



Managing Caring and Employment

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CARERS look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.

Acknowledgements

The CES research team at the University of Leeds also included Leah Harris and Amanda Rodney, who both made important contributions to the project and to collecting the qualitative data reported here. The CES team wishes to thank staff at Carers UK, especially Madeleine Starr, for help and guidance throughout, and all members of the ACE2 partnership. Although the carers who responded to the CES survey and took part in the interviews for the study must remain anonymous, we would particularly like to thank them for their time and contributions. We are also very grateful to the staff of the local authorities, employers and other agencies in the localities in England, Wales and Scotland which were selected for detailed study, who provided valuable information, helped us to access survey respondents, and in some cases gave research interviews.

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Managing Caring and Employment

Report No. 2 is about how services are used by carers to support them in managing caring alongside paid employment.

The report also explores the difficulties carers face when trying to combine work and care if services do not meet their needs or are not available, and considers the situation of carers who have had to give up work in order to care, or who are trying to return to paid work after or during a period of caring. The report draws on evidence from the new CES survey which included 812 carers aged 16-64 who were employees – 444 employed full-time and 368 employed part-time – as well as 56 carers who were self-employed. We also use data from 93 carers in full-time or part-time employment who were interviewed face-to-face, and from the 50 unemployed carers in the CES survey who were actively seeking work.

Executive Summary

This report, *Managing Caring and Employment* arises from the **Carers, Employment and Services** (CES) study conducted in 2006-7 at the University of Leeds, and commissioned by Carers UK, lead partner in the *Action for Carers and Employment* partnership. The findings reported are based on 1,909 responses to a national survey targeting carers of working age, and 134 face-to-face interviews with carers aged 25-64 living in ten selected localities in England, Wales and Scotland. The report, which also outlines the focus of the other reports available in the CES Series, explores the situation of over 800 carers who were combining paid employment with their unpaid caring role, and 56 carers who were self-employed. It also considers the circumstances and views of 400 carers who had left work to care, 50 carers who were unemployed and actively seeking paid work, and over 500 carers who were looking after their home and family as their full-time role.

Background

Managing Caring and Employment is one of a series of publications arising from the CES study, and should be read in conjunction with the other reports. The CES study was commissioned to strengthen the evidence base available to inform future public policy and service development. It builds on previous research, also commissioned through the *Action for Carers and Employment partnership*, and published separately, which looked mainly at what can be done within the workplace to support carers in combining work and care.

Carers and paid work

The 2001 Census showed there are 4.27 million carers of working age in Great Britain: 66% of them, representing 2.83 million people, are also in paid employment. About half of the carers who responded to the CES survey were in paid work, most caring for 50 or more hours per week. This means that the CES data is a good guide to understanding the situation of Britain's 'heavy end' carers, but tells us less about those who care for fewer than 20 hours a week.

Working carers in the CES survey

- 812 working carers took part in the survey: 654 women and 156 men.
- 93 working carers were interviewed face-to-face.
- 21% of the CES working carers were in poor health.
- 32% of the CES working carers were 'struggling to make ends meet'.

Support for working carers

- About three quarters of working carers in the survey had help from family and friends which assisted them in combining work and care.
- Two thirds of working carers (but only about a half of those working in the private sector) said their employer was supportive and ‘carer-friendly’.
- Only about a quarter of working carers felt they had adequate support from formal services to enable them to combine work and care.

Working carers’ use of services

- Most working carers said they needed at least one type of formal service which they were not currently receiving.
- About a third said the services they were using were free, and 13% said Direct Payments were being used. 42% said they were paying privately for services, while one in ten said no services were being used.
- Very few working carers were getting carer’s breaks, and less than a quarter had access to respite services.
- Many survey respondents provided details of additional services they needed.

Working carers’ views about care services

- Between 40 and 50% of working carers indicated that they felt a lack of flexibility and sensitivity in the delivery of services was hampering them in obtaining support.
- Large minorities of working carers felt they were poorly informed about available services.

Combining work and care: carers’ experiences

- Many carers stressed that they were keen to continue in work, although over a third had considered giving up work to care.
- Almost half of those working part-time said they were only in work of this type because of their caring responsibility.
- Most carers acknowledged that their caring responsibility affected their job.

Carers who are self-employed

- A third of the self-employed carers were struggling to make ends meet.
- Compared with other working carers, they were more likely both to be highly educated or to have no formal qualifications at all.
- Half of this group were caring for someone who was frail or had limited mobility; almost a third were caring for a partner or spouse.

Carers who have left employment to care

- 400 carers in the CES survey were under 65 but said they had given up work to care.
- Compared with working carers, they were more likely to be struggling financially and to be in poor health.
- Most were ‘heavy end’ carers who had been caring for 5 years or longer.
- A significant number were caring for a sick or disabled child, often a son or daughter who had now reached adulthood.
- These carers were more dissatisfied with available services than working carers.
- Despite their relatively intense and long experience of caring, a third still felt that their use of services was limited because they lacked information about what was available.

Carers who want to work

- 50 carers who responded to the survey said they were unemployed and actively seeking work.
- These carers were finding it hard to find jobs that were flexible enough to meet their needs, and felt they lacked support in returning to work; some also felt they had lost confidence.
- Over 40% of the 511 carers who were looking after their home and family full-time said they would rather be in paid work, but could not return to employment because the services available did not make a job possible.
- More than two thirds of carers outside employment said their caring responsibilities had caused them to leave paid work.

Policy Implications

The detailed policy implications of the evidence presented in the report, and a full set of recommendations, are presented in CES Report 6 *Carers, Employment and Services: time for a new social contract?* There we stress the need for radical new thinking, and significant policy change, to enable carers, in their many different circumstances and situations, to integrate their caring roles with their everyday lives, without compromising their health, finances, jobs or careers, emphasising the need to address carers' concerns about the flexibility, sensitivity and availability of support suitable to assist them in combining work and care.

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Introduction

This report is about how services are used by carers of working age to support them in managing caring alongside paid employment, and about the situation and perspectives of those who have given up work to care, or who, as carers, are finding it difficult to enter or return to work. Carers provide regular, unpaid, support or assistance to someone who needs their help because they are ill, disabled or frail. Many carers support a relative, such as an elderly parent, a sick or disabled partner, or a disabled child. But carers are not always related to those they care for, and we have therefore taken carers' own definition of themselves as our starting point. We emphasise that in using the term 'carer' we are not referring to parents who are caring for a dependent child, unless that child also has an illness or disability¹, and that we are not referring to 'care workers' who are paid to provide care in the home. The report includes evidence about the kind of support available to and needed by carers of working age, especially those who are in paid work or who would like to combine paid work with their unpaid care responsibility. It thus considers how carers can be helped to care and to have 'a life outside caring' too, with particular reference to a life which involves continuing in paid work or with a career.

The main focus of this report is on the detailed findings of the *Carers, Employment and Services* (CES) research project, commissioned by Carers UK from a team of researchers at the University

of Leeds as part of the *Action for Carers and Employment* (ACE2) partnership, and funded by the European Social Fund under the *EU EQUAL Community Programme Initiative*. The study was carried out in 2006-7. The CES project collected data from a completely new questionnaire survey of carers in England, Scotland and Wales, obtaining 1,909 responses from carers, accessed through a wide range of employers, through carers' and other voluntary organisations, via agencies responsible for the provision of social care, and using other means². The study also included follow-up personal interviews with a sub-sample of 134 carers who had completed the CES questionnaire. Each of these interviewees lived in one of 10 localities³ selected for detailed investigation. In these localities, we also collected detailed information about the provision of services – both those services specifically designed to support carers, and those used by the people they care for – and interviewed local stakeholders with specialist knowledge and expertise.

Managing Caring and Employment is one of a series of publications arising from the CES study. The full range of study findings is reported in the complete series, listed below. In addition, a set of short, specialised reports relating to Scotland, Wales and the six English localities studied will be available from late 2007 to assist local agencies involved in providing support for carers in their policy development and planning.

No. 1 Stages and Transitions in the Experience of Caring

Becoming a carer – the impact of caring in the first two years, as experienced by carers of working age; the longer term impact of caring on carers' lives when a caring role is sustained over two or more years; carers' views and perspectives as they deal with the different ways in which caring can come to an end.

No. 2 Managing Caring and Employment

Carers who are combining unpaid care with paid work – how they manage and cope and the difficulties which sometimes arise; why some carers have left employment to care, and what this means for them and their families; the perspectives and experiences of carers who want to work but do not have a paid job.

No. 3 Diversity in Caring: towards equality for carers

The many different characteristics of Britain's 4.27 million carers of working age – carers in Britain's ethnic minority communities; caring and its challenges for carers in rural and urban contexts; caring in different financial circumstances, and the problems faced by those who are 'caring in poverty'; carers and how caring affects their health; caring in its various personal contexts – the relationships between carers and those they support, and the different conditions and needs of those they care for.

No. 4 Carers and Services in their local context

Recent developments affecting local service provision for sick and disabled people and their carers; differences in the arrangements made in Scotland, Wales and England under devolved government; carers in 10 local contexts – differences between carers, and in the demand for care support at the local level; local arrangements for supporting working carers; the resources allocated to supporting carers; examples of best practice and innovation in supporting carers.

No. 5 Action for Carers & Employment: Impact of the ACE partnership 2002-7

The objectives, design and outcomes of the ACE projects; the role of research in supporting the ACE strategic aims and summary of the findings of the Carers, Employment and Services (CES) study; the

work undertaken by the ACE partners in England, Scotland and Wales, and their main achievements; the role of transnational activities in ACE, and their significance for future policy-making at European level.

No. 6 Carers, Employment and Services: time for a new social contract?

Main findings from the CES study about carers in England, Scotland and Wales, description of the study methodology; the implications of the findings for the future public policy agenda on working carers; the rationale for developing better support for working carers at local and national levels; key challenges and how they can be tackled; recommendations about policy and practice for service providers, employers, central/local government and the voluntary sector.

The reports in the CES Series contextualise the findings of the CES study in the evidence available from the 2001 Census (which asked a question about unpaid care in 2001 for the first time⁴), and from other official sources. In this report, we focus on carers who are in, or actively seeking, paid work, and on the circumstances of those who told us they had had to give up work to care:

- Carers in employment
- Carers who have left work to care
- Carers who want to work

Carers and employment: background to the study

As pointed out in *Who Cares Wins: the business and social benefits of supporting working carers*⁵, carers in paid employment find themselves in a changing public policy environment, in a labour market undergoing significant change, and in organisations where managerial practices and employers' expectations of their employees are highly variable. That earlier report, which also contained a summary of main themes in the literature on carers and employment⁶ also outlined developments in legislation and policy affecting carers of working age, focusing on what employers, managers and organisations can do to enable carers to combine work and care.

Whereas the earlier research focused on the workplace, the *Carers, Employment and Services*

study has been chiefly concerned with the role of services in supporting carers who want to work. Report 4 in the CES Series, *Carers and Services in their local context*, describes new developments in public policy since the earlier research was published, and highlights the similarities and differences between relevant legislation in England, Wales and Scotland. It shows that carers have been 'moving up the agenda' for policymakers and practitioners in recent years, with working carers successfully brought to public attention, primarily through the efforts of campaigning organisations. The situation of working carers has now been addressed in law (for example through the *Work and Families Act 2006* which extended the right to request flexible working arrangements to most carers in employment from April 2007), with carers also gaining other (limited) rights and entitlements, yet finding that there remain significant omissions and weaknesses in legislation, service provision and collaboration between agencies.

The CES study was commissioned to strengthen the evidence base which could inform future public policy and service development in this area. The present report, No. 2 in the CES Series, presents detailed evidence about carers in employment, and about other carers who would like, or have tried, to combine paid work with their unpaid caring role.

1. Carers in employment

Many carers want to continue in paid work while they give care to a family member or friend who is ill, frail or disabled. Some manage to combine work and care successfully, but many need better support in doing so, and some suffer damaging impacts to their health, relationships, leisure and financial situation. In Section 1 of this report we explore the circumstances, views and experiences of carers who were combining work and care at the time of the study, before considering the evidence about carers who had given up work to care (Section 2) or who were outside paid work, but wanted to return to work (Section 3).

Working carers in the 2001 Census

The 2001 Census, conducted just a few years before the CES study, and the most comprehensive count of carers ever made in the UK (no full census of the population had ever before asked a question about caring), provides an essential benchmark against which we can examine the new evidence in the CES study. A detailed analysis of the 2001 Census data on carers of working age has shown⁷ that:

- Over 1.5m carers work full-time, among them almost 185,000 caring for 50+ hours per week.
- 90% of working carers are aged 30+, in their prime employment years.
- Working carers pay a heavy penalty in terms of their own health, with those with heavy caring

responsibilities two to three times more likely than workers without caring responsibilities to be in poor health.

- Those who care for 20+ hours a week are much less likely to be in higher level jobs.

The numbers of carers in Great Britain who provide 50+ hours of care each week, the group most strongly represented in the CES data, are shown, by economic activity status, in Table 2.1.

The CES study, which included questionnaires completed by 1,909 carers, collected extensive information about carers, their caring roles and the support they get or need to enable them to care. It was designed to add to the knowledge about carers of working age gained through the 2001 Census. It is therefore important to assess how far the CES data are representative of all carers, or of a sub-group of carers. Figures 2.1-2.3 show how far the CES respondents resembled all carers of working age in terms of: their economic activity (Figure 2.1); their age structure (Figure 2.2); and the hours of care they provide (Figure 2.3).

