



# Diversity in Caring: towards equality for carers

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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.**

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# Diversity in Caring: towards equality for carers

**Report No. 3 highlights new evidence about carers in all their diversity and about how different groups of carers experience their caring situation, especially in relation to their ability to combine caring with paid employment.**

The CES study includes responses from ethnic minority carers, and extensive data about carers supporting someone living in a rural area, carers in difficult financial circumstances, and carers in poor health. This report illustrates the situation of these groups of carers with data from our qualitative interviews to explore how far carers with these characteristics have distinct needs or experiences, and explores how far these carers have needs which differentiate them from other carers.



# Executive Summary

This report, *Diversity in Caring: towards equality for carers*, arises from the **Carers, Employment and Services** (CES) study conducted in 2006-7 at the University of Leeds, 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 five issues related to caring: carers and ethnicity, caring in rural and urban areas, carers in different financial circumstances, how caring affects carers' health, and caring in its various personal contexts.

## Background

*Diversity in Caring: towards equality for carers*, 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 ethnicity*

- The 2001 Census showed that caring is more prevalent among people of working age in some ethnic minority groups, especially younger Indian, Pakistani and Bangladeshi men and women.
- 204 ethnic minority carers, 130 from non-White groups, responded to the CES survey.
- Non-White carers in the CES study were more likely than White British carers to be 'struggling' financially.
- Ethnic minority carers were especially likely to be caring for a sick or disabled child or for someone with a mental health problem.
- Proportionately more ethnic minority carers were caring in circumstances where Direct Payments were being used to arrange services.
- Ethnic minority carers were especially likely to say they felt restricted in using services because they lacked information, or because services were too expensive, lacked flexibility, or were not suitable for their individual needs.

- Our interviews with ethnic minority carers raised some issues about the skills of paid care workers, especially where service users spoke languages other than English, and about culturally appropriate provision. In general, however, common issues were more important than differences.

### *Caring in rural and urban areas*

- 424 carers in the CES survey provided care for someone living in a rural area. Urban and rural carers in the study cared for very similar kinds of people, and there were (perhaps surprisingly) few differences between the experiences and circumstances of urban and rural carers.
- Rural carers are very slightly more likely than urban carers to mention a lack of suitable services in their area, to say they do not know what is available locally, or to be held back in using services because they are too expensive.
- Rural carers are a little less likely than urban carers to say services are not sensitive to their needs, or to raise issues of flexibility, reliability or service organisation / delivery.
- Particular issues raised by rural carers in detailed personal interviews included: travelling to and from services, which was time-consuming and costly; difficulty in finding appropriate services; and limited choice about services.
- Carers who provided care for someone living at least half an hour's travelling distance away (a separate, small, group of carers) were better qualified, more likely to be in full-time employment, and relatively 'new' to caring, compared with other carers. Their caring responsibilities also tended to be lighter in terms of hours of care per week.

### *Caring in different financial circumstances*

- Among those of working age, 36% of carers responding to the CES survey were 'struggling to make ends meet'. 38% said they were 'managing on the money coming in', while 26% were 'reasonably comfortable financially'.
- Carers who were struggling financially were more likely to be: in poor health themselves (34%); unqualified (21%); caring for 20+ hours per week (88%).
- They were also more likely to be caring for a child under 19 (37%), someone with a learning disability (42%) or someone with a mental health problem (27%).
- 40-50% of carers in the unemployed, sick or disabled and 'looking after home and family full-time' categories were struggling financially, compared with just under a third of carers in full or part-time work.
- 61% of carers wanted at least one service which was not currently received: this figure varied only very slightly with financial circumstances.
- Carers in financial difficulties were a little more likely than other carers to lack information about service provision, or to say that the person cared for did not want to use services.
- Better off carers were slightly more likely than other carers to say their use of services was restricted by cost, or by their perception that services were not sufficiently reliable, flexible or sensitive to individual needs.
- Overall, when carers were compared according to their financial situation, the similarities in their views about services were more striking than the differences; in detailed interviews, however, poorer carers particularly noted worries and concerns about managing their day-to-day situation.

### *Caring and how caring affects carers' health*

- 484 carers in the CES survey reported poor health.
- An association between hours of weekly care provided and carers' poor health was confirmed in the 2001 Census.

- The CES survey reveals, additionally, a link between the length of time carers have spent caring and carers' poor health.
- Among carers in employment, men were slightly more likely to report poor health than women. Unemployed carers were especially likely to report poor health.
- Carers in poor health were considerably more dissatisfied than other carers with the services available.
- Our interview data indicate that carers' frustrations in accessing services, and the limited support they receive, contribute to their poor health.
- Carers in poor health, whether in paid work or not, are more likely to be struggling financially than other carers.

### **Caring in its various personal contexts**

In a final section, the report highlights examples of carers who are caring in a range of different circumstances, for people with different needs and conditions. This material highlights the varied situations carers face, according to the needs of those they care for, their particular stage in their caring journey, and the support they receive, both in their place of work and from local services.

### **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 carers of working age in a variety of different circumstances and caring situations, and their experiences of the support and services they need to combine their (unpaid) caring role with paid employment. 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 disability<sup>1</sup>, 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 Initiative Programme*. 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 means<sup>2</sup>. 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 localities<sup>3</sup> selected for detailed investigation, where we also collected detailed information about the provision of services.

This report, *'Diversity in Caring: towards equality for carers'*, is one of a series of publications arising from the CES study. It presents new evidence about carers, diversity and equality, and about how different groups of carers experience their caring situation, especially in relation to their ability to combine caring with paid employment. The CES study included 218 responses from ethnic minority carers, data about 424 carers supporting someone living in a rural area, information from 612 carers in difficult financial circumstances, and from 484 carers in poor health. This report illustrates the situation of these groups of carers with additional data from our qualitative interviews, and explores

how far carers with these characteristics have distinct needs or experiences. The full range of study findings is reported in the complete series (see below). There is also a set of short, specialised reports relating to Scotland, Wales and the six English localities studied, 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 different characteristics of Britain's 4 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 different 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? Report summary and recommendations**

*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 time<sup>4</sup>), and from other official sources. In this report, we focus on equality and diversity in carers' lives, paying particular attention to the following carers and caring situations:

- Caring and ethnicity
- Caring in rural and urban contexts
- Carers in different financial circumstances
- Carers and how caring affects carers' health
- Caring in its various personal contexts

The 2001 Census showed that carers include both men (38% of all carers) and women (62%), and that they are mostly people of working age (81% are aged 16-64). Among those of working age, 72% of male carers are in paid work, 77% are economically active and 6% have retired early (before age 64).

Among women who are carers, 62% are in paid work, 66% are economically active, and 3% have retired early. Combining paid work with caring is thus an important part of most carers' lives. The CES survey, which included 1,909 respondents who identified themselves as carers, enables us to go beyond the important new evidence revealed by the question on carers in the 2001 Census. In this report we use the CES data to focus on a number of sub-groups within the total population of carers, and to explore to what extent their experience of being a carer is mediated by their ethnicity, by where the person cared for lives, by their financial situation, by their health, by their relationship to the person they care for, and by the condition or circumstances of the cared for person. Some of these characteristics (for example poor health and poverty) are associated with being a carer, and may arise, at least in part, from their caring commitment. In what follows we discuss this relationship. We also use the data in our CES in-depth follow-up interviews with 134 carers to gain a more detailed and contextualised picture of how carers in many different situations experience combining work and care.



# 1. Caring and Ethnicity

## Evidence from the 2001 Census

As shown in Table 3.1, caring occurs among men and women of working age in all ethnic groups, but is a more common experience for people in some ethnic groups than in others. This variation is related to differences in the health, socio-economic circumstances, family/cultural preferences and age structure of each population group. Among men of working age, those of South Asian origin are the most likely (and those in the Chinese/ White Other groups the least likely) to be carers. Young men (aged 16-30) from the Bangladeshi and Pakistani communities in Britain are two and a half times more likely to be carers than young White British men. Among young women we also find that those of South Asian origin are by far the most likely to be carers – although this difference is less marked in the 30-59 age group among women, where rates of caring are similar (16-19%) among all the groups shown (except Black African, Chinese and White Other women).

Other researchers<sup>5</sup> who have studied the relationship between health, poverty and ethnicity have noted that, when affected by poor health and financial difficulty, people in ethnic minority communities sometimes face particular difficulties: concealing their ill health, experiencing lower levels of employability, being held back by reduced opportunities for social participation, and lacking the support they need (such as appropriate care workers who can speak their native language) or being hampered by limited ‘coping skills’. Others<sup>6</sup> have

drawn attention to inappropriate assumptions about carers in ethnic minority groups preferring to ‘look after their own’.

We turn now to detailed consideration of the responses received from ethnic minority carers in the CES study, contrasting them where possible with those of carers in the White British group. The categories used were selected to parallel those employed in the 2001 Census.

## The attitudes and circumstances of ethnic minority carers

Table 3.2 describes the sample of CES carers according to a range of measures associated with their caring situation, distinguishing between the main group within the CES sample (White British carers) and two other groups, those 74 carers who described themselves as either ‘White Irish’ or ‘White Other<sup>7</sup>’, and the 130 carers who identified their ethnicity as in one of the other (non-White) categories<sup>8</sup>.

