older People*. HMSO, London.
- Mintz S and Marosy JP. 2000. Family caregivers and home care: a declaration of interdependence. *Caring Magazine*, June 2000: 24-6.
- Office of National Statistics. 1999. Population of Working Age: by gender and social class. Social Trends 30, Spring 1999. (www.statistics.gov.uk).
- Office of National Statistics. 2000. *General Household Survey 2000*. HMSO, London.

- Office of National Statistics. 2003. *General Household Survey 2003*. HMSO, London.
- Office of National Statistics. 2003. *People aged 65 and over*. HMSO, London.
- Office of National Statistics. 2004a. Focus on Older People: Older People and Caring (www.statistics.gov.uk).
- Office of National Statistics. 2004b. Focus on Older People: Personal Income (www.statistics.gov.uk).
- Office of National Statistics. 2004c. Focus on Older People: Housing (www.statistics.gov.uk).
- Office of Population Censuses and Surveys. 1989. *General Household Survey 1985*. HMSO, London.
- Palmer G, Mohibur R and Kenway P. 2002. *Monitoring poverty and social exclusion 2002*. Joseph Rowntree / New Policy Institute, York.
- Pickard L. 2004. Caring for Older People and Employment: A review of the literature prepared for the Audit Commission. Audit Commission (www.audit-commission.gov.uk).
- Royal Commission on Long Term Care (RCOLTC). 1999. *With respect to old age*. HMSO, London.
- Sandifer QD et al. 1998. Foot morbidity and exposure to chiropody. *British medical Journal*, 316: 1608.
- Schulz R and Williamson GM. 1997. The measurement of caregiver outcomes in AD research. *Alzheimer's Disease and Related Disorders*, 11 (Supplement 6): 1-6.
- Services Consultation and Representation Act. 1986. HMSO, London.
- Seshamani M and Gray A. 2002. The impact of ageing on expenditures in the National Health Service. *Age and Ageing*, 31: 287-294.
- Seymour JE and Hanson E. 2001. Palliative care and older people. In M Nolan, S Davies and G Grant. eds. *Working with older people and their families: Key issues in policy and practice*. Open University Press, Buckingham.
- Siddell M, Katz JT and Komaromy C. 1998. Death and dying in residential and nursing homes for older people. Unpublished report to Department of Health.
- Smith C, Snelgrove S, Armstrong-Esther CA and Clark J. 2003. Is there a future for the informal homecare of older people in a changing society? *Quality in Ageing*, 12(1 / 2): 147-67.
- Snyder JR. 2000. Impact of caregiver-receiver relationship quality on burden and satisfaction. *Journal of Women and Aging*, 12(1 / 2): 147-67.

- Social Policy Research Unit (SPRU). 2001. *Research Works: Informal Care Over Time*. SPRU, University of York.