Taking those carers in the CES sample who were aged 16-64 only, we find that our female respondents were rather similar in their patterns of economic activity to all female carers (Figure 2.1), except that those in the CES study were slightly less likely to be in paid work, and slightly more likely to be looking after their home and family full-time. In

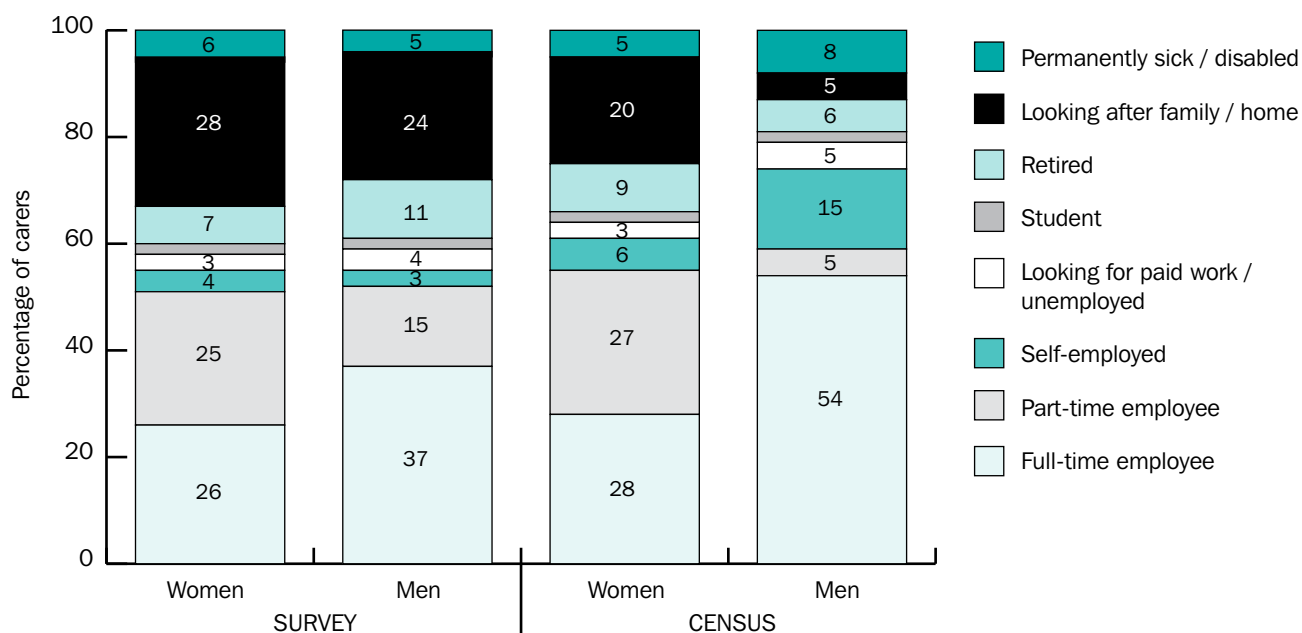
Table 2.1 Men and women with 'heavy' caring responsibilities (50+ hours per week), by economic activity status: Great Britain

Source 2001 Census data supplied by National Statistics and the General Register Office for Scotland © Crown Copyright.

	ALL 16-64/59	MEN 16-64	WOMEN 16-59
ALL	747,685	293,708	453,977
<i>Economically Active</i>	313,022	146,998	166,024
Employee - Part Time	90,329	9,590	80,739
Employee - Full Time	156,779	97,697	59,082
Self Employed - Part Time	12,015	4,800	7,215
Self Employed - Full Time	28,059	20,162	7,897
Unemployed	22,490	13,438	9,052
Full-time student	3,350	1,311	2,039
<i>Economically Inactive</i>	434,663	146,710	287,953
Retired	32,152	21,421	10,731
Student	7,784	2,643	5,141
Looking after home/family	264,366	59,928	204,438
Permanently sick or disabled	98,954	50,985	47,969
Other	31,407	11,733	19,674

Figure 2.1 Economic activity status of carers, by sex: CES survey respondents compared with all carers of working age, Great Britain

Sources: CES Survey, University of Leeds 2007; Office for National Statistics (2006) 2001 United Kingdom Sample of Anonymised Records, Individual Licensed File [computer file] distributed by the Cathie Marsh Centre for Census and Survey Research, University of Manchester, Crown Copyright.



other respects the similarities, for women, are rather more striking than the differences. Where men are concerned, the differences between the CES sample and the census data are more marked. In particular, the CES sample under-represents male carers in full-time employment, and over-represents male carers working part-time, and this should be borne in mind when considering the wider significance of the study findings.

The ages of employed female carers in the CES sample are also very similar to those of women carers found in the 2001 Census (Figure 2.2). Although the CES sample contains very few employed carers aged 16-24, and slightly more aged 60-64, otherwise the differences are rather small. Among employed male carers, the differences are a little more noteworthy, as the CES sample has fewer young (aged 16-24) and older (age 50-64) male working carers, and somewhat over-represents those in the 25-49 age group.

The most important difference between the CES sample of employed carers and employed carers in the 2001 Census is shown in Figure 2.3. Here we

see that the CES sample has many more ‘heavy-end’ carers – those who care for 50 or more hours per week – and also more carers with ‘substantial’ caring responsibilities (20-49 hours per week). In consequence, it ‘under-represents’ those whose caring roles are only ‘moderate’ (1-19 hours per week). One possible reason for this may be that those who care for less than 20 hours per week are less likely to think of themselves as carers, and thus to respond to surveys and research.

This does not mean that we cannot make generalisations from the CES study. On the contrary, the CES sample is large enough to use as a basis for appropriate generalisation, particularly to the situation of working carers who care for 50+ hours per week (especially women). These ‘heavy end’ carers are the most important focus of policy attention, and better data are urgently needed about them; indeed this was a key aim of the research. There are about 300,000 working carers in Great Britain who care for 50+ hours per week (some working full-time, others part-time, and a small number who are self-employed). As we will see in

Figure 2.2 Age of carers in employment, by sex: CES survey respondents compared with all carers of working age

Sources: CES Survey University of Leeds 2007 and Office for National Statistics (2006) 2001 United Kingdom Small Area Microdata Licensed File [computer file] distributed by the Cathie Marsh Centre for Census and Survey Research, University of Manchester, Crown Copyright.

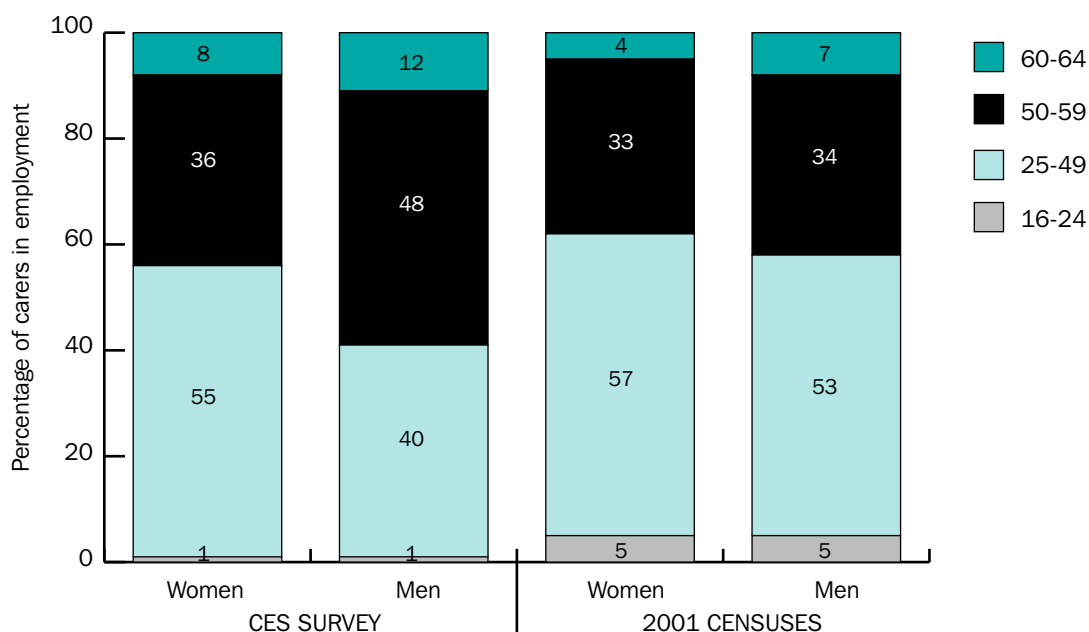
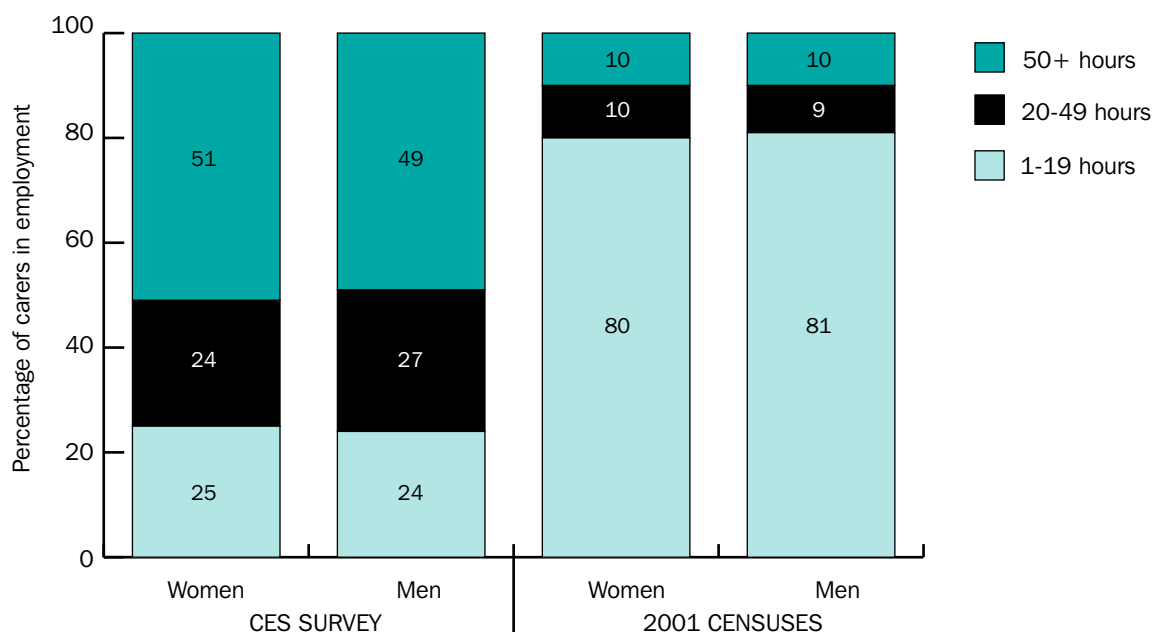


Figure 2.3 Carers in employment, by weekly hours of care and sex: CES survey respondents compared with all carers of working age

Sources: CES Survey University of Leeds 2007 and Office for National Statistics (2006) 2001 United Kingdom Small Area Microdata Licensed File [computer file] distributed by the Cathie Marsh Centre for Census and Survey Research, University of Manchester, Crown Copyright.



this report, at present their needs for information, support and services are by no means adequately met, perhaps because previously their detailed circumstances and situation have not been well known or understood⁸.

Working carers in the CES survey

The CES survey obtained responses from 812 men and women in the 16-64 age group who, as well as being carers, had paid jobs working for an employer: 654 women and 156 men⁹, including 442 people (331 women and 111 men) working full-time. Many were contacted directly through their place of work¹⁰, although others were put in touch with the study through their contacts with voluntary organisations, social and health services and other publicity.

Most of the women in this group of carers were aged over 50 (56%), while the men were on average rather younger (60% of male carers were under 50). The majority of the men cared for a spouse or partner (59% compared with only 26% of the women) and only a quarter of male working carers (23%) looked after a child (including 8% whose sick or disabled

child was aged 20 or older, Figure 2.4). By contrast, far more of the women in the CES sample were looking after a sick or disabled child (43%, including 13% whose child was aged 20 or older), and more of them were looking after a parent (32% compared with only 20% of the men). Related to this, we also found that more than two thirds of the men (68%) were looking after someone in the 25-64 age group, with only one in five (21%) looking after an older person. This compares with a quite different situation among the women, where just 36% were caring for someone aged 25-64, and well over a third (37%) were supporting a person aged 65+.

For reasons discussed in CES Report 6, we think these patterns – of male working carers tending to support mainly wives and partners who are disabled, terminally ill or suffering from a long-term illness, and female working carers tending more often to care for a sick or disabled child or an elderly parent – are likely to apply, in broad terms, to Britain’s wider total population of over 2.8 million working carers.

The detailed characteristics of carers who were in paid employment at the time of the CES survey are

presented in Table 2.2. This shows that most of the working carers in our sample had been caring for 5 years or more (with this tendency most pronounced among those working part-time, especially women), although among those working full-time 12% of the men and 15% of the women were relatively new to caring (less than two years). As we have shown, many had 'heavy' caring responsibilities, caring for 50 or more hours per week (about half of all male working carers, and among the women rather more of those working part-time than full-time).