From Table 3.2 we can note that, compared with White British carers in the sample:

- White Irish/White Other carers were more likely, and all other ethnic groups less likely, to be combining their caring with part-time employment.
- Those in the non-White ethnic groups were considerably more likely to report that it was ‘a constant struggle to make ends meet’.
- Those in the White Irish/White Other group were more likely to be qualified to degree level.

- Those in the White Irish/White Other group had been carers for longer.
- A higher percentage of carers in the other (non-White) groups provided 20 or more hours of care each week – but fewer were at the very ‘heavy’ end of the carer spectrum, providing 50+ hours of care weekly.

Carers in both the other groups (i.e. all who were not White British) were:

- More likely to be caring for a sick or disabled child, especially for a child aged 20-24.
- Less likely to be caring for a parent or for a person aged 85+ (especially the non-White group).
- More likely to be caring for someone with a mental health problem.
- More likely to be using a Direct Payment arrangement to pay for services.

### Carers, ethnicity and use of services

There were also some differences between these three groups in their answers to the question, ‘Is your/their use of services limited by any of the following factors?’ These are shown in Figure 3.1. Once again, compared with the White British carers who responded to the survey, carers in both the

other groups were more likely to say their use of services was limited because:

- Services are too expensive.
- Services are not flexible enough.
- Services are not sensitive enough to my/their needs.
- I/they don’t know what is available locally.

Compared with both groups of White carers, however, those in the non-White group were considerably less likely to say that ‘the person I care for does not want to use services’, and only quite a small minority (15-16%) of carers in all three groups said that the use of services was limited, in their own particular situation, because they or the person they cared for ‘did not like the people who deliver services’.

The CES survey also collected data about the different types of services used by carers and those they care for, and about the types of services (in addition to those they were currently using) which they would like to have available. Carers’ responses to these questions are shown in Table 3.3. We can see that:

- White Irish/White Other carers made more use of mental health services, but less use of specialist/nursing services, than other carers.

**Table 3.1 Carers by sex and ethnicity (selected groups): England and Wales**

Source: 2001 Census SARS, Crown Copyright 2004. This work is based on the SARS provided through the Centre for Census and Survey Research of the University of Manchester with the support of ESRC and JISC. Note: The 2001 Census used different ethnicity categories in Scotland, so the data here is for England and Wales only.

	% of working age MEN who are carers by age			% of working age WOMEN who are carers by age		
	16-29	30-64	16-64	16-29	30-59	16-59
All people	4	13	10	6	18	14
White British	4	13	11	6	18	15
White Irish	5	11	9	4	16	13
White Other	3	8	6	4	11	8
Indian	8	15	12	10	16	14
Pakistani	10	13	12	13	19	16
Bangladeshi	10	12	12	13	17	16
Black Caribbean	5	9	8	7	13	11
Black African	5	7	7	5	10	8
Chinese	4	6	6	4	9	7

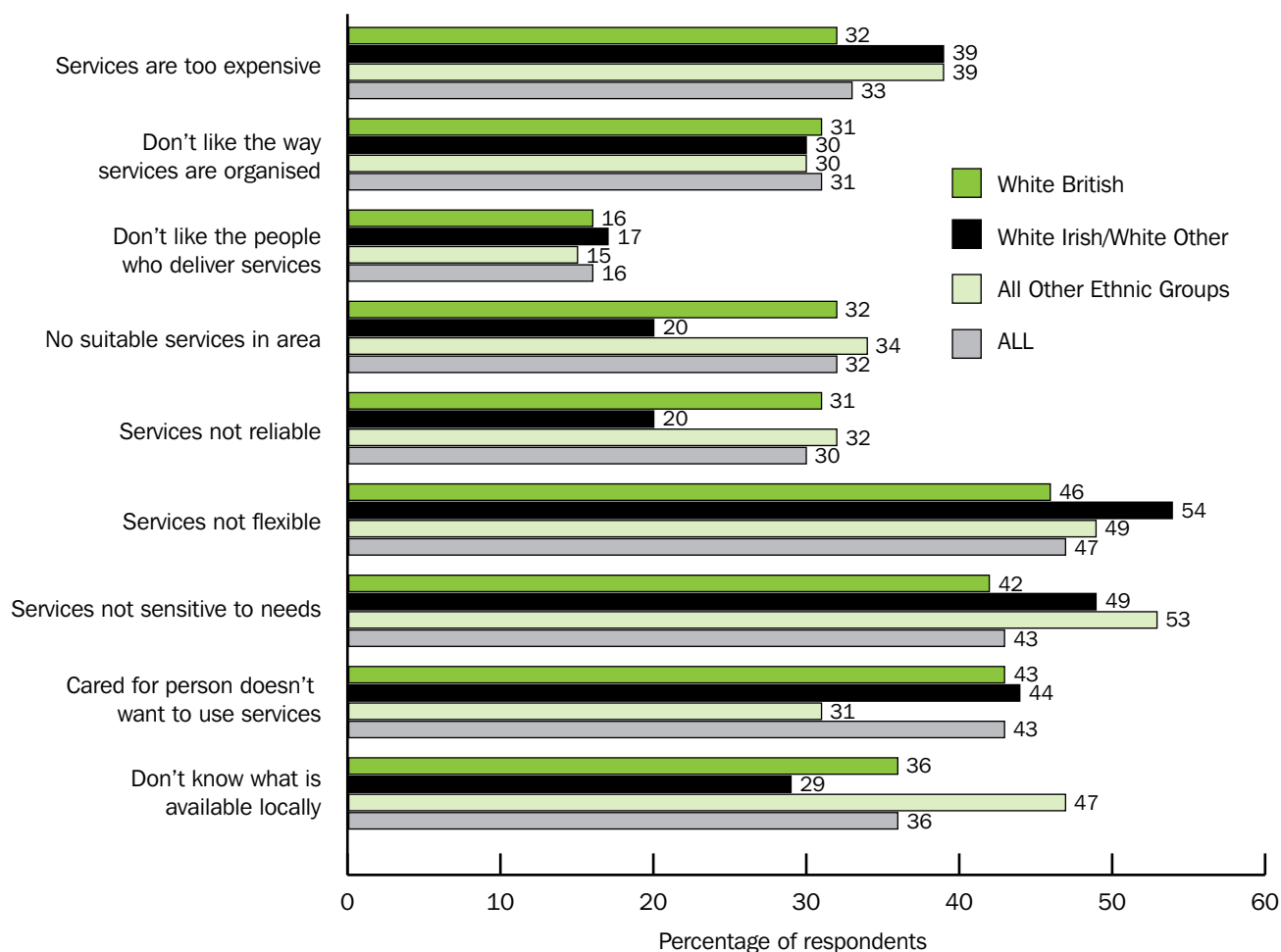
**Table 3.2 Characteristics of carers aged 16-64, by ethnic group**

Source: CES Survey, University of Leeds, 2007.

	White British	White Irish/ White Other	All other ethnic groups	ALL
<b>Number of CES survey respondents</b>	<b>1,443</b>	<b>74</b>	<b>130</b>	<b>1,647</b>
<i>Economic activity status:</i> Full-time employee	28	24	26	27
Part-time employee	23	31	17	23
Self-employed	4	1	2	3
Looking after home/family	27	32	30	28
<i>Financial situation:</i>				
Constant struggle to make ends meet	35	31	52	36
<i>Health:</i>				
Own health in last 12 months 'not good'	25	24	33	26
<i>Qualifications:</i> No qualifications	18	19	16	18
University degree or higher	28	39	30	29
<i>Length of time caring:</i> < 2 years	11	7	13	11
2-5 years	21	20	22	21
5+ years	68	73	65	68
<i>Amount of time spent caring:</i>				
20+ hours a week	81	89	84	81
50+ hours a week	60	54	49	59
<i>Person cared for:</i> Spouse	32	32	27	31
Parent	30	20	23	29
Child <20	29	37	31	29
Child 20+	13	15	18	14
<i>Age of person cared for:</i> <19	30	32	32	30
20-24	5	14	12	6
25-64	39	43	38	39
65-84	21	14	25	21
85+	15	10	5	14
<i>Condition of person cared for:</i>				
Physical condition	53	46	50	52
Learning disability	36	39	34	36
Sensory impairment	22	27	18	22
Mental health problem	22	37	33	24
Frail and/or has limited mobility	43	41	35	42
Dementia	13	12	11	13
Long-term illness, terminally ill	32	37	36	33
<i>Services used and how paid for:</i>				
Services paid for via a Direct Payment	12	16	24	13
Service user/family pays fee for services	40	34	34	40
No fee paid, but services received	38	41	33	38
No fee paid, and no services received	10	9	9	10

**Figure 3.1 Limitations on use of services, by ethnicity: people aged 16-64**

Source: CES Survey, University of Leeds 2007



- Compared with White British carers, carers in the other two groups (White Irish/White other and all other ethnic groups) were slightly more likely to be using carers' services/breaks, and slightly less likely to be using sitting services.
- About two thirds of carers in all groups reported that they and/or the person they cared for were using at least one of the types of service mentioned.
- Carers in the non-White ethnic groups were the most likely to say they would like to have residential care available.
- Only a minority of carers – 13% of White Irish/White Other carers, 18% of those in non-White groups, and 20% of White British carers, said there were no services (or additional services) which they wanted. However carers in the non-White groups were the least likely (7%) to mention a type of service other than those listed as something which they would like to have available.