Women, especially those working part-time, were more likely than men to report that, financially, they found it a 'constant struggle to make ends meet' (33% of women working part-time, compared with 20% of men; and 32% of women working full-time, compared with 30% of men). About a quarter of both men and women working full-time said their health in the past year had not been good, with male part-time workers particularly likely to report that they had health problems. Thus while it might be thought that those combining paid work and unpaid care would be people in good health themselves, this was certainly not always the case.

Support for working carers

Working carers, potentially, have a range of different types of support available to assist them in combining work and care: the support of their families and friends; the support of their managers and work colleagues; the support of employment, and other local agencies responsible for skills, education, and careers; and the support of local services, primarily those provided through the health and social care system. The latter include services which respond to the needs of the cared for person, as well as some services designed and developed specifically to address carers' own needs.

The different kinds of help needed by carers to help them in combining work and care are fully discussed in CES Report No. 6 *Carers, Employers and Services: time for a new social contract?* That report also contains detailed policy recommendations arising from the research evidence presented here and in the other reports in the CES Series, and that discussion there is not repeated here. It is important to note, however, that the support carers often receive from members of their families and from their friends is

Figure 2.4 Employed Carers: relationship to person cared for, by carer's employment status and sex

Source: CES Survey, University of Leeds, 2007.

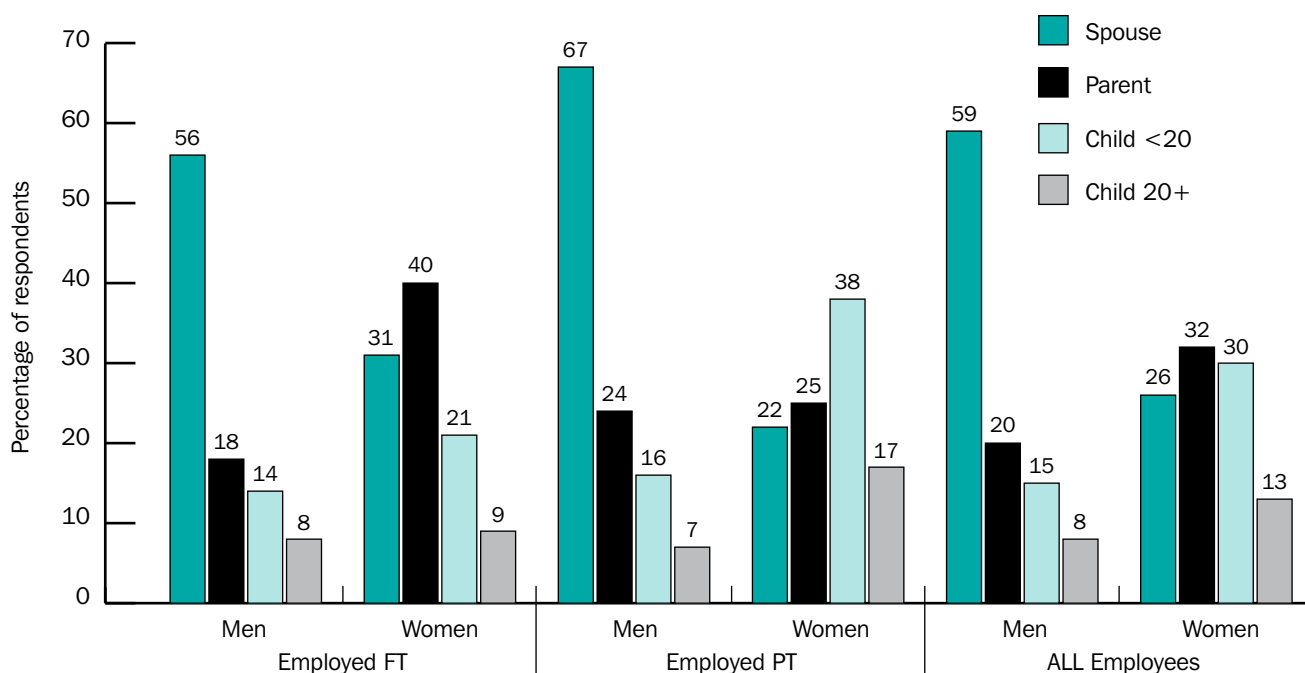


Table 2.2 Characteristics of working carers

Source: CES Survey, University of Leeds, 2007.

	Employed FT		Employed PT		All employees	
	Men	Women	Men	Women	Men	Women
Number =	111	331	45	323	156	654
<i>Age:</i> Under 50 years old	41	57	38	54	40	56
<i>Finances:</i> Constant struggle to make ends meet	30	32	20	33	27	32
<i>Health:</i> Own health 'not good'	24	23	29	19	26	21
<i>Qualifications:</i> None	13	7	13	9	13	8
Degree or higher	40	35	29	29	37	32
<i>Length of time caring:</i> < 2 years	12	15	5	11	10	13
2-5 years	27	24	30	19	28	21
5+ years	61	61	65	70	62	66
<i>Amount of time spent caring:</i> 20+ hours a week	76	68	79	81	77	75
50+ hours a week	51	43	50	58	50	50
<i>Carer's Assessment:</i> Yes	18	16	31	24	22	20
<i>Person cared for:</i> Spouse	56	31	67	22	59	26
Parent	18	40	24	25	20	32
Child <20	14	21	16	38	15	30
Child 20+	8	9	7	17	8	13
<i>Age of person cared for:</i> <20	14	22	16	40	15	31
20-24	3	5	4	8	3	6
25-64	69	42	64	29	68	36
65-84	13	26	20	18	15	22
85+	5	15	7	14	6	15
<i>Condition of person cared for:</i> Physical condition	62	52	67	48	64	50
Learning disability	15	25	16	48	15	36
Sensory impairment	15	18	29	26	19	22
Mental health problem	20	21	29	22	22	22
Frail and/or has limited mobility	37	45	49	39	40	42
Dementia	10	14	9	14	10	14
Long-term illness, terminally ill	41	39	47	28	42	33
<i>Fees:</i> Direct payments used for services	15	11	21	15	16	13
Other (private) fees paid for services	40	43	32	41	38	42
No fee paid, but receives services	34	31	32	39	34	35
No fees paid and no services received	11	15	15	4	12	10

available only to those who have such networks and who can mobilise their support. Many working carers say they rely on this kind of help, as we will see, but not all carers have family and friends who live nearby or who are in a position to help them. Support from their managers and from their colleagues in the workplace is available to many working carers, too. In this study more than half of respondents reported that their employers were 'carer-friendly'. We can also report that the study included some working carers whose experience of combining work and care was enhanced by the high quality, flexible and sensitive local services which were available to support them – although this was a much less common experience. The support of flexible, sensitive and appropriate services really makes a difference to carers – yet many working carers in this study felt there were significant weaknesses in the way local services were designed, delivered and made available, as we will see in the evidence presented.

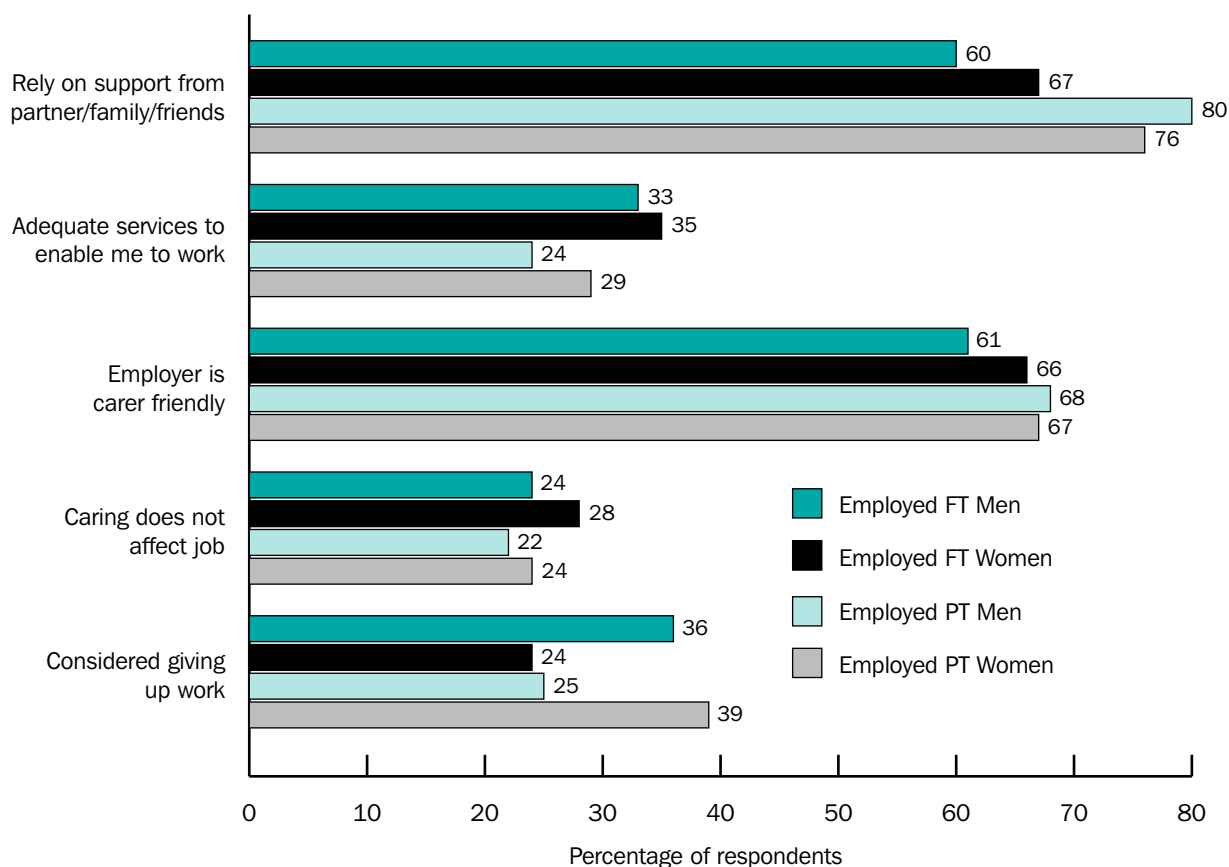
In what follows, we explore our respondents' views and experiences in negotiating and accessing the services they need, a process which usually involves formal assessment of the needs of the cared for person, and, in recent years, since the *Carers and Disabled Children Act 2000* and the *Carers (Equal Opportunities) Act 2004*, sometimes involves assessment of their own needs as a carer too.

As we have seen, working carers provide unpaid care in a wide variety of circumstances, usually supporting their spouse or partner, a parent, or a child. Since caring is, for most, a crucial part of family life, it is not surprising that most working carers (about two thirds of those working full-time, and three quarters of those working part-time) said they were able to rely on the support of family and friends to help them manage their dual work and care responsibilities (Figure 2.5).

Only quite a small percentage of working carers (a quarter or less in all categories) said that their caring role did not affect their job. We examined

Figure 2.5 Employed carers' views about combining work and care

Source: CES Survey, University of Leeds, 2007.



the characteristics of this group (177 working carers) and found that while in some respects they were rather similar to those whose caring role did affect their work (635 carers), there were some differences between the two groups. Overall, those who felt their caring did not affect their work were considerably more likely to care for someone who (in their opinion) did not want to use services (58% compared with 39%). However these carers were also less likely to:

- Be in poor health (16% compared with 23%);
- Be providing 20+ (68% compared with 77%) or 50+ hours of care each week (43% compared with 52%);
- Be co-resident with the cared for person (68% compared with 73%);
- Be caring for someone living in a rural area (19% compared with 23%);
- Be caring for a child aged under 20 (21% compared with 30%);
- Be caring for someone with a learning disability (27% compared with 34%);

- Be struggling financially (27% compared with 32%);
- Be caring for someone using services (53% compared with 63%)
- Want additional services (44% compared with 63%)
- Be unsure about what services are available locally (41% compared with 34%)

Most working carers felt their employer was 'carer-friendly' (about two-thirds agreed with the statement 'My employer is carer-friendly and I feel supported at work when my caring responsibilities affect my job'). As we also found in our interviews (see below), employer support can involve allowing some flexibility about how work is done, and offering entitlements to leave, time off to care and breaks from work, but it could also be primarily about treating employees with consideration, respect and sympathy when problems in the care situation arise.

The survey revealed some interesting, though quite small, differences on a number of the measures we investigated according to the sector in which carers

Figure 2.6 Employed carers working full-time: experiences of combining work and care, by sector of employment

Source: CES Survey, University of Leeds, 2007.

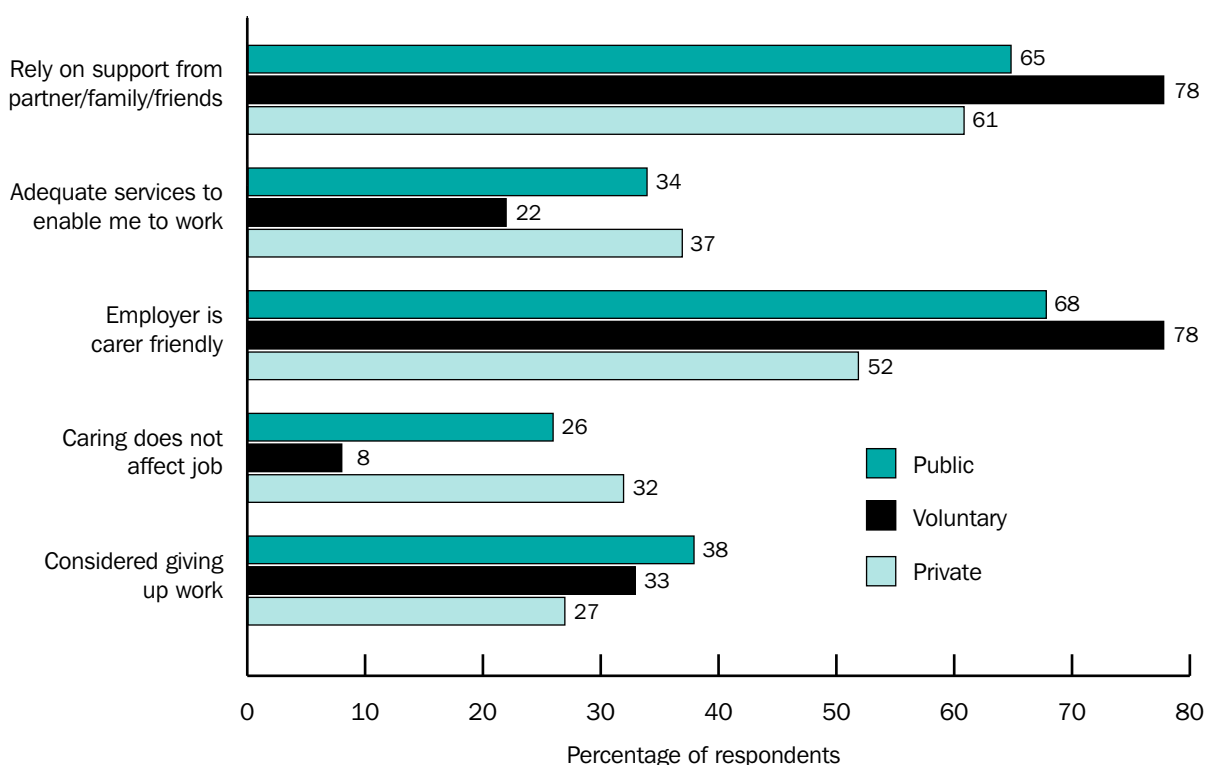
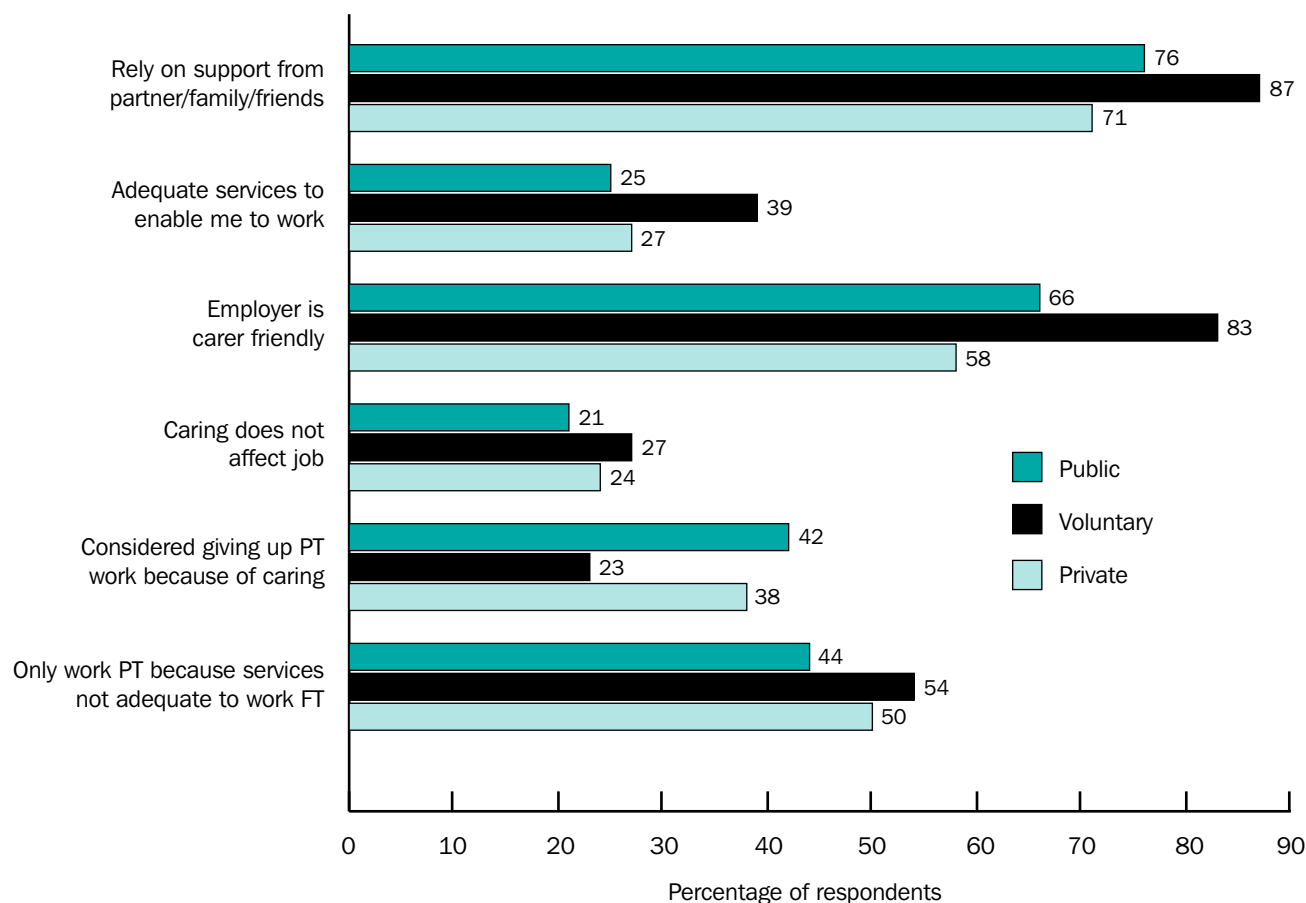


Figure 2.7 Employed carers working part-time: experiences of combining work and care, by sector of employment

Source: CES Survey, University of Leeds, 2007.



worked (Figures 2.6 and 2.7). Carers working in the private sector were the least likely to say that their employer was carer-friendly (52%, compared with 68% of public sector employees) – but even here a (small) majority of carers were positive about support at work. Those working in the voluntary sector, where a striking 78% thought their employer carer-friendly, were perhaps in the best position, tending to have more support from their employers, family and friends, and also having more access to services than other groups. More than half of carers who worked part-time in the private sector (and almost as many in the other sectors) said they only worked part-time because the services available to them were not adequate to enable them to work full-time. And among both full-time and part-time employees, about a third of carers (particularly those working in the public sector) reported that, because of caring, they were thinking of giving up their current job.

Working carers and care services

In terms of the support available to them through local services, those carers who worked part-time were considerably more likely than other employees to have had their own needs as a carer formally assessed. 31% of men and 24% of women working part-time, compared with 18% of men and 16% of women working full-time, had had a Carer's Assessment (Table 2.2). Male working carers, whether in full-time or part-time work, were also slightly more likely than their female counterparts to have in place services arranged through a Direct Payment (15% compared with 11% among full-time workers, and 21% compared with 15% among part-time workers). Over 40% of full-time employees (slightly more women than men) said they used their private resources to fund some of the services they needed, and only a small minority (among part-time female employees only 4%) received no services at all.

Table 2.3 Working carers: services used and wanted: by carer's employment status and sex

Source: CES Survey, University of Leeds, 2007.

	SERVICES USED				SERVICES WANTED			
	FT employees		PT employees		FT employees		PT employees	
	Men	Women	Men	Women	Men	Women	Men	Women
N =	111	333	45	323	111	333	45	323
Home/Domiciliary care	36	28	27	18	22	21	22	17
Day centre	19	15	13	18	23	14	13	11
Specialist nursing	19	12	16	9	11	10	2	6
Mental health services	14	12	22	12	10	6	7	8
Respite	16	13	18	25	25	24	24	22
Carers breaks	5	4	4	9	14	13	13	22
Sitting	8	5	7	10	28	19	27	21
Residential care	5	6	2	5	11	7	2	6
Community transport	11	11	7	10	22	17	18	15
At least one of above	64	56	67	64	65	57	53	60
No services	35	41	36	31	22	28	27	19
Other services	11	14	11	14	20	10	16	14

Thus most working carers reported that they were using services of some kind; more details of these are shown in Table 2.3. Two thirds of part-time employees (both sexes) and two-thirds of male full-time employees said that at least one of the types of service listed was currently being used in their caring situation. (The figures were slightly lower for female full-time employees.) As can be seen, these services could be services to the sick, frail or disabled person they cared for, or services to them in their own right as carers.

Home/domiciliary care, specialist nursing (often palliative care), mental health services, day centres and respite care were the services most commonly used. 36% of male carers working full-time had the support of domiciliary care services; in general, male carers reported greater use of this support (possibly as a result of their greater tendency to provide support for a partner or spouse suffering from illness or disability). Very few carers (4% or 5% in most cases, and 9% among female carers working part-time) had the use of carer's breaks (although many more, between 13% and 22%, depending on

sex and type of employment, wanted this type of service). Very few working carers reported that they were providing care in a situation where there was also use of residential services.

The services working carers did not have, but most wanted (also shown in Table 2.3) were respite and sitting services, domiciliary care and community transport. There was also evident an unmet demand for carer's breaks and for other services. When responding to the survey, over 80 working carers took the trouble to write in details of 'other' services they felt were needed, including:

- More after-school services and holiday schemes/ activities; 16 carers of children and young people wrote in their suggestions about additional services of this type, while 12 others, who already had some access to such services, wanted increased hours or other improvements to existing provision.
- 5 carers identified the need for a day care centre for children with autism.
- 9 carers said they would like befriending services.

- 10 thought it would be helpful to have social events and activities.
- Other requests included better information and advice; counselling services or just 'someone to listen'; relaxation therapy; and a helping hand around the home or in the garden.

In our in-depth interviews with carers, we also obtained information about the type of services working carers wanted but were not currently using. The issue most frequently raised was the need for information to be available in a clear and understandable manner in one place or package, right from the beginning of caring:

I found that if you didn't ask, you didn't get to know, and you didn't always know what to ask. Very much a case of information is power – once you know what to ask, or what you're entitled to (...) But you shouldn't really need to ask, that information should be forthcoming. (...) You've got to get out there and learn it for yourself, because no one's going to tell you.

Female, 35-49 age group, in part-time employment

Information at the beginning of caring was especially important for carers, not only in terms of service provision but also in relation to advice and guidance about the condition of the cared for person. Some carers felt hospitals were so concerned with short term matters that the longer term issues were neglected:

I would say they prepared me at the start for the fact that it was crucial, the next couple of days, what would happen with the clots in the head, you know. But no, I wouldn't say they prepared me well.

Female, 50-59 age group, in full-time employment

Several carers mentioned the need for financial advice and thought more could be done to help them with benefit applications, which they found complicated and bureaucratic:

I think someone needs to sit down and go through that a bit more.

Female, 35-49 age group, in full-time employment

Those carers of school age children who wanted specialist or inclusive after school and holiday clubs and activities often felt frustrated about developments:

Surely they could come up with something? They must have the resources somewhere along the line. If they're paying out all this money for Direct Payments¹¹ and NCH, which get like double the amount of money that direct payments do, surely, why can't you have these clubs? Do you know what I mean?

Female, 35-49 age group, in part-time employment

Other carers with well established, formally agreed, care packages and routines had other concerns. Several wanted greater continuity with the care workers allocated to work with them. They felt this would foster better relationships, build trust and improve the service:

He has one very, very good carer, x, he thinks the world of him and x thinks the world of Dad. But he has every Thursday off, every other weekend off, and he goes on holiday a lot. He goes on holiday for 6 weeks in the summer. Then I have major problems, and I'm talking 3 o'clock in the afternoon and I turn up there one day and all the curtains are closed. Nobody had been there, and Dad doesn't always think to ring me. (...) I said, 'Can we have the same carers come in, he gets familiar with them, they get familiar with him', and she said, 'We can't do that - they become too familiar with their clients'. (...) The last meeting I had they told me they would send the same person on the other days, but it hasn't happened.

Female, 50-59 age group, self-employed part-time

Working carers' views about care services

Working carers in the survey indicated a range of factors which limited their use of services (Figure 2.8). Top of their list here was the fact that services were not flexible enough (over 40%, and in the case of male part-time workers more than half). Many also said that their use of services was limited because what was on offer was not sensitive enough to their specific needs – about a third (here there were few differences between men and women or between full- and part-time employees) said services were too expensive and a similar number said that they did not like the way they were organised.