### Views on employment and accessing services

A number of carers who identified themselves as from non-White ethnic groups claimed that they would feel uncomfortable if they did not seek some form of employment, because of the value placed on paid work in their culture. For instance, an African carer observed:

*I don't believe in sitting at home. In our whole culture, it's - you have to work, you have to study, do something. If you just come and sit down in that seat they would say something is wrong with you. When you are doing something full-time you feel as though you are using your potential, but if you sit at home because of something, [even] though maybe you are getting some type of support... But psychologically, at your age, I don't think it's right. So ideally I would like to go to work [full-time].*

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

**Table 3.3 Services used and services wanted, by ethnicity: carers aged 16-64**

Source: CES Survey, University of Leeds 2007

	SERVICES USED				SERVICES WANTED			
	White British	White Irish/ White Other	All other ethnic groups	All	White British	White Irish/ White Other	All other ethnic groups	All
<b>Number of CES survey respondents</b>	<b>1,443</b>	<b>74</b>	<b>130</b>	<b>1,647</b>	<b>1,443</b>	<b>74</b>	<b>130</b>	<b>1,647</b>
Home/Domiciliary care	25	18	24	25	16	23	20	17
Day centre	19	19	17	19	12	14	19	13
Specialist nursing	11	8	14	11	8	10	12	9
Mental health services	12	22	15	13	8	11	13	8
Respite services	22	19	20	22	24	27	22	24
Carer's breaks	9	11	11	9	22	27	25	22
Sitting services	9	7	6	9	23	32	19	23
Residential care	4	1	4	4	7	5	10	7
Community Transport	10	10	12	10	15	23	15	16
At least one of above	62	66	63	63	60	69	63	60
No services	33	32	29	33	20	13	18	19
Other services	12	19	9	12	12	19	7	12

Other carers from non-White ethnic groups claimed that seeking formal assistance from social services would be frowned upon by members of their culture. For instance, a Pakistani carer caring for her adult son, who has cerebral palsy, claimed:

*I would think about respite. I would think about sending him to a residential place, because that's his learning curve. But culturally, that would hold me back, because people's opinion, 'Oh, she's sent him off, what's she doing?' – and even my husband wouldn't agree to that.*

Female, 35-49 age group, early retired

We should note, however, that these issues were raised by only a handful of our carers from non-White ethnic groups. In general, ethnic minority carers expressed very similar concerns to other carers in the study: their need for information, and for more

accessible and appropriate services; their desire for recognition of their role and of their need for respite and breaks from time to time; the importance of flexibility, both in service provision and in the response of employers.

### Cultural appropriateness of services

A significant issue for carers looking after people with needs which were specific to their cultural background was the lack of appropriate, tailored support and services. Major problems arose if paid care workers providing services did not share the language of the cared for person. Thus a Polish-speaking family living in Scotland had difficulty with a care worker who not only lacked experience of the cared for person's condition, but was also unable to communicate with her effectively:

*It didn't work. One, they didn't seem to understand dementia; they couldn't relate to her. Two, there was a language problem.*

Female, 35-49 age group, unemployed

In such cases carers felt it was important for care workers to share a similar cultural background with the cared for person. In another case, a Black Caribbean carer who cares for her son who has paranoid schizophrenia spoke about the benefits when needs of this type were met:

*The staff team there actually reflect the community that we live in, so a lot of them were from the Black and ethnic groups. And that actually helped my son a great, great deal. That helped my son to recover, and to engage - and once he started doing that, that was it. He was sort of on his way to recovery.*

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

Good quality support of this kind could be particularly important to carers when carers felt they were not being supported at work. The carer just quoted also noted, in relation to her employer:

*Because I would take it as annual leave, they would have no choice. But they wouldn't say, 'Oh, take it as carer's leave.' If I need to do something with my son, I would book it in advance – or, if he was really, really bad, I would work so many hours and then make them up.*

Even when suitable care workers are not available to make combining work and care more manageable, difficulties could be offset to a degree by understanding and sensitivity on the part of a social or care worker who understands the different cultural needs of cared for people in ethnic minority groups. The Polish carer quoted above also observed:

*She's a lovely social worker. I'm very pleased with her. She's understood our situation and I think that's what counts. Our social worker understood from the very beginning the ethnic problem. She's really, really good.*

Female, 35-49 age group, unemployed

Some of the differences between carers from ethnic minority groups and White British carers noted above are likely to be related to the socio-economic circumstances of people in ethnic minority groups (who, on average, have relatively low incomes and are more likely to live in deprived areas). The differences are also related to the age profiles of people of different ethnicities living in Great Britain

(most ethnic minority groups have a younger age profile). These factors are relevant in interpreting the data presented above. Carers in minority communities undoubtedly value specialised services when they are needed and are available; however, as we have seen, like all carers, what they particularly want is for their specific situation to be taken into account and recognised, and to participate, as partners, in making arrangements for care provision and support. In this, they are very like other carers, as shown elsewhere in the CES Report Series.

We turn now to consideration of how caring is affected by where the cared for person lives.

## 2. Caring in rural and urban contexts

The CES survey included 424 carers supporting someone living in a rural area (Table 3.4). Here we outline our data about caring in urban and rural contexts. By caring in a rural/urban context we mean that the carer indicated that he or she was providing

care for someone who was living (according to their own judgment) in a rural or urban area; we use the terminology 'rural carer' and 'urban carer' to denote this.

**Table 3.4 Carers of people in rural areas, by locality in which carer lived**

Source: CES Survey, University of Leeds 2007. Note: some carers did not supply information enabling their location to be identified; some carers provided care for two or more people living in different places. 26 carers caring for someone living in a rural area as well as for someone living in an urban area were not included in this analysis.

	Urban	Rural	Both	TOTAL
Hertfordshire	95	13	3	111
Leeds	101	3	0	104
Sandwell	75	2	0	77
Sheffield	36	7	0	43
Southwark	48	0	0	48
West Sussex	62	20	1	83
East Ayrshire	32	25	0	57
Falkirk	47	13	1	61
Highland	60	73	1	134
Anglesey	15	33	1	49
Swansea	103	22	1	126
Outside the above areas	404	148	14	566
All in ENGLAND	674	134	14	822
All in SCOTLAND	163	115	3	281
All in WALES	131	64	2	197
ALL in CES sample	1078	359	22	1459

### Services in urban and rural areas

When asked about the factors limiting their use of services, rural and urban carers' answers are rather similar (Figure 3.2). As might be expected, rural carers are slightly more likely than urban carers to mention a lack of suitable services in their area (35% compared with 31%), or to say that they do not know what services are available locally (38% compared with 36%). Rural carers are also very slightly more likely than urban carers to claim that services are too expensive (34% compared with 32%). However, rural carers are rather less likely than urban carers to say services are not sensitive to their needs (40% compared with 44%), that their use of services is limited because provision is not sufficiently flexible (46% compared with 48%) or reliable (29% compared with 31%), and that they do not like either the way services are organised (28% compared with 30%) or the people who deliver them (14% compared with 16%).

In terms of services received, Table 3.5 shows that rural carers are less likely than urban carers to be supporting someone who uses home/domiciliary care (22% compared with 27%); however they are also slightly less likely than urban carers to be caring in a situation where no services are being used (30% compared with 33%).

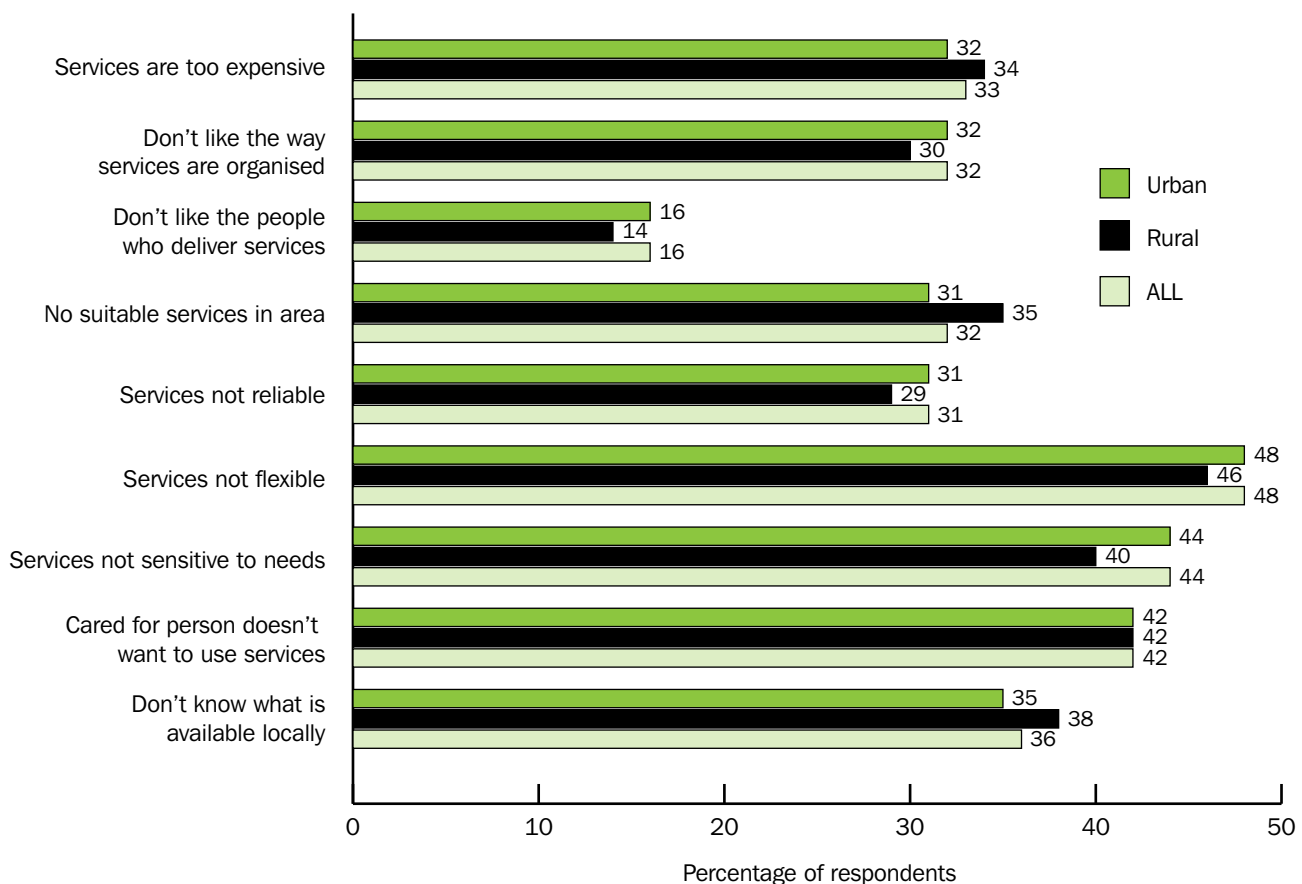
Rural carers are less likely than urban carers to say they want (but do not have) day centre services (11% compared with 14%), but they are slightly more likely to want respite services (27% compared with 24%) and carer's breaks (25% compared with 21%).