Part-time workers were more likely than full-timers to say that there were no suitable services in their

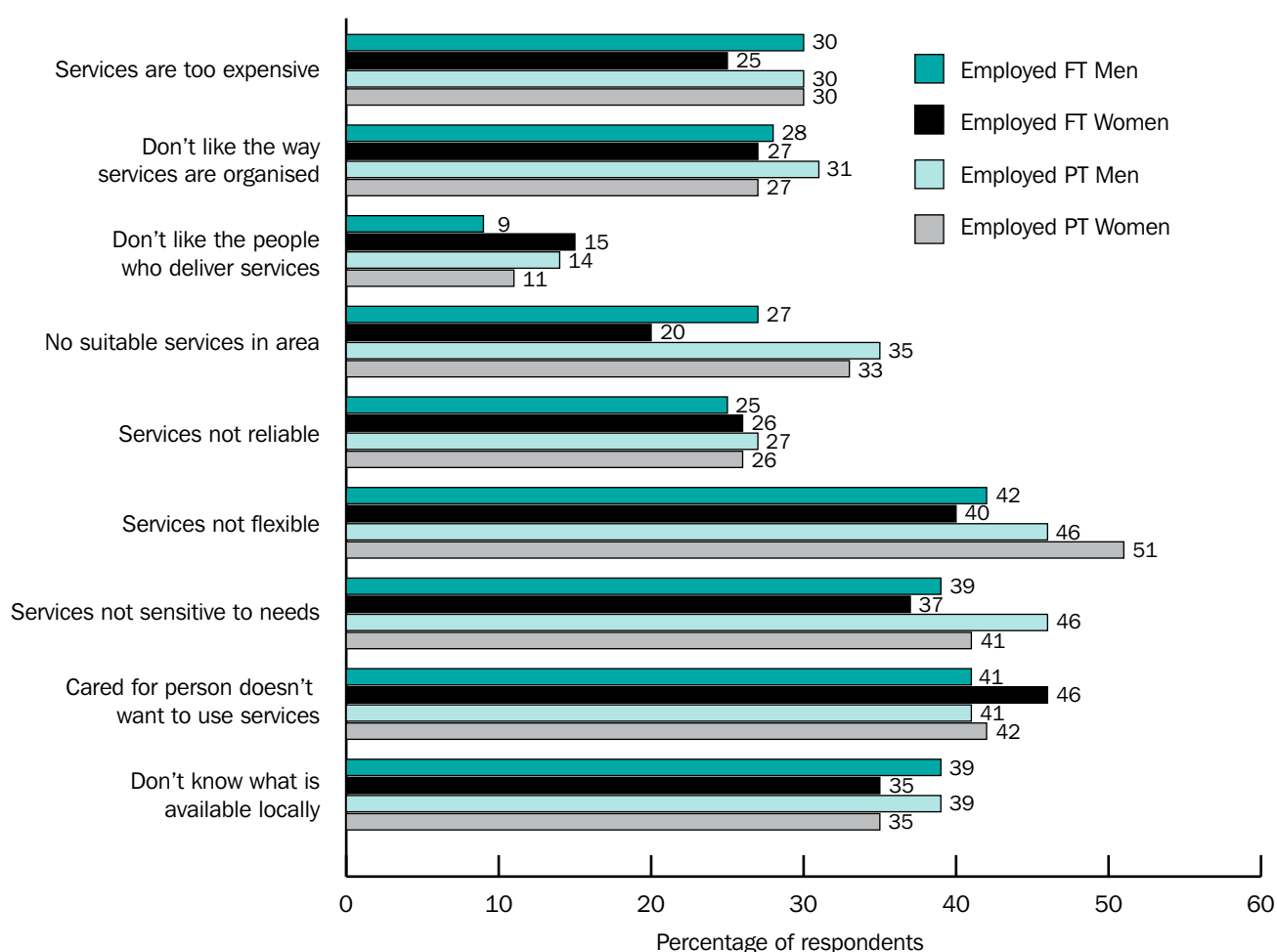
area, and - rather worryingly - well over a third, particularly male carers, felt they were held back in using services because they did not know what was available locally. Over 40% of all working carers said that a further limitation was that the person they cared for did not want to use services. This was an issue for 57% of women carers working full-time, a group in which 40% (as shown in Table 2.2) were caring for a parent. Our qualitative evidence relating to this indicates a range of reasons why people are reluctant to use formal services. Sometimes there is a concern to retain privacy, a reluctance to acknowledge dependency, or a desire to draw the carer to the centre of the caring situation. This is not surprising, given that caring often involves the distress of a loved one, and may involve situations charged with difficult or upsetting emotions. But often, as our material presented

here shows, the available services fall short of what the cared for person, the carer, or both, feel is needed. Reluctance to use services in these situations tends to be about the way services are provided, the lack of control which can be involved in accepting services, and about the timing, frequency, flexibility and responsiveness of what is on offer.¹² Sometimes, although less often (as we will see), it is also about who delivers the service. Some carers noted that those they cared for did not like to have many different people involved in their care, much preferring continuity and the opportunity to build trusting and friendly relationships.

Our detailed evidence makes it clear that most working carers have the support of friends and family in combining work and care, and that most feel quite well supported by their employers. Most do not want to give up work to care, although many

Figure 2.8 Factors limiting carers' use of services, by carer's employment status

Source: CES Survey, University of Leeds, 2007.



are under pressure and are considering reducing their hours or quitting their jobs. Where these carers feel most let down, and see the greatest room for improvement, is in the way services in their local area are designed, delivered, and made available to them. In the next section of the report we consider what a difference services can make – listening to what some carers had to say about the benefits they gain when service provision is suitable and of high quality; and highlighting some of the stress and difficulty they face when they cannot find support, or when support is not appropriate.

Combining work and care: carers' experiences

Our follow-up interviews with a sub-sample of working carers who completed the CES questionnaire shed further light on their experiences in combining work and care. Almost all of the 93 working carers we interviewed¹³ felt under some pressure, although some were coping better than others. It was common for carers to reduce their hours, and some of those in part-time posts were very clear that working part-time was part of their coping strategy. As one carer put it:

I work part-time. I'd rather work full time, but I decided I'd work part time because of Michael's needs.

This carer nevertheless found her approach somewhat undermined by difficulties in keeping to her (reduced) contractual hours. She often worked 'overtime', and felt this was needed to sustain her flexible working arrangement:

Actually they get more work out of me than they pay me for. That's what you've got to do. That's what I feel you've got to do to get the flexible hours you want. Working weekends, working evenings.

Female, 50-59 age group, in part-time employment

The majority (527 out of 810) of the working carers in the CES survey worked in the public sector. When interviewed, carers working in office based public sector positions mentioned that they were often helped to combine work and care by their access to formal flexible working practices, which enabled them to 'bank' time to use later in the week, month or year when they needed it:

Fortunately you're on flexitime so that was a benefit, but since my daughter went into hospital I've just done for her what she wanted me to do, and my employer has been absolutely brilliant.

Male, 35-49, in full time-employment

Other carers aspired to find employment in the public sector. One carer, currently working as an inventory clerk in the private sector, said she was applying for administrative positions in the NHS and local authority, as she recognised that in these organisations more flexible working practices were in place:

You get flexitime if there's medical problems in your family – children, partners, whatever. They're quite considerate. Because I would like to be employed in a normal environment.

Female, 35-49, in part time employment

By contrast some of those working in private sector organisations commented on their difficulty in managing time boundaries at work. A carer who worked as an IT consultant in London explained:

He's an old type boss, you know, he phones me up at half-past-six, so I turn my mobile off now; the pressure's on all the time...He's totally unsympathetic to anything like this...That type of firm, business comes first.

Male, 35-49 age group, in full-time employment

Several interviewees had had unhappy experiences leading to leaving their previous jobs, as one former retail outlet manager explained:

You're asking me about this, so I'll tell you. About 2 years previously I had a breakdown at Company X, and had something like 4 or 5 months off sick and had gone back part-time and then full time. (Later) two or three months after my father died, I was asked how I was feeling. I thought that was not done in a kind way. I thought it was done in a way that was, 'You're not coping emotionally, therefore you're not doing your job properly, therefore you shouldn't be here.' I said a bit, but I didn't pour my heart out, and afterwards I regretted what I did say. I wished I'd said, 'It's none of your business, you don't really care, I'm just here to make money for you'. I was actually told that I would be put on a first stage (of the) disciplinary process. I just felt

very insulted. We had been the top shop, and stuff like that. I'm pretty peeved off with Company X. In retrospect, I think it would have been better if I hadn't gone back after the breakdown.

Female, 50-59 age group, in part-time employment

The highest praise was often given to employers by carers working in the voluntary sector:

I think they're just brilliant in how flexible they are – and there's never an issue if you can't come in. It works both ways, because the people there give 110%.

Female, 35-49 age group, in part-time employment

Those in more senior positions, in both the public and private sector, often said they had been able to take advantage of flexible working conditions too, although this did not usually involve a formal flexitime system. Here it was more common for their performance and contribution to be defined by their output rather than by the hours they put in, and there was often scope for working from home or leaving early on a particular day:

My work were bloody brilliant. It makes sense, because I would have left (otherwise) – and all the work that I had done would have been lost.

Female, 35-49 age group, in full-time employment

Flexibility of this sort could have its downside as well, however. One carer in a senior position working in the private sector noted that while his employer offered him support, he knew he would now be overlooked for promotion in consequence:

I know for instance they are looking for a Sales Director in the near future – but I haven't got any chance of getting it because of the problems I've got at home, because I might need to take time off. The whole thing has a negative effect. Although they're very understanding and that, I know within myself I won't go any further than I am. I'm not happy with it, but I am happy. I'm comfortable.

Male, 50-59 age group, in full-time employment

Some carers had found working in a small business worked better for them. One participant explained how she had come to leave her position as a supervisor, where she felt unsupported in combining work and care, for a more flexible role in a small company:

I was a supervisor there and I wanted to do more flexible working as in finishing half an hour before everybody else to get back so that my evenings wouldn't be so late – because it could take me two hours to get back from Teddington. Obviously I came here first, and I would cook the meals here, or help with the meals, make sure everything's ok – then go home. I was getting home so late so I thought if I could beat the rush by leaving half an hour earlier, (I would) cut my journey time down to about an hour. They, basically, pulled me up one day into a meeting and said it couldn't continue, because I couldn't be a supervisor because I wasn't attending, because I work different hours to what other people did. Although it was (only) a half an hour difference. At that point they gave me another meeting, and went over the same thing again. My partner had already told me, 'just hand your notice in', and I did.

Her new employer, a sole trader, is far more understanding and flexible:

I'm a very lucky person at the moment. This is how understanding my boss is. He turned round to me and said, bearing in mind I've only been there since October, he said 'What would you like to do for yourself?' I said, 'What do you mean?' and he said, 'Well you never do anything for yourself ever. You're always running around after other people'

Female, 35-49 age group, in full-time employment

Some carers who had found part-time work which fitted in with caring stressed that they nevertheless had other ambitions, and hoped in time to find different opportunities. For one carer, part time childminding was currently practical, as she was able to work from home, but she hoped to find work in a more demanding position, and found that working from home left her isolated and depressed:

I can't see any way me moving forward. I'd love to go into nursing or mental health because I've got that interest now, but I can't see how I'm ever going to be able to do the training or anything I want to do anyway because I'm stuck.

Female, 35-49 age group, self-employed part-time

In their comments about the services and support they had in place, working carers were frequently very positive, and extremely aware of the difference

appropriate services made to their lives. Those using day care centres pointed out that these not only give carers time, but also provide peace of mind:

Roland is at Headway today, so I'd normally be out at work, because I know Roland is in a situation that is quite safe....They are valuable to quite a large degree, because they do give me those extra hours in the week.

Female, 35-49 age group, in part-time employment

Those using Direct Payments were strongly in favour of the flexibility these gave them in arranging the kind of support that was right for them. One carer managed her Direct Payment to cover care during school holidays. For her, the flexibility of the Direct Payments system had been pivotal in her return to employment:

It's only in the last year that I've had Direct Payments that's enabled me to have any time to myself at all, because I dread holidays. I'm a prisoner in my own home... It's worked absolutely brilliantly. So well, in fact, that I was able to think about getting a job...I hadn't worked since I had my first child. I could not work at all without Direct Payments. I just wouldn't be able to do it at all. I wouldn't even entertain it.

Female, 35-49 age group, in part-time employment

Another carer commented:

It lets me get on with my work without having to worry. And I know if there's anything at all, they'll phone me. It takes a bit of weight off your shoulders for a few hours a day, so you can go about your normal business.

Female, 35-49 age group, in full-time employment

However, carers in a variety of caring situations also reported that the number and timing of appointments they were required to attend hindered or disrupted their work routines. Some carers experienced this as a conflict between work and care or a barrier to employment, and felt appointments could be arranged to be more sensitive to their needs at work:

I have to take time off. I had one a couple of weeks ago which I took a leave day for. If they're first thing in the morning I probably wouldn't [take annual leave]. I would make the time up [instead].

Female, 35-49 age group, in full-time employment

The support from family and friends on which so many working carers rely is often crucially important in enabling carers to work. One carer explained his understanding of his own situation, in which his mother-in-law provided a good deal of his wife's care, without which he felt he would have to leave work:

Without her mother around I honestly don't know what would be the case. Probably I would need to give up work because I couldn't see any other way of managing the situation. (...) It's not something I relish, a life with caring for my wife – and my goal is to continue working to my retirement. Whether that's feasible and realistic at this stage I just don't know.

Male, 35-49 age group, in full-time employment

Among our interviewees there were a number of carers who, although still managing to combine work and care, had reduced their working hours or downgraded their job in order to carry out both roles. One carer in this group had resigned from her store manager position at a leading retail outlet to work part-time as a check-out assistant at a supermarket:

The fairest thing to say is; I would once have described myself as highly ambitious, and I did achieve some of my ambition in my previous job. I now have no career ambition whatsoever. I work hard for, you know, pay and hopefully something that's fairly congenial, but I never want to have such an all consuming job again. I have plenty to do here (at home).

In downgrading her job role and prioritising providing care for her mother, she also mentioned that she had come to feel closer to her mother:

I suppose – it's quite complicated – but it's part of trying to make things better. She's had quite a hard life, and she was quite a tough mother. My relationship with her now is very good. It's more loving than it's ever been, tremendously affectionate, and it's making things right. (...) I'm happy to do it. I'm really happy to do it. She's said things to me on more than one occasion, particularly when she's been experiencing some pain; 'I don't know what I'd do without you. If it wasn't for you I'd walk into the river...I would find a way of doing something like that'. I have promised her, and I have to keep saying it to her, 'You are

Table 2.4 Characteristics of self-employed carers, compared with other employed carers

Source: CES Survey, University of Leeds, 2007.

	Employed FT	Employed PT	Self-employed	All
Number =	444	368	56	868
Age: >50	47	48	46	47
Sex: Male	25	12	20	19
<i>Finances:</i> Constant struggle to make ends meet	31	31	31	31
<i>Health:</i> Own health in last 12 months 'not good'	23	20	23	22
<i>Qualifications:</i> None	9	10	18	10
Degree or higher	36	29	48	34
<i>Length of time caring:</i> < 2 years	15	10	14	13
2-5 years	25	20	27	23
5+ years	60	70	59	64
<i>Amount of time spent caring:</i> 20+ hours a week	70	81	72	75
50+ hours a week	45	57	50	50
<i>Carer's Assessment:</i> Yes	17	25	33	21
<i>Type of area cared for person lives in:</i> Rural	22	23	31	23
<i>Person cared for:</i> Spouse	37	27	30	33
Parent	34	25	32	30
Child <20	19	36	25	37
Child 20+	9	16	7	12
<i>Age of person cared for:</i> <20	20	37	29	28
20-24	4	8	4	6
25-64	49	34	36	42
65-84	23	18	27	21
85+	13	13	14	13
<i>Condition of person cared for:</i> Physical condition	55	50	39	52
Learning disability	23	44	34	33
Sensory impairment	18	26	20	21
Mental health problem	21	23	30	23
Frail and/or has limited mobility	43	40	48	42
Dementia	13	13	13	13
Long-term illness, terminally ill	39	30	36	35

safe, you are secure, I am your guardian, nothing's going to happen, you won't have to do without me, I'm here, I'm looking after you.'

Female, 50-59 age group, in part-time employment

Carers who are self-employed

Only a small number of carers who responded to the CES survey were self-employed, so we can make only tentative comments about this group of carers as a whole from our data. As can be seen in Table 2.4, this group of carers was in many ways very similar to other working carers in the study. However we can observe that self-employed carers were more likely than other working carers to:

- Have either no qualifications or to be degree educated
- Have had their own situation as a carer assessed
- Be caring for someone living in a rural location

About half of the working carers in this group were looking after someone who was frail or had limited mobility and about a third were supporting someone who was terminally ill or suffering from a long-term illness. 50% of the self-employed carers were providing care for 50 or more hours per week.

In Section I of this report, we have explored different dimensions of working carers' views, situation and experiences. We have seen that combining work and care is possible for some, and that support at work, the existence of family and social support and – most importantly – of adequate, good quality services to assist the person cared for really can make all the difference.

Many working carers' experiences were far from positive, however, and the CES study strongly underscores their need for better services and support. Without this their health, wellbeing and financial security suffers, a situation which can also jeopardise their capacity to care. In the next section of the report we turn to our evidence about a different group of carers – those who have, often reluctantly, given up work to care.

2. Carers who have left employment to care

We now turn to another large and important group within the CES survey respondents, carers who had given up their paid employment in order to provide care¹⁴. There were 400 carers aged under 65 in this category, 48% of them younger than 50, and 85% of them women. Their circumstances are described in Table 2.5.

Characteristics

Compared with those still in employment these carers were more likely to be struggling financially (39% compared with 31%) and were in poorer health (30% compared with 22% in 'not good' health). They were slightly more likely to be male, and much more likely to be poorly qualified. Most were 'heavy end' carers, and three quarters had been caring for 5 years or longer, more than half of them looking after a sick or disabled child, sometimes well into that child's adulthood.

Use of services

The services which they were using, and those they would like to have, are shown in Table 2.6. These carers were comparatively high users of day centres (23%), domiciliary care (28%), respite services (29%), sitting services (14%) and carer's breaks (12%), and most of them (69%) were receiving at least one of the services listed. However they were also a group needing and wanting further support: almost a third were not currently using

sitting or respite services or carer's breaks but said they wanted them, and 60% identified at least one service, not currently received, which they felt they needed or wanted.

Often these carers who had left paid employment to care had experienced a dramatic drop in income, necessitating major changes in lifestyle:

I did find it hard to start with, because I always had money. Money had not been a problem, we've always had money. It was nae bother just to go to the bank and £200, £300, £400, and this and that. But I found it hard to start with.

Male, 35-49 age group, not in paid employment

Others, whose jobs had been lower paid or less secure, believed they were financially better off receiving benefits than they would have been continuing in paid employment. One carer, who had worked as a 'temp', pointed out that on occasions when she could not work, she was not paid:

If I had been able to work all the days that I could without taking time off for appointments and things then I might have been [better off]. But the fact is there was several days, sometimes a week here and there, that I had to take off and I wasn't getting paid for it.

Female, 35-49 age group, not in paid employment

Several male carers looking after their wives had been out of the labour force for a long time. A few

Table 2.5 Characteristics of carers, who had left work to care compared with other carers

Source: CES Survey, University of Leeds, 2007.

	In employment	Left work to care	Other	All
Number =	868	400	379	1647
Age: <50	53	48	50	51
Sex: Male	19	22	15	19
<i>Finances:</i>				
Constant struggle to make ends meet	31	39	44	36
<i>Health:</i> Own health 'not good'	22	30	30	26
<i>Qualifications:</i> None	10	19	35	18
Degree or higher	34	26	19	29
<i>Length of time caring:</i> < 2 years	13	9	11	11
2-5 years	23	17	20	21
5+ years	65	74	70	68
<i>Amount of time spent caring:</i>				
20+ hours a week	75	90	86	81
50+ hours a week	50	72	64	59
<i>Carer's Assessment:</i> Yes	21	38	32	28
<i>Person cared for:</i> Spouse	33	28	29	31
Parent	30	30	26	29
Child <20	27	34	30	29
Child 20+	12	17	15	14
<i>Age of person cared for:</i> <19	28	34	32	30
20-24	6	8	6	6
25-64	42	35	39	39
65-84	21	23	20	21
85+	13	17	13	14
<i>Condition of person cared for:</i>				
Physical condition	52	57	47	52
Learning disability	33	42	38	36
Sensory impairment	21	27	19	22
Mental health problem	23	23	26	24
Frail and/or has limited mobility	42	47	37	42
Dementia	13	12	13	13
Long-term illness, terminally ill	35	34	26	33
<i>Fees:</i> Direct payments	14	13	12	13
Other fees	42	37	38	40
No fee paid but receives services	34	42	40	38
No fees paid and no services received	10	9	10	10

Table 2.6 Services used and wanted, carers who had left work to care, compared with other carers

Source: CES Survey, University of Leeds 2007.

	SERVICES USED				SERVICES WANTED			
	In employment	Left work to care	Other	All	In employment	Left work to care	Other	All
N =	868	400	379	1647	868	400	379	1647
Home/Domiciliary care	26	28	20	25	19	19	10	17
Day centre	16	23	22	19	14	14	10	13
Specialist nursing	12	14	7	11	8	11	7	9
Mental health services	13	12	14	13	7	9	10	8
Respite services	18	29	23	22	23	31	19	24
Carer's breaks	6	12	13	9	17	31	25	22
Sitting services	8	14	8	9	21	29	20	23
Residential care	5	3	3	4	7	8	6	7
Community transport	10	9	12	10	16	16	15	16
At least one of above	61	69	60	63	58	67	57	60
No services	35	30	31	33	24	11	18	19
Other services	13	10	11	12	14	12	10	12

had accepted redundancy at a time which coincided with the start of their partner's serious illness or disability, but others said they had felt forced to quit their jobs even though their employers were supportive:

My gaffer at the time said, 'Right you've been here seven years, we don't want to lose you, is there anyway we can work round this?' I said no...it just wasn't feasible.

Male, 60-64 age group, not in paid employment

Attitudes to services

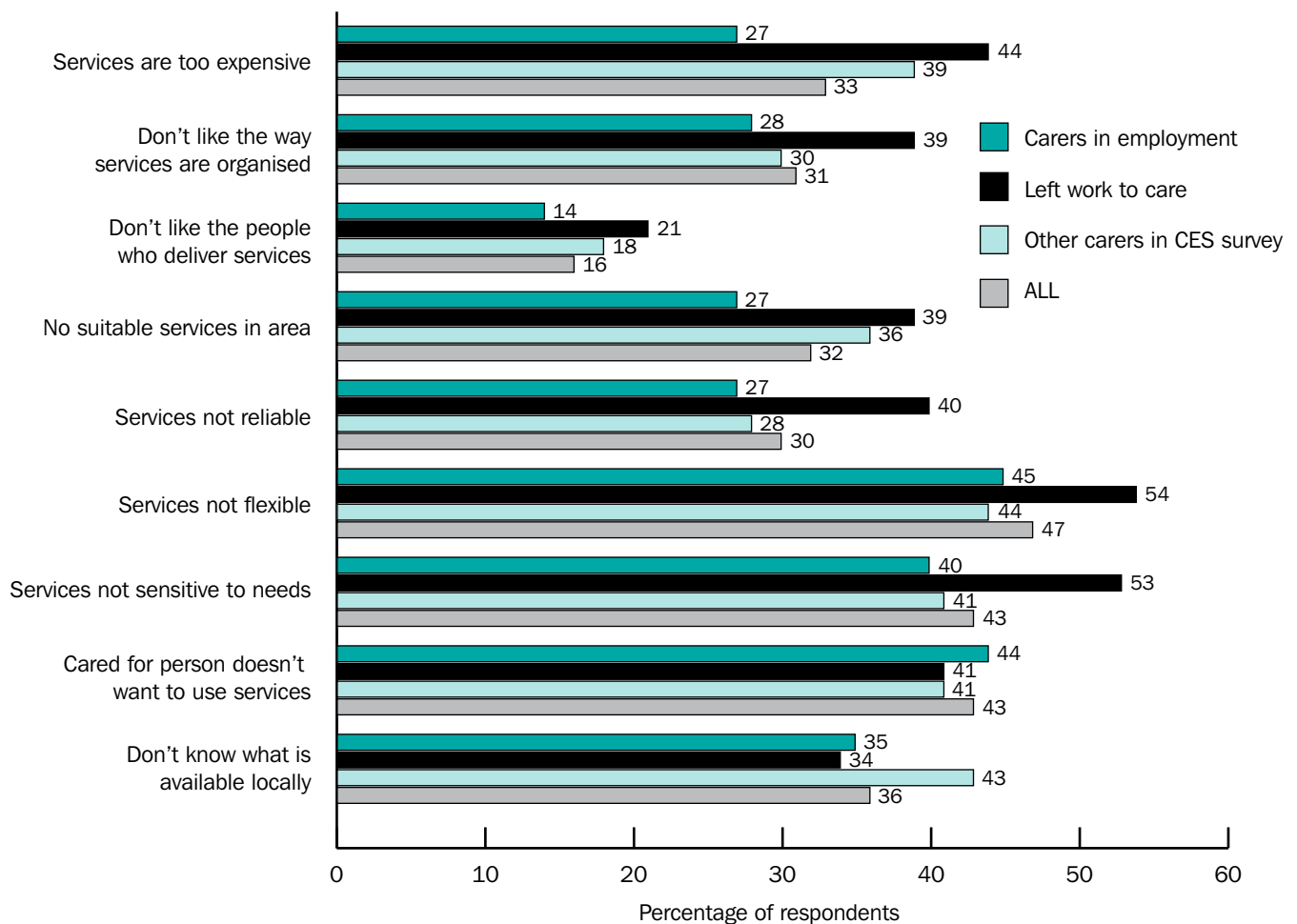
As can be seen in Figure 2.9, these carers were particularly conscious of the factors which limited their use of services to support them in their caring.

More than other carers, they felt services were inflexible (54%), insensitive to their needs (53%), unreliable (40%) and expensive (44%). A significant minority also found it hard to use services, often because they disliked the way they were organised (39%) or those who delivered them (21%). Many felt there were no suitable services in their area (39%). They were a little less likely than other carers to say their use of services was limited by the cared for person's unwillingness to use services (41%) or because they lacked information about local services (34%).