### Urban and rural carers: similarities and differences

The urban and rural carers in the CES study provide care for almost identical types of person (in terms of their family relationship - parent, spouse, child, etc.); although there were some (very small)

**Figure 3.2 Limitations on use of services, by whether caring for someone living in an urban or rural area: carers aged 16-64**

Source: CES Survey, University of Leeds, 2007



**Table 3.5 Services used and wanted by whether caring for a person living in an urban or rural area: carers aged 16-64**

Source: CES Survey, University of Leeds, 2007.

	SERVICES USED			SERVICES WANTED		
	Urban	Rural	ALL	Urban	Rural	ALL
<b>Number =</b>	<b>1108</b>	<b>367</b>	<b>1475</b>	<b>1108</b>	<b>367</b>	<b>1475</b>
Home/Domiciliary care	27	22	25	17	17	17
Day centre	19	21	20	14	11	13
Specialist nursing	12	11	12	9	10	9
Mental health services	13	14	13	9	8	8
Respite	23	24	23	24	27	24
Carers breaks	10	8	10	21	25	22
Sitting	10	9	10	24	22	23
Residential care	4	4	4	7	6	7
Community Transport	11	10	11	16	16	16
At least one of above	63	63	63	61	63	61
No services	33	30	33	19	19	19
Other services	11	14	12	13	11	12

differences in the circumstances of those they care for. Rural carers are a little more likely to care for someone with a long-term or terminal illness (36% compared with 30%) or with a physical disability (55% compared with 51%); and they are very slightly less likely to care for someone with a learning disability (33% compared with 35%) or with dementia (11% compared with 13%).

### Rural carers' experiences

Our interviews with carers shed some light on a few specific problems faced by carers in rural areas. One significant concern, an issue for many rural carers, was the need to travel to and from services. This was a difficulty both because it involved significant fuel costs and because it took up a great deal of time. A carer in Anglesey, caring for her frail mother, explained:

*(It's) both expensive and time-consuming. Once you've been there and come back, you only have a very few hours to do anything.*

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

This difficulty could be compounded in wintertime or when poor weather restricted mobility in more

remote areas. A carer in East Ayrshire (caring for her mother who has Alzheimer's disease) pointed out that, although free transport was available to take her to the day centre, it was quite often compromised by bad weather:

*They don't come till 10 o'clock, so I'm at my work by that time. So she wouldn't get (there) unless someone takes her there. Also, at the winter time up here it can be pretty wild.*

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

In these circumstances, carers emphasised that it is essential to have an understanding employer; the same carer was getting some support in her workplace, but felt it was not enough:

*My employers know the situation. I talk about things - and things like that. But just, in general, there's no sitting down and, 'Are you managing, how's your mum?'*

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

Rural carers thus reported the difficulty and expense of travelling to and from services, but could also be faced with a lack of suitable services in their locality. Even when these existed, they were often thought

inappropriate for the specific needs of the cared for person. Thus a carer living on Anglesey, caring for her mother who has MS, claimed:

*The day centre here is more for people with mental problems rather than physical problems. We can't find one on the island. We've been looking at finding a gym or something that would be good for her, but there's nothing on the island. It's behind the times. I don't know, I just think there's a lack of help on the island.*

Owing to the difficulties of caring in a rural area, this carer had needed to reduce her hours of work in her job as a catering and hospitality coordinator:

*Going down to 4 days, I know it's my decision but it has stretched me financially as well. It has made a difference.*

Female, 25-34 age group, in part-time employment

### Travelling to care

The responses to the CES survey showed that more than three-quarters of carers were living with the person they cared for (Table 3.6). Of the rest, 210 carers cared for someone living less than 30 minutes' travelling time away, while 100 had to make a journey of 30 minutes or longer to carry out their caring responsibilities.

Analysis of their circumstances shows that the carers living at least 30 minutes from the person they cared for were better qualified than co-resident carers (48% compared with 27% had a degree or equivalent); more likely to be in full-time employment (37% compared with 26%); and relatively 'new' to caring. They were also very much less likely to have 'heavy' caring responsibilities (only 12%, compared with 70% of co-resident carers, cared for 50 hours per week or more). They were more likely than co-resident carers to be supporting a parent or someone aged 65+, and to be supporting someone with a long-term or terminal illness, limited mobility, dementia or a mental health problem.

This part of the report has examined the significance, for the carer's experience, of where the cared for person lives. We have highlighted a small number of minor differences between rural and urban carers, but emphasised that the similarities in their perceptions and experiences are much

greater than the differences. Caring at a distance, however, is a rather different experience from caring for someone in the same, or a nearby, household, and we have highlighted the specific characteristics of this group, which contains quite a high proportion of well qualified, employed carers. We now turn, in section 3 of the report, to carers' financial circumstances.

**Table 3.6 Characteristics of carers who travel to care: carers aged 16-64 only**

Source: CES Survey, University of Leeds, 2007. Note: This excludes the 100 carers who care for someone in their own home and for someone else living at a distance, and those respondents who did not answer this question.

	Cared for person lives in own home	Carer travels < 30 minutes	Carer travels 30+ minutes	ALL
<b>Number =</b>	<b>1,194</b>	<b>210</b>	<b>100</b>	<b>1,504</b>
<i>Age:</i> >50	46	61	48	48
<i>Sex:</i> Male	22	13	12	20
<i>Ethnicity:</i> Non-White groups	8	4	11	8
<i>Finances:</i> Constant struggle	38	25	31	36
<i>Health:</i> Own health in last 12 months 'not good'	27	16	23	25
<i>Qualifications:</i> None	20	13	11	18
Degree or higher	27	30	44	29
<i>Economic activity status:</i> Employed FT	26	37	37	28
Employed PT	23	23	18	23
Looking after home/family	30	14	14	27
Permanently sick/disabled	6	4	10	6
<i>Length of time caring:</i> < 2 years	10	19	21	12
2-5 years	18	36	26	21
5+ years	72	45	53	67
<i>Amount of time spent caring:</i> 20+ hours a week	91	42	38	81
50+ hours a week	70	11	12	58
<i>Carer's Assessment:</i> Yes	29	22	17	27
<i>Type of area cared for person lives in:</i> Rural area	26	21	21	25
<i>Person cared for:</i> Spouse	36	3	8	30
Parent	16	73	59	27
Child <20	36	2	6	30
Child 20+	14	9	12	13
Other relative	3	9	17	5
Friend	1	3	5	1
<i>Age of person cared for:</i> <19	38	2	8	31
20-24	7	2	5	6
25-64	42	19	29	38
65-84	12	46	38	18
85+	7	35	37	13
<i>Condition of person cared for:</i> Physical condition	53	47	41	51
Learning disability	43	7	15	36
Sensory impairment	21	25	20	22
Mental health problem	22	24	29	22
Frail and/or has limited mobility	36	59	51	40
Dementia	8	31	20	12
Long-term illness, terminally ill	33	26	40	32

## 3. Carers in different financial circumstances

There is now clear evidence that many carers experience financial difficulties as a direct result of being a carer, through loss of earnings if they leave work to care or reduce their working hours, through the impact on household earnings of the cared for person's changed financial circumstances, and through the direct costs of caring which carers often incur (Carers UK 2007<sup>9</sup>). Caring also 'happens' to people across the full range of socio-economic circumstances, with some people beginning caring in the context of affluence and a comfortable standard of living, while others may become carers when their financial situation is already very difficult.