As we have shown, carers who have given up work to care are a disadvantaged and in many ways dissatisfied group. Often caring over long periods, and very intensively, many have sacrificed income,

Figure 2.9 Factors limiting use of services: carers who have left work to care, compared with other carers

Source: CES Survey, University of Leeds, 2007.



career opportunities and sometimes a 'life outside caring' to provide unpaid care. In our interviews with them, these carers rarely complained about their caring, but they often stressed the need for better and more responsive services, and for protection from the health and income penalties, which (as also shown in CES Report 1, *Stages and Transitions in the Experience of Caring*) those involved in longer-term caring so often suffer.

In the final section of the report, which follows, we now turn to the situation of carers outside employment who wish to work.

3. Carers who want to work

In this final section of *Managing Caring and Employment* we consider those carers (a small group of 50 survey respondents) who said they were unemployed and actively seeking work, as well as our evidence from the larger group of carers who were outside work, usually describing themselves as ‘looking after their home and family full-time’, who told us that they would like to return to work if suitable arrangements could be made to make this possible.

Characteristics

Fifty carers (38 women and 12 men) in the CES survey were ‘looking for paid work/unemployed’. In this small group, 33 were currently seeking employment and 11 were planning to start an educational course in the next year. 24 said their caring situation had led to them giving up work. Only 5 said they preferred not to work alongside caring, while 24 said they would rather be in work, but that the services available did not make this possible. 19 felt they had been out of the labour market for so long that they would not be able to get a job without extra help. We show their situation, contrasted with that of carers in employment, and others not working, in Table 2.7.

Attitudes and behaviour

Among the 511 carers who described themselves as looking after their home and family full-time, only 23 reported that they were currently seeking employment.

Despite this, however, 209 said ‘they would rather be in paid work, but services available do not make a job possible’, strongly suggesting that there is significant latent and unmet demand for paid work among this group of carers. As there are well over half a million carers in this situation, over 260,000 of them providing 50 or more hours of care each week, and about 85% of them women¹⁵, this is an important policy issue, with serious gender implications.

One full-time carer explained that he was struggling to look after his father, despite his preference for being in work. He felt that if his father had been able to access a place in the (oversubscribed) local day care centre, this would have eased the pressure on him and enabled him to return to work part time. But without this support, he has recently decided it is in both their interests for his father to move to a care home:

If they had got me day care before now, I wouldn't even consider putting my father in a home. Because the only thing wrong with my father is boredom. He's not got any interaction with adults his own age. (...) I volunteered for it without realising the real implications. I didn't think I'd be brought down so mentally as I have been – to the point where you're bored and depressed. If I had day care, would it have been better for me? Aye. Would it have been better and beneficial for my father? Aye.

Male, 35-49 age group, not in paid employment

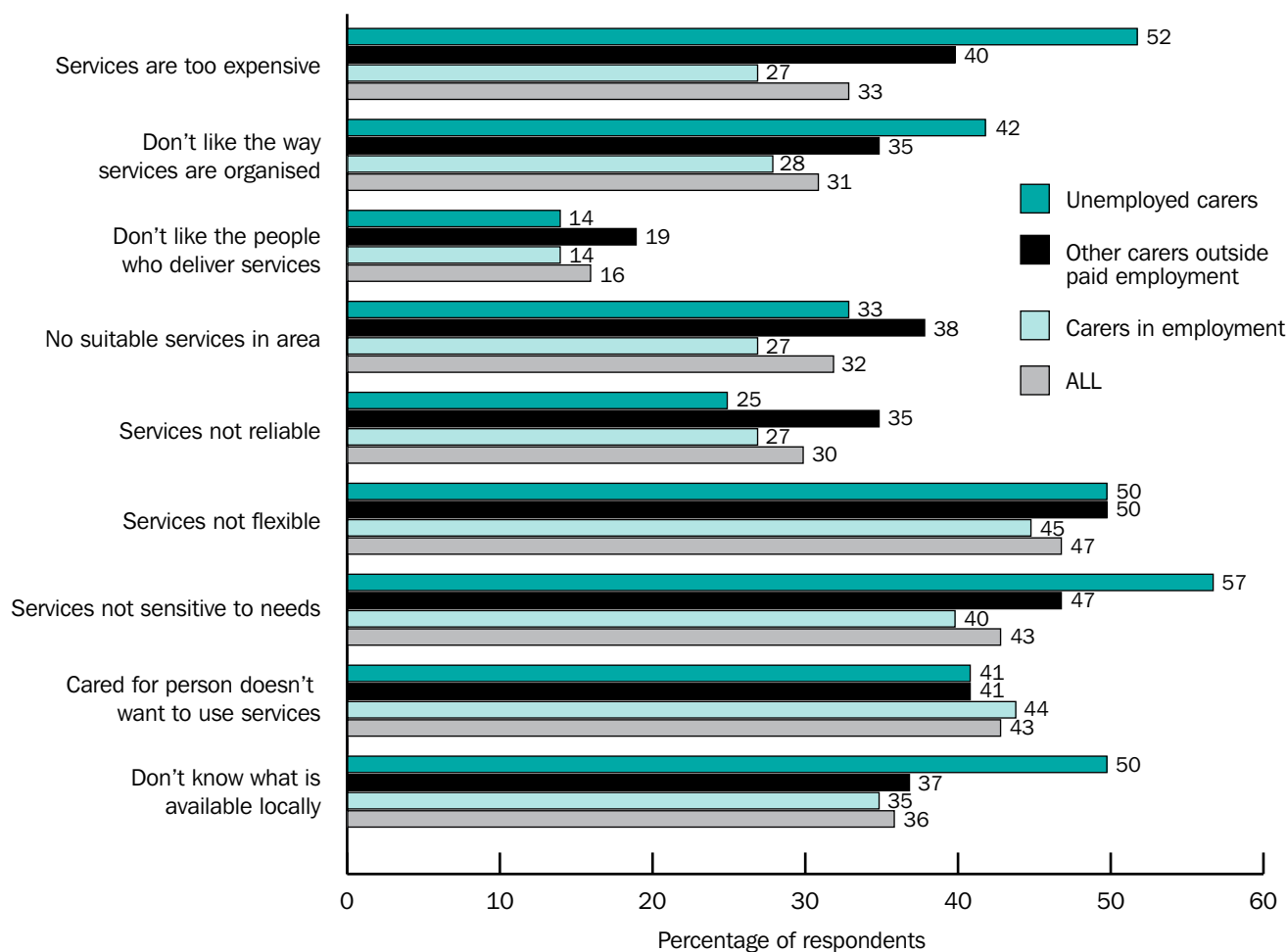
Table 2.7 Characteristics of unemployed carers, compared with employed carers and other carers outside work

Source: CES Survey, University of Leeds, 2007.

	Unemployed carers	Carers in employment	Other carers outside paid work	ALL carers in CES survey
Number =	50	868	701	1619
Age: <50	42	47	50	48
Sex: Male	24	19	18	19
<i>Finances:</i> Constant struggle to make ends meet	53	31	41	36
<i>Health:</i> Own health 'not good'	36	22	29	26
<i>Qualifications:</i> None	36	10	26	18
Degree or higher	18	34	23	29
<i>Length of time caring:</i> < 2 years	16	13	9	11
2-5 years	12	23	19	21
5+ years	72	64	72	68
<i>Amount of time spent caring:</i> 20+ hours a week	87	75	88	81
50+ hours a week	52	50	69	58
<i>Carer's Assessment:</i> Yes	30	21	35	28
<i>Person cared for:</i> Spouse	18	33	29	31
Parent	32	30	28	29
Child <20	34	27	32	29
Child 20+	20	12	16	14
<i>Age of person cared for:</i> <20	36	28	34	31
20-24	8	6	7	6
25-64	32	42	37	39
65-84	28	21	20	21
85+	8	13	15	14
<i>Condition of person cared for:</i> Physical condition	44	52	53	52
Learning disability	44	33	40	36
Sensory impairment	16	21	23	22
Mental health problem	26	23	25	24
Frail and/or has limited mobility	32	42	44	42
Dementia	6	13	12	12
Long-term illness, terminally ill	24	35	32	33
Problems relating to substance abuse/addiction	4	2	1	2

Figure 2.10 Factors limiting use of services: unemployed carers compared with other carers

Source: CES Survey, University of Leeds, 2007.



Views about services

As some pointed out, even those who have day care places often find the opening hours are not geared to working carers:

That's not a good use of resources. There is no reason why they can't have staff there from eight while six. Yes, it costs money because they're paid on an hourly rate, but who are we running the service for? The service that's there...they really have to decide what the service is. Is it a luncheon club that also has sort of a bit more to do? Is it a service for people who are living in their own homes and want to come out to meet people? Or is it a service for carers? At the moment, the day care centre is a service for people who are living in their own home, who maybe couldn't get ready before

half-past-nine and maybe want to be back before it's dark...It's trying to do two things. (...)

...the service as it exists at the moment prevents people from working unless they have extremely flexible employers.

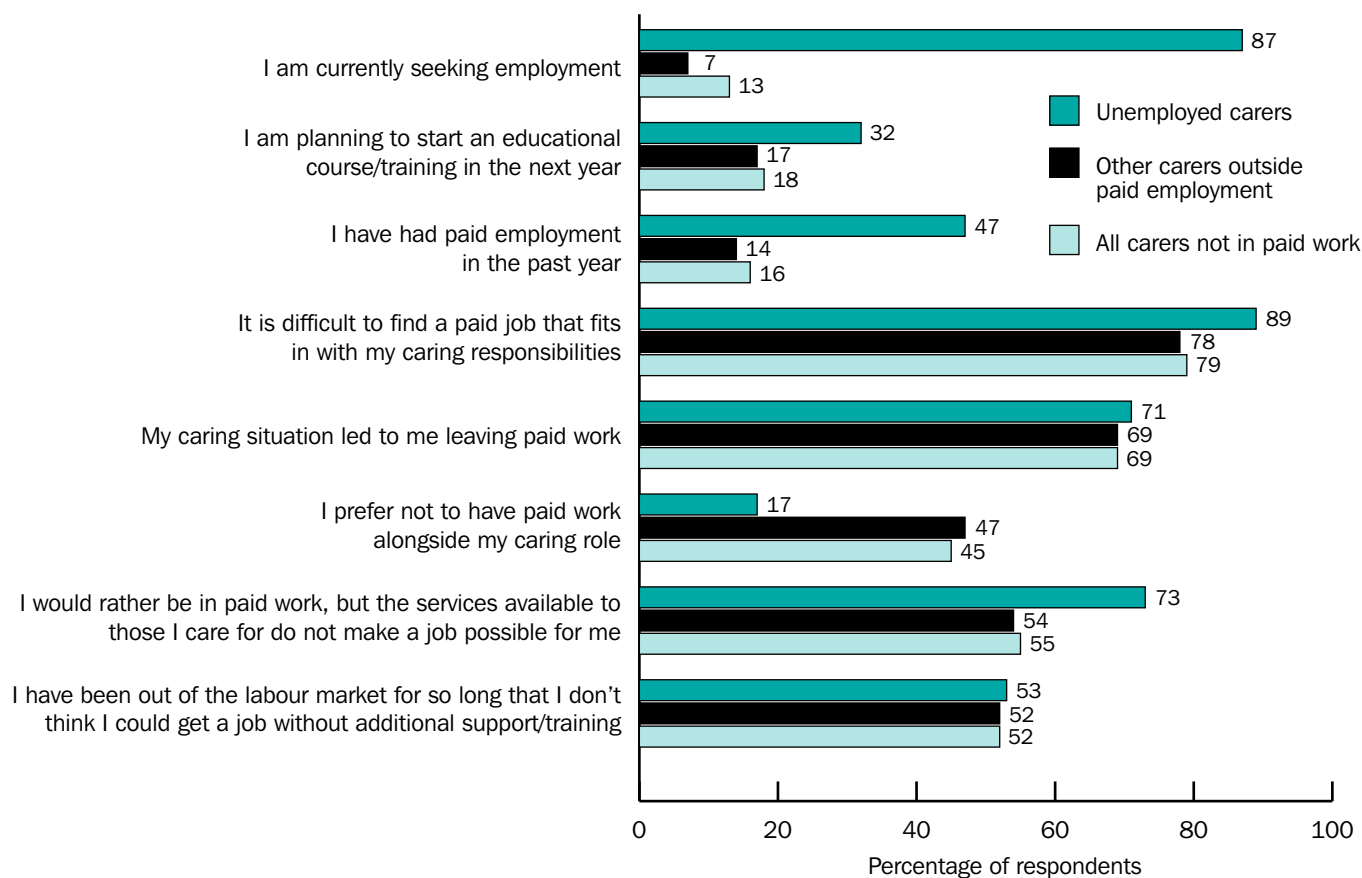
Female, 60-64 age group, in part-time employment

Many carers felt discouraged from going back to work, and were not looking for paid employment primarily because they just could not see how it would be possible. For some, finding appropriate childcare was initially the principal challenge:

I would like to have had support from birth to enable me to go back to work. I gave up work for two years because [my daughter] needed me, but when I wanted to come back to work, I was faced with: we don't provide childcare to let you go back

Figure 2.11 Carers outside employment: attitudes and behaviour relating to paid work

Source: CES Survey, University of Leeds, 2007.



to work. But I've got as much right as anyone else to work. I can't put my child in childcare because my child requires two people most of the time and no childcare service is going to take her, £25 a day, for four times as much work

This carer had now returned to work as a teacher, but this had only been made possible by paying for a nanny privately. Recently she had started to receive support for her child through a Direct Payment calculated to provide 8 hours' worth of care a week. Clearly this did not cover the cost of her existing childcare, but it did enable her to extend the number of hours on the nanny's rota:

It would be nice to know that – because I want to go back to work – that there's some kind of financial support. I think there are an awful lot of mums (with sick or disabled children) who think it's just not financially viable to go back to work, I might as well sponge off the state because I would lose all those benefits and they would take tax off

me every which way. ... The problem is a lack of quality affordable nannies via direct payments.

Female, 35-49 age group, full-time employment

Where the person cared for suffered from a very serious or debilitating condition, the difficulties of returning to work were further exacerbated. One carer in the study had not worked since the birth of her daughter with cerebral palsy, 17 years ago. She is also a single parent and now has some additional caring responsibilities, towards her elderly mother:

It's got harder, as she's got bigger. I think as a baby you care for them anyway, even as toddlers, 5 or 6 years old you're still caring for them in a way. But now she's 17, she's a young woman – and you're still doing personal care which is sometimes degrading for her – and it feels as if it never ends.

Female, 50-59 age group, not in paid employment

Other carers now looking after their homes and families full-time highlighted the fact that their

Table 2.8 Services used and wanted, by carers' employment situation

Source: CES Survey, University of Leeds 2007.

	SERVICES USED				SERVICES WANTED			
	Unemployed	Other not in employment	In employment	All	Unemployed	Other not in employment	In employment	All
N =	50	701	868	1619	50	701	868	1619
Home/Domiciliary care	16	25	26	25	12	15	19	17
Day centre	20	23	16	19	22	11	14	13
Specialist nursing	10	11	12	12	4	10	8	9
Mental health services	12	13	13	13	4	10	7	8
Respite services	24	26	18	22	16	26	23	24
Carer's breaks	12	12	6	9	20	29	17	22
Sitting services	6	12	8	9	14	26	21	23
Residential care	2	3	5	4	4	7	7	7
Community transport	6	11	10	10	10	16	16	16
At least one of above	50	65	61	63	54	64	58	61
No services	38	30	35	33	30	14	24	20
Other services	8	11	13	12	10	11	14	12

caring role increased over time, impacting on their employment¹⁶:

I had to gradually give up (working), the more and more I couldn't leave him. There was a time when you could stay at home on your own, and I was still working for quite sometime.

Female, 50-59 age group, not in paid employment

There were difficulties too when the cared for person did not wish to use services. This could have major implications for the carer's role and time commitment. Looking after his wife with advanced MS one carer stated:

(I recognised that) she needed looking after virtually 24 hours a day, and there was nobody else to do it. The maximum amount of time I can

leave her is 3 hours – after that the alarm bells start ringing, and you get twitchy and you can't concentrate on what you're doing, because you need to be here to look after her.

Male, 60-64 age group, not in paid employment

We have considered in this final section some of the difficulties and problems experienced by carers outside employment, and considered some of the factors, including their limited access to and satisfaction with formal services, which prevent them from combining their caring role with paid work, again emphasising the need for more responsive and sensitive services, tailored to their specific circumstances.

Conclusions

In *Managing Caring and Employment* our main focus has been on carers and paid work. Using evidence from the CES survey, contextualised in our analysis of the 2001 Census, we have shown that while most working carers can rely on the support of friends and family to help them combine work and care, they often find that the services they need – usually for those they care for, but also sometimes for themselves – do not provide the help they require.

Even among working carers, we found worrying numbers of carers in poor health and struggling to make ends meet. Although the majority, and especially those in public and voluntary sector jobs, felt their employers were ‘carer friendly’, weaknesses in services, particularly a lack of flexibility and sensitivity to their specific circumstances, caused frustration and difficulties for many working carers, with only about a quarter feeling they had adequate support from formal services to enable them to combine work and care.

Most working carers felt they needed at least some services which currently they were not getting at all, and only a few were getting carer’s breaks, or had access to respite services. While many were able to describe the additional services they required, they nevertheless felt they were poorly informed about available options, and frequently found their attempts to gain different or additional support were frustrated. Strikingly, almost half of working carers

in the study reported that the lack of flexibility and sensitivity in the delivery of services was hampering them in obtaining support.

In the study, significant numbers of working carers stressed that, although they were keen to continue in work, they had considered giving up work to care – and nearly half those working part-time reported that they had chosen a part-time job only because of their caring responsibility.

We have also seen that, among the many carers who - well in advance of normal retirement age - had given up their paid job in order to care – many were now struggling financially and in poor health. They included large numbers of ‘heavy end’ carers with very demanding, long-term caring responsibilities, often caring for a sick or disabled child who was now an adult. This group of carers was even more dissatisfied with available services than working carers – and despite the length of time they had been caring, a third still felt they lacked information about the support available locally.

We also found that significant numbers of carers outside employment wanted to work – but were unable to get the support and services they needed to make this possible. While some were finding it hard to locate jobs with the flexibility they needed, and some had lost confidence or worried about the relevance of their skills, the main barrier they faced, a problem identified by 40% in this group, was that

the services available were not adequate to make taking a job possible.

The detailed policy implications of the new evidence presented in the report, and a full set of recommendations, are presented in CES Report 6 *Carers, Employment and Services: time for a new social contract?* There we stress the need for radical new thinking, and significant policy change, to enable carers, in their many different circumstances and situations, to integrate their caring roles with their everyday lives, without compromising their health, finances, jobs or careers. As also discussed in CES Report 4, the contemporary 'carers and employment' policy agenda is a very compelling one, thanks to the particular combination of demographic, labour market and technological developments which Britain faces. If in the future working carers are to sustain their caring roles and also make their contributions in the workplace, while avoiding damage to their own health and wellbeing, it will be essential for strong emphasis to be placed on the development of better support and services which take full account of the realities of their working and caring lives.

Appendix 1 Research Methods

The Carers, Employment and Services (CES) study (2006-7) was directed by Prof. Sue Yeandle and based at the University of Leeds. Here we outline the methods used in collecting data for this report (CES Report No. 1). Fully described in CES Report No. 6, they included:

- A national survey of carers (1,909 responses), targeting carers of working age.
- In-depth interviews with carers in ten selected localities in England, Wales and Scotland.
- Interviews with 'key informants' in the selected localities.
- Documentary analysis of publicly available sources and other relevant materials.
- Detailed statistical analysis of the 2001 Census.

The CES Survey

The survey questionnaire was specially designed for the project and tested in a range of pilots. It was distributed to respondents in two formats, a postal (paper) and an electronic version, and collected information about carers' personal/demographic characteristics, their caring responsibilities and the services they were accessing, their employment and financial situation, and their perceptions and attitudes. In the ten selected localities (which targeted both urban and rural carers, White and Ethnic Minority carers; and carers in affluent and deprived areas), the questionnaire was distributed via major employers, carers' organisations and other voluntary groups, social care and health services, and at relevant events such as conferences on carers' issues. The questionnaire was also made available on the websites of a number of relevant national organisations, and some employers distributed it electronically outside the target localities. Our aim was to access carers of working age, with a special focus on those who were in employment, wanting to work alongside their caring role, or had given up work to care. All questionnaire responses were entered in an electronic database and subjected to detailed analysis.

In-depth interviews in the ten localities

Researchers selected 134 interviewees on the basis of information supplied in the questionnaires, attempting to achieve a balance in each area among various caring situations. Contact was made with carers who had given consent to further involvement in the study, and an appointment booked by telephone; interviews took place either in the interviewee's home or at their workplace. For each interview, anonymity was guaranteed and the purpose of the study explained; interviews were tape-recorded with consent. The interview schedule was structured to capture the carer's experience of social and other services in relation to their employment situation, including the strengths and weaknesses of the existing system, their employer's attitude to working carers, and perceptions of ideal services; there was also flexibility for the interviewee to focus on issues specific to their own situation. The interview material was transcribed by the interviewer, using a template which focused on key issues relating to the project. Field-notes were included as well as verbatim quotations to capture interviewees' direct experiences of caring, and the completed templates were then subjected to a thematic analysis.

Notes

- ¹ Many parent/carers of sick or disabled children nevertheless also have one or more dependent children who are unaffected by their own illness or disability.
- ² A full description of the study methodology is available in Report 6. Appendix 1 provides an outline of the main elements of the study relevant to the analysis presented here.
- ³ The 10 localities selected were all areas where a single local authority had responsibility for the provision of social care services, and included: Hertfordshire; West Sussex; Southwark, Leeds, Sheffield, Sandwell, Falkirk, East Ayrshire, Anglesey and Swansea.
- ⁴ The question used in the 2001 Census was: 'Do you look after or give any help or support to family members, friends or neighbours or others because of: long-term physical or mental ill-health or disability or problems related to old age?'
- ⁵ Yeandle, S, Bennett, C, Buckner, L, Suokas, A and Shipton, L (2006) *Who Cares Wins: the social and business benefits of supporting employed carers* London: Carers UK.
- ⁶ The literature discussed in the 2006 report also relates primarily to Great Britain and is referenced in that report. For other contributions, see also: Arksey, H, Kemp, P, Glendinning, C, Kotchetkova, I and Tozer, R (2005) *Carers' aspirations and decisions around work and retirement* Leeds: Department for Work and Pensions Research Report No. 290 (pages 13-38 provide a review of existing evidence up to 2005); Arksey, H and Kemp, P (2006) 'Carers and Employment in a Work-focused Welfare State' in Glendinning, C and Kemp, P (eds.) (2006) *Cash and Care: policy challenges in the welfare state* Bristol, Policy Press; Bernard, M and Phillips, J E (2007) 'Working Carers of Older Adults: what helps and what hinders in juggling work and care?' *Community, Work and Family* Vol. 10 No. 2 pp 139-160; Davey, J. and Keeling, S. (2004) *Combining Work and Eldercare: A study of employees in two city councils who provide informal care for older people*. New Zealand Institute for Research on Ageing, Victoria University of Wellington; Glendinning, C (2004) *Support for Carers of Older People - Some International and National Comparisons: A review of literature prepared for the Audit Commission*, London, Audit Commission; Martin-Matthews, A (2004) 'Aging and families: Ties over time and across generations', in Mandell, N and Duffy, A (eds), *Canadian Families: Diversity, Conflict and Change*, 3rd edition. Toronto: Nelson Canada; Smith, P et al, (2006) *Carers of the Terminally Ill and Employment Issues: a comprehensive literature review*, Palliative and End-of-Life Research Group, Sheffield: University of Sheffield; Watson, J (2005) *Whose Rights are they anyway? Carers and the Human Rights Act*, London: Carers UK and Calouste Gulbenkian Foundation.
- ⁷ Buckner, L and Yeandle, S (2006) *Who Cares Wins: the business and social benefits of supporting working carers: statistical appendix* London: Carers UK.
- ⁸ Maher, J and Green, H. (2002) *Carers 2000* London: The Stationery Office, reports analysis of the General Household Survey, which collected information about carers at 5-year intervals between 1985 and 2000. Although this explored the situation of carers in some detail, it did not particularly highlight the evidence about working carers, or explore the relationships between carers' own employment circumstances and the cared for person's access to services. Arksey et al (2005) op. cit. also explored caring and employment; their analysis drew on a smaller qualitative sample of 43 carers in paid employment (37 women and 6 men).
- ⁹ 2 respondents did not answer this question.
- ¹⁰ Among other approaches, we gained access to our sample by distributing questionnaires by email to carers working for major employers in ten target localities in England, Wales and Scotland.

- ¹¹ Direct Payments are arrangements in which care users and carers receive an allocation of cash rather than directly provided services, enabling them to purchase the care or other services they require. The origins and development of Direct Payments are discussed in Yeandle, S and Stiell, B (2007) 'Issues in the development of the Direct Payments scheme for older people in England' in Ungerson, C and Yeandle, S (eds.) *Cash for Care in Developed Welfare States* London: Palgrave Macmillan.
- ¹² There is a useful discussion about this in relation to domiciliary care services for older people in Martin-Matthews, A (2007) 'Situating 'Home' at the Nexus of the Public and Private Spheres', *Current Sociology*, Vol. 55(2):229-249, Los Angeles: Sage.
- ¹³ The 93 working carers interviewed face-to-face included 42 working part-time and 51 working full-time.
- ¹⁴ These carers told us that "*my caring situation led to me leaving paid work*".
- ¹⁵ Buckner and Yeandle (2006), op. cit.
- ¹⁶ This issue is discussed in more detail in CES Report 1, *Stages and Transitions in the Experience of Caring*.

Finding out more

Carers UK improves carers' lives through information provision, research and campaigning. This research was commissioned by Carers UK on behalf of the ACE National partnership, and part-funded under the European Social Fund's EQUAL Community Initiative Programme. To find out more about Carers UK, contact:

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Designed and printed by: Rap Spiderweb
Copyright: University of Leeds
Publication Code: EWS4027
Published: October 2007
ISBN number: 1-873747-38-1