In the CES survey we asked carers to tell us which of the following best described their own financial situation:

- *It's a constant struggle to make ends meet*
- *I manage on the money I have coming in*
- *Most of the time I am reasonably comfortable financially*

We felt this would give a better indication of how, in financial terms, carers were experiencing their caring situation than could be obtained by asking for details of either their personal or household income<sup>10</sup>.

This part of the report explores the difference that poverty and affluence, as measured by this question, make for carers, and considers how their financial situation affects how they cope with their caring situation or with combining work and care. There

is a well-established relationship between socio-economic circumstances and health<sup>11</sup>, with poorer people suffering more illness and disability than the better off, and our own analysis of the 2001 Census showing that the geographical distribution of caring reflects spatial patterns of socio-economic deprivation in the UK<sup>12</sup>.

### Financial circumstances of carers in the CES survey

Of the 1,909 carers who responded to the CES survey, the overwhelming majority (1,860) answered the question about their financial circumstances. Of these, about a quarter (27%) said they were reasonably comfortable financially, about a third (33%) said they were finding it a constant struggle to make ends meet, and the remainder (40%) said they were 'managing' on the money they had coming in. The responses of those aged 16-64 in these three groups of carers are presented in Table 3.7; when those aged 65+ are excluded, the percentage struggling financially rises to 36%.

Compared with other carers, carers who are struggling to make ends meet are more likely to be:

- in poor health (34%)
- unqualified (21% have no formal qualifications)
- caring for 20 or more hours per week (88%, with 66% caring 50+ hours per week)
- caring for a child aged 19 or under (37%)

**Table 3.7 Characteristics of carers, by carer's financial situation: people aged 16-64**

Source: CES Survey, University of Leeds, 2007.

	Struggling to make ends meet	Managing on money coming in	Reasonably comfortable financially	ALL
<b>Number =</b>	<b>585=36%</b>	<b>611=38%</b>	<b>424=26%</b>	<b>1620=100%</b>
<i>Age:</i> <50	58	49	46	51
<i>Economic activity status:</i> Full-time employee	24	29	30	28
Part-time employee	20	27	21	23
Self-employed	3	4	4	3
Looking after home/family	34	23	25	27
Permanently sick/disabled	8	5	5	6
<i>Health:</i>				
Own health in last 12 months 'not good'	34	20	23	26
<i>Qualifications:</i> None	21	19	10	18
Degree or higher	24	28	37	29
<i>Length of time caring:</i> < 2 years	9	13	12	11
2-5 years	22	19	23	21
5+ years	69	69	65	66
<i>Amount of time spent caring:</i>				
20+ hours a week	88	81	71	81
50+ hours a week	66	59	49	59
<i>Person cared for:</i> Spouse	30	30	35	31
Parent	24	31	33	29
Child <20	37	27	21	29
Child 20+	13	14	13	14
<i>Age of person cared for:</i> <19	39	28	22	31
20-24	7	6	6	6
25-64	39	36	43	39
65-84	18	23	23	21
85+	9	15	18	14
<i>Condition of person cared for:</i>				
Physical condition	52	51	55	52
Learning disability	42	35	29	36
Sensory impairment	22	21	22	22
Mental health problem	27	23	20	24
Frail and/or has limited mobility	37	42	50	42
Dementia	8	15	16	13
Long-term illness, terminally ill	33	31	36	33
<i>Fees:</i> Direct payments	12	13	16	13
Other fees	38	40	41	39
No fee paid but receives services	44	36	31	38
No fees paid and no services received	7	11	12	10

- caring for someone with a learning disability (42%)
- caring for someone with a mental health problem (27%)
- receiving some free services (as a carer or as services to the person cared for)

On some of the dimensions shown in Table 3.7, there is a direct statistical relationship between the item measured and the degree of financial hardship or affluence, with the least well off the most likely to be in the situation identified, and the comfortably off the least likely. This does not always apply, however; for example, those who were ‘managing’ financially had slightly better health than those who were ‘comfortable’, although poor health was much more evident among those who were struggling to make ends meet.

### Carers, employment and financial circumstances

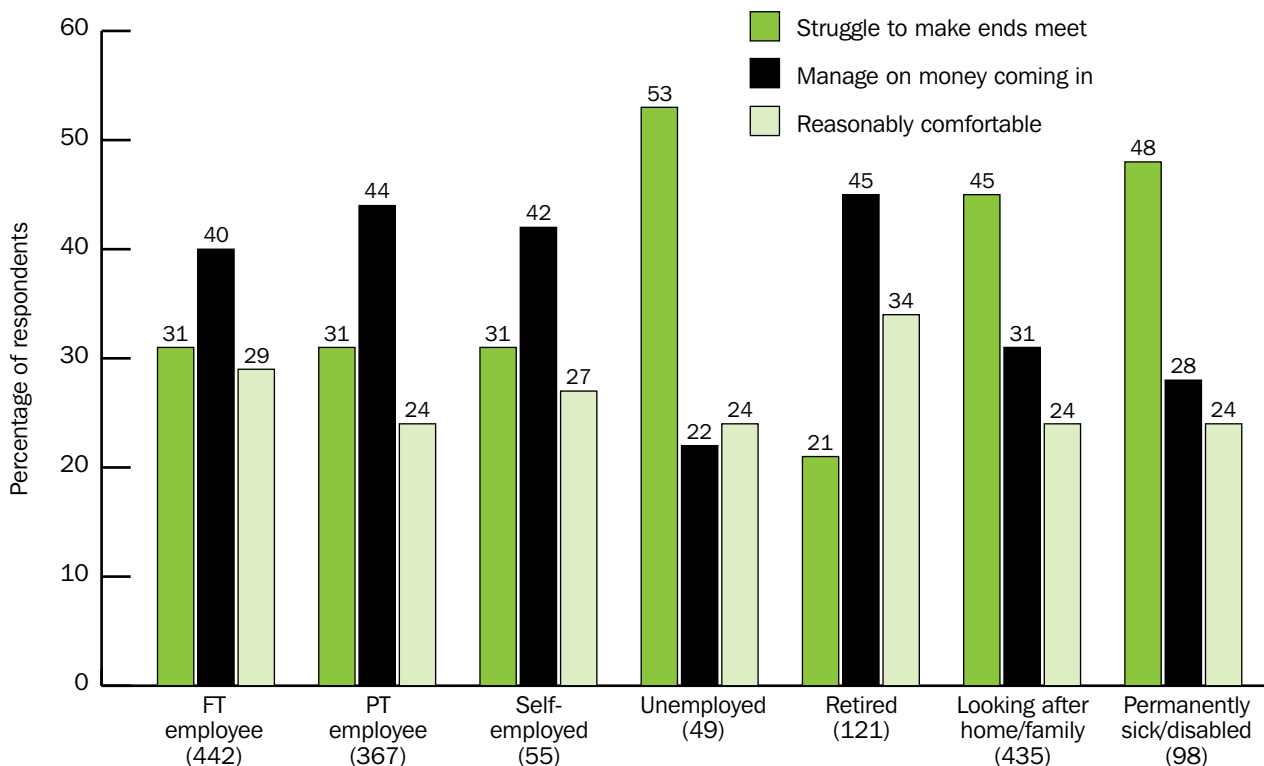
Carers who are comfortably off financially are more likely to be in full-time employment (30%) than other carers (Table 3.7), although it is carers who

are ‘managing’ on the money they have available who most frequently report being in part-time work (27%). The poorest carers were more likely to be looking after their home and family full-time, and more likely to be sick or disabled and unable to work themselves. Comments made by carers interviewed in the CES study are helpful in understanding the relationship between employment and financial circumstances among carers. (See below; we discuss this issue in further detail in CES Report 2.)

We can also note (Figure 3.3) that while among employed carers (in all three categories, full-time [31%] and part-time [31%] employees and the self employed [29%]), fewer than one third of carers were struggling to make ends meet; in the categories ‘unemployed/looking for work’; ‘looking after home and family full-time’; and ‘permanently sick or disabled’, between 40 and 50% were in the ‘struggling financially’ category. However, only 15% of the 214 retired carers in the survey reported that they were struggling financially, with early retired carers most often reporting that they were ‘managing’.

**Figure 3.3 Carers’ economic activity status, by financial situation**

Source: CES Survey, University of Leeds, 2007



**Table 3.8 Services used and wanted, by carer's financial situation: carers aged 16-64**

Source: CES Survey, University of Leeds 2007

	SERVICES USED				SERVICES WANTED			
	Struggling to make ends meet	Managing on money coming in	Reasonably comfortable financially	All	Struggling to make ends meet	Managing on money coming in	Reasonably comfortable financially	All
<b>N =</b>	<b>585</b>	<b>611</b>	<b>424</b>	<b>1620</b>	<b>585</b>	<b>611</b>	<b>424</b>	<b>1620</b>
Home/Domiciliary care	22	26	29	25	16	16	20	17
Day centre	17	20	22	19	13	12	14	13
Specialist nursing	13	11	11	12	9	7	10	9
Mental health services	14	12	12	13	10	8	7	8
Respite	22	23	20	22	24	23	26	24
Carers breaks	11	8	9	9	28	22	16	22
Sitting	9	11	8	9	21	23	26	23
Residential care	3	5	3	4	7	6	7	7
Community Transport	10	8	13	10	17	13	18	16
At least one of above	64	63	61	63	62	57	64	61
No services	29	34	38	33	15	23	20	19
Other services	13	11	12	12	14	10	13	12

Some carers highlighted the way their earnings from paid work affected their benefits situation:

*Suddenly, by going back to work, I lost Carers' Allowance, I lost the tax credit, and you just think - that's just because I don't want to sit back and sponge everything - but you take three times...my tax off me.*

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

Others noted that it was working full-time in particular which did not work for them, because of the way higher earnings from employment affect these benefits:

*I'd have to do over 20 hours just to earn the same, you know - so it's not worth doing any more really. That's why I do the twelve. I did go back to do more, but it didn't work out, so that's why I had to reduce them...I didn't mind cutting down a bit, but you know, I enjoy my work, it's a nice job. Financially we could have done with doing more hours.*

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

Some said they would really prefer to work, but found the demands of their caring role made this impossible:

*I could just go to work, find myself a job and earn ten times what I earn in a week. The thing is I can't, because I'm caring.*

Female, 16-24 age group, in part-time employment

### Accessing services in different financial situations

Almost two-thirds of carers, irrespective of their financial circumstances, were caring in a situation where support from at least one of the range of services commonly available to support them was being used (Table 3.8). Carers who were comfortably off were using home/domiciliary care more often than other carers. This may be related to the fact that more of them were caring for an older person; 18% of carers who were comfortably off were caring for a person aged 85+, and 23% were caring for a person aged 65-84, compared with just 9% and

18% respectively for carers who were struggling financially and 15% and 23% of carers who were 'managing' (Table 3.8). Carers who were comfortably off were more likely to say that they were not currently receiving/using any services at all. They were also a little more likely than other carers to use Direct Payments, and to be paying for services from private resources. The differences between the three groups of carers considered here are not large, however.

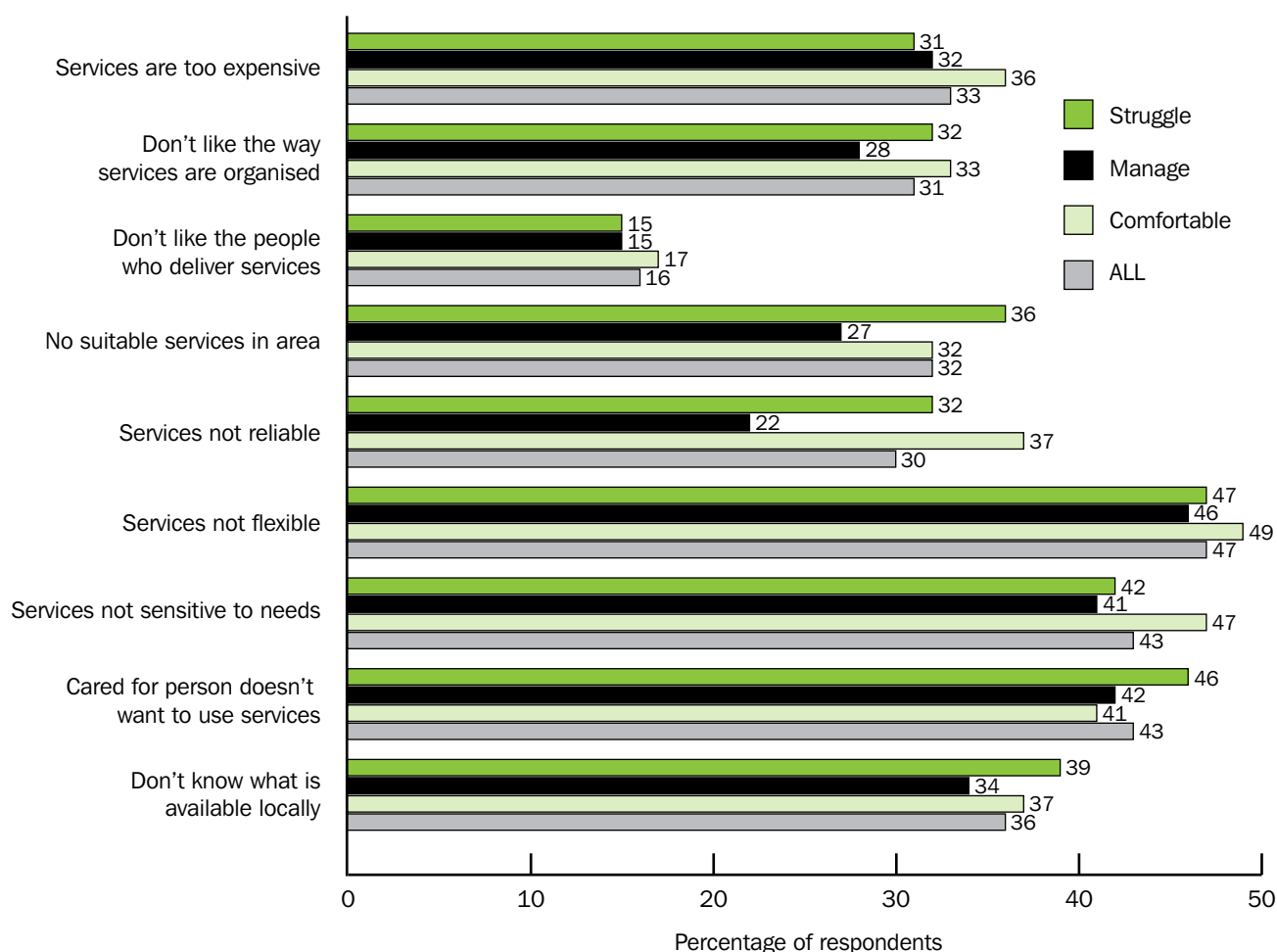
Data in the CES study thus suggest that affluence or poverty currently make only a quite small difference to carers' experiences of access to services and support. Table 3.8 shows that 64% of the comfortably off carers, compared with 62% of those struggling financially, and 57% of those 'managing' on the money they have, wanted, but were not getting, at least one (additional) service.

Related to this, we can see also that there are relatively few differences between these three

groups in carers' perceptions of what limits them in accessing and using services (Figure 3.4). Carers who are struggling financially are more likely than other carers to say that there are no suitable services in their area (36%), that the person they care for does not want to use services (46%), and that they do not know what is available locally (39%). By contrast, those who are comfortably off are the most likely to say that services are too expensive (36%), not reliable (37%) or flexible (49%) enough, and insufficiently sensitive to their needs (47%), and that they do not like the way services are organised (33%). Overall, then, the similarities in the perceptions and experiences of carers in different financial circumstances on these matters are more striking than the differences, with the most crucial point to note being that between a third and a half of all carers felt their use of local services was limited by most of the factors on which they were

**Figure 3.4 Limitations on the use of services, by carer's financial situation: carers aged 16-64**

Source: CES Survey, University of Leeds, 2007



questioned. Consistently, the people who deliver services were identified as a problem by a much smaller percentage of carers, between 15 and 17% in all three of the affluence/poverty categories.

### Carers in poverty or financial difficulties

For carers in the most difficult financial circumstances, it is mainly a matter of ‘surviving’ financially, especially if carrying debts, such as mortgage commitments or credit card balances, from their days before their caring role began:

*I would say that I get by now, I don't have extra money. I get by. It's very much about coping with the present.*

Female, 35-49 age group, unemployed

*You start off with debts anyway from your previous life, and you still have to pay them off somehow - unless you find £600 to go bankrupt!*

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

Some carers living in poor circumstances fear applying for additional benefits in case they lose what they already have:

*I mean, we really could do with middle care rate, but you're just frightened of going for it, in case they take it all off you, because that's what they do, they can take it all from you, and then you've nothing and you've got to try and fight all over again. They're very good at tying you in so many knots that you don't know what you're doing.*

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

*If it was financially viable for you not to work, I mean, that would be a big thing. For someone to go into a home, it's £400 a week - but for you to look after them, it's £45 a week. There's a big difference, and I don't know how they can say it's (only) worth £45 a week.*

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

Another carer explained how unfair she thought it was that she would lose Carer's Allowance when she reached pensionable age:

*Why should you lose it? I know you get a pension, which I've paid into - I did, for 17 years. Why should I lose that £40 a week because of my age?*

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

### Carers, poverty and relationships

Some carers stressed that coping with a care situation in straitened financial circumstances affected their other family relationships:

*I find that one particularly hard, I think...As well as a carer, I'm a father and you want to do the best for your children, and if you don't support them properly, you don't feel too good inside.*

Male, 50-59 age group, self-employed

Another observed that there were social divisions in different carers' ability to negotiate access to services and to identify the services and benefits to which they were entitled, with better educated carers more able to find their way through the complexities of the system:

*I'm lucky that I'm educated and literate, and a stroppy little bugger as well. I've read about everything, I've thought about everything. The majority of mums I know don't and can't. And it's another sort of division, isn't it, a social division. If you know how to, you might be able to - but if you don't, you're left relying on some people telling you things.*

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

Our evidence in this section certainly does not indicate that carers who are reasonably comfortable in financial terms have their needs fully met. While theoretically their greater affluence might give them more choice and options, in reality the kind of services they and other carers need are often not available, even for private purchase; and like poorer carers, this group also has unmet needs for information and advice. Poverty undoubtedly causes some carers additional stress and worry, but affluence does not solve all carers' problems and difficulties. We now turn to the question of carers' health.

## 4. Carers and how caring affects carers' health

The CES survey respondents include 484 who described their own health as 'not good', and 107 carers who described their employment status as 'permanently sick or disabled'. This section of the report highlights their situation, contrasting it with our data about carers who are in better health.

We have already shown<sup>13</sup> the very clear relationship between health, caring and the hours of care given. That analysis showed that for both men and women, and for those working full-time and part-time, self-assessed health (in the previous year) deteriorates as weekly hours of caring increase. Others have also shown how a variety of conditions, including stress-related illnesses, are commonly experienced by carers<sup>14</sup>. Here we can use the CES survey to shed further light on this robust finding (based on data in the 2001 Census), which we could not previously examine by additional factors such as length of time caring, circumstances of person cared for, or experience of using services, as these questions were not asked in the Census.

In the CES survey, 26% of all respondents of working age reported that their health was 'not good'. This compares with 10% of all working age carers in the 2001 Census, representing 471,500 carers across Great Britain, and - given the over-representation of 'heavy' end carers in the CES study - the figure is, although a matter for serious concern, not particularly surprising.

### Carers of working age and poor health

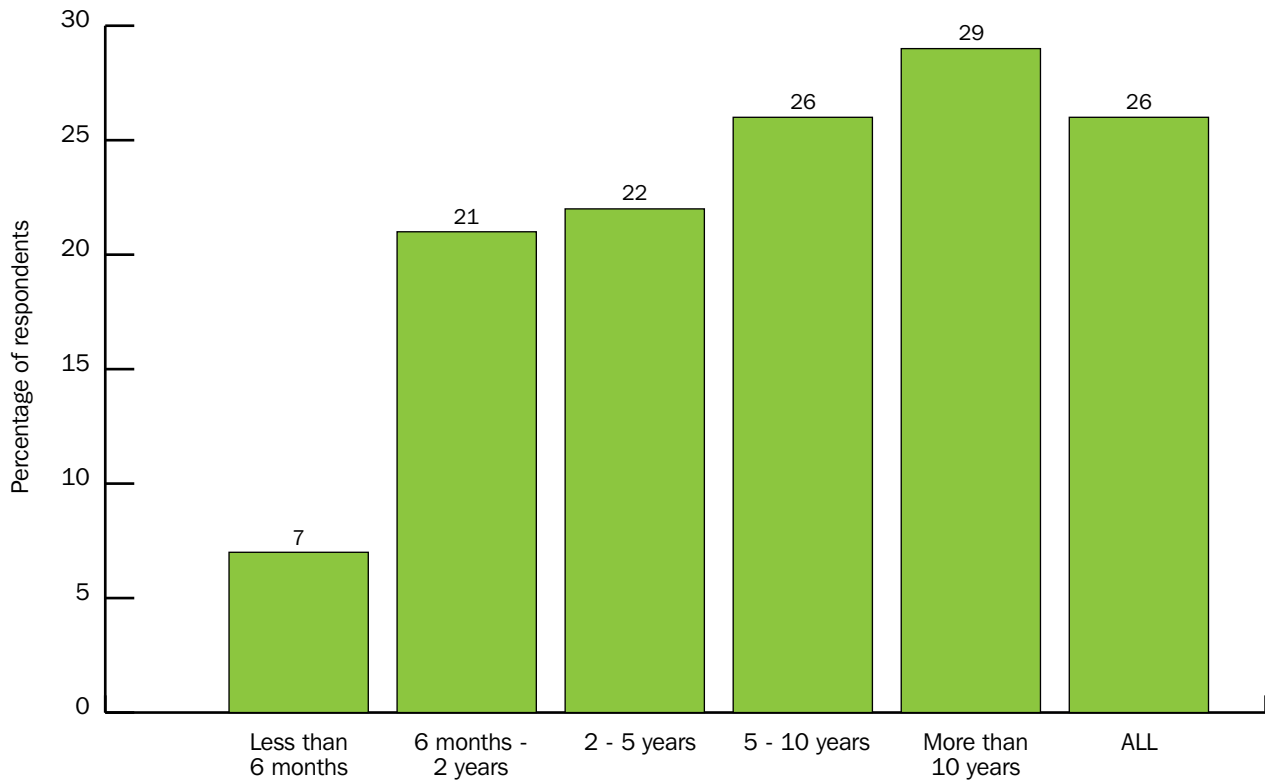
Poor health among carers, as well as being bad for them as individuals, and for those they care for, has significant implications for policy-making. Our focus here, then, is on those who reported that their health was 'not good'. As can be seen in Figure 3.5, a quarter of all carers in the CES survey were in this situation, and there was a clear relationship between length of time caring and the likelihood of reporting poor health.

Carers who provide care for 35 or more hours each week are considerably more likely than other carers to report being in poor health (Figure 3.6). It is likely that the slightly lower figure seen among those caring for 50 or more hours per week arises because sustaining caring at this level of intensity becomes impossible for some of those who are not well themselves.

In Figure 3.7 we see, as might be expected, that the highest proportion of those reporting poor health in the past year are found in the (self-defined) 'permanently sick or disabled' (where the figures are around a half of all carers, slightly more among men) and the 'unemployed' economic activity statuses (about a third of all carers, slightly more for women). Over a quarter of carers who have retired early (both men and women) are themselves in poor health, and among those in employment, the figures range from 19% to 29% - with the worst health found

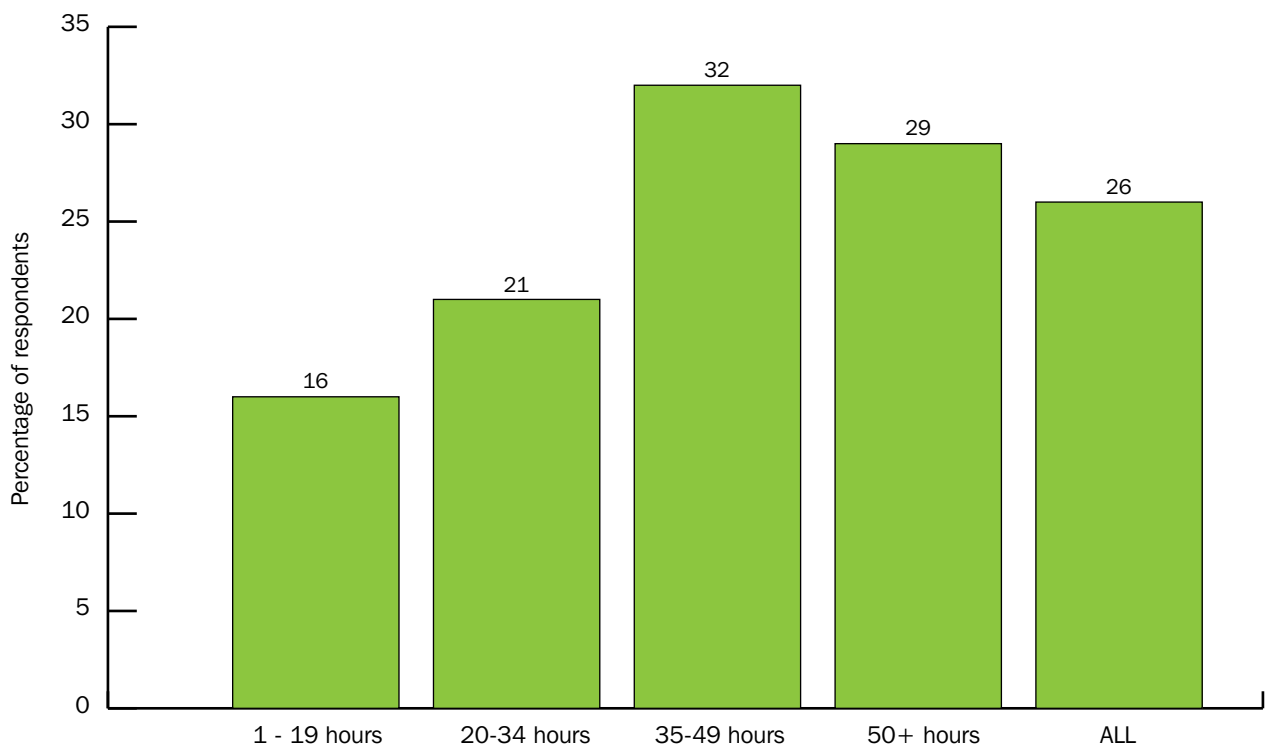
**Figure 3.5 Carers whose health is 'not good' – by length of time caring**

Source: CES Survey, University of Leeds, 2007



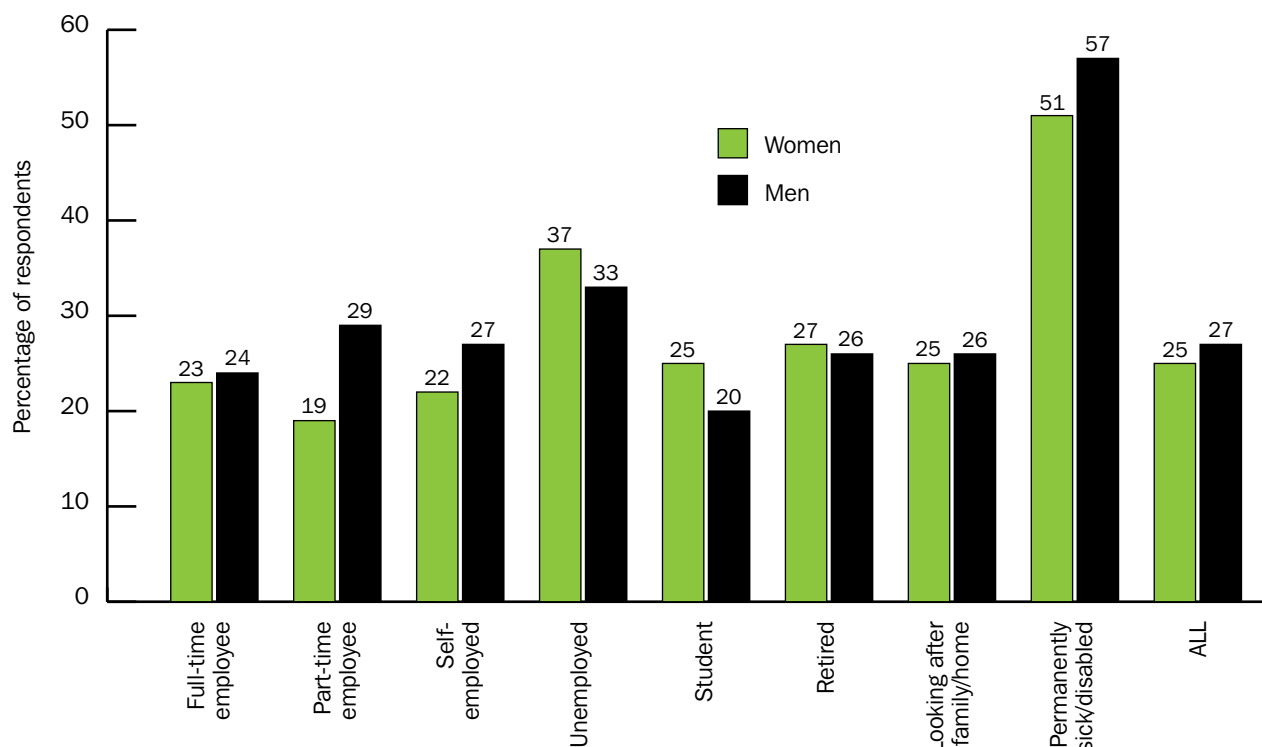
**Figure 3.6 Carers whose health is 'not good' – by amount of care**

Source: CES Survey, University of Leeds, 2007



**Figure 3.7 Carers whose health is 'not good' – by economic activity and gender**

Source: CES Survey, University of Leeds, 2007



among male carers who work part-time (29%), and the lowest rates of poor health seen among female carers who work part-time (19%). There are likely to be significant age differences between these two groups, as there was quite a large number of women caring for a disabled child (who tend to be a younger group of carers), in the CES survey.

### Carers' health and their experience of services

In the CES survey, carers who are not in good health themselves are considerably more dissatisfied than other carers with the services available to support them in their caring situation. More than half of them say services are neither flexible enough nor sensitive enough to meet their needs, and their responses, on every aspect we measured, were more negative than those of carers who reported being in 'good' or 'fairly good' health. Our in-depth interviews with carers also revealed that some feel that their frustrations in accessing services, and the limited

nature of the support they can secure, contribute to their poor health.

Carers also often reported putting their own health needs to one side, giving priority instead to their caring role, and focusing on the person they support. One explained that, despite being diagnosed with skin cancer:

*In my situation, I feel I have to put my caring role first. [Social services] would just leave you plodding on at a non-functioning level really, and that's the thing that's really wrong with the system.*

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

Another told us that lifting his wife, who needed substantial care, had caused permanent damage to his back:

*I don't think I'll ever be able to work again, I'm 50, and even if my wife was ok I canna sit at a desk for five or six hours a day. I just couldn't do that.*

Male, age group 50-59, unemployed

Others emphasised that continuous caring in a long-term situation took its toll on their health, with those combining work and care identifying their care as 'like a second shift', and noting that heightened stress was a common experience:

*(Caring) doesn't affect (my health), except I am tired all the time. I work full-time in quite a stressful job, then I come home like the good subservient housewife to my second shift with my husband.*

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

*I was going to a meeting one time, and I was in the meeting and looked down at my feet - and I had a black shoe and a brown boot on. Now that's stress, and anybody like that needs time out.*

Male, 35-49 age group, unemployed

Some felt desperate as they contemplated the impact caring was having on their lives, not just in the present, but stretching out long into their futures too:

*I go to work - and for those couple of hours, I'm Fran, just Fran. [You] switch off and yet get to use your brain - which is nice, you know? It's not a choice you make - do you know what I mean? I have to work; I need to work - because otherwise I would probably hang myself. I have to work, because - you can get to a point where you can dwell on it, you know, and it is depressing, it is. I will, one day, have to give it up, I'll have no choice. To be 36 and to not ever work again - you know, what do you do - if you've always worked? To be that young - it's just, you know, it's not for me. If you give it up, then autism has completely taken over my life, you know...and that little bit of fight that you have left in you. It's like - I will not allow that to happen.*

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

Our survey data show an association between carers' health and their experiences of using services, too (see Figure 3.8). Those in poor health were always more likely to feel negative about the services available to them, complaining especially that services are not flexible (56%) and sensitive to the needs of their particular caring situation (52%), and being much more likely than carers in better health to say their use of services is limited because: they are not reliable (40% compared with 27%); they

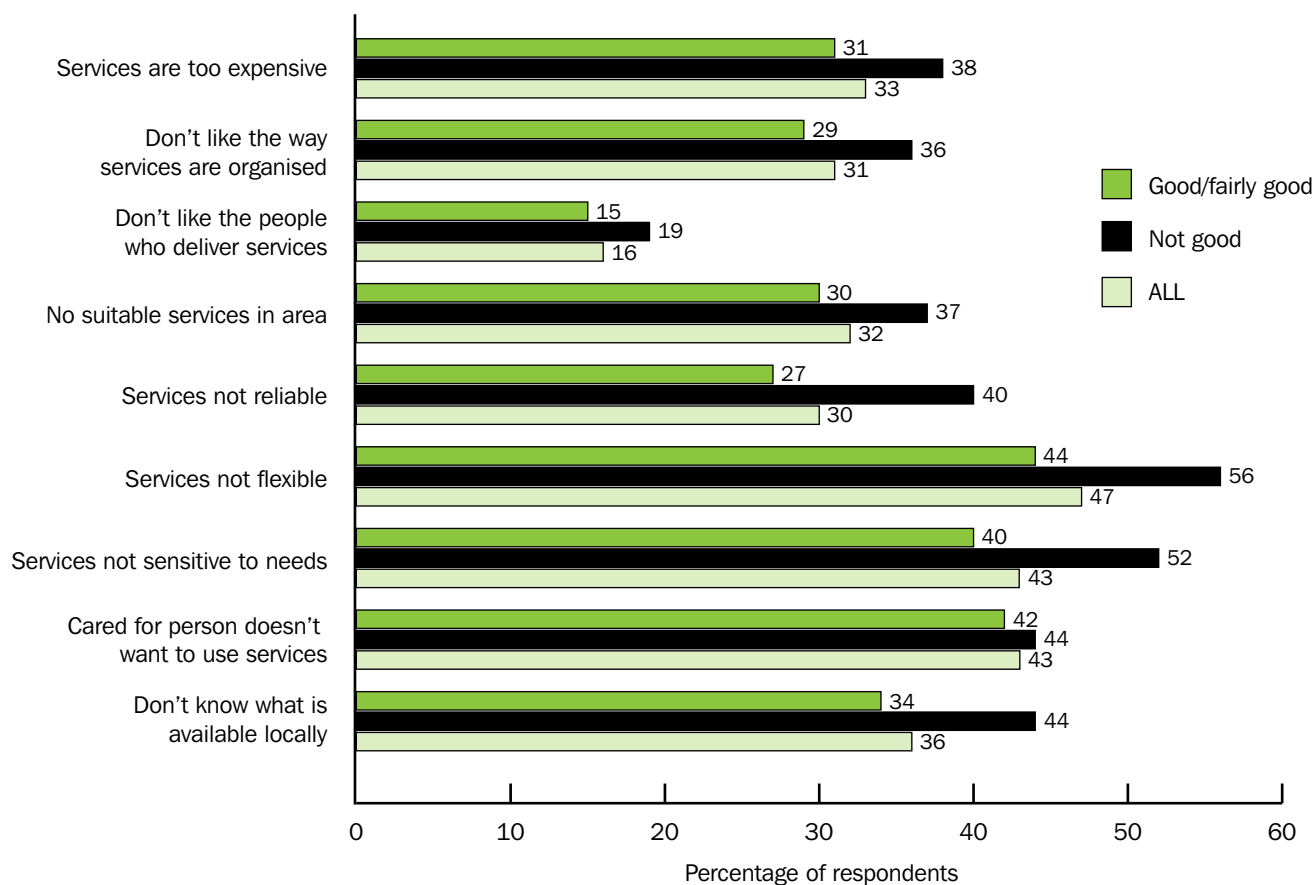
do not like the way services are organised (36% compared with 29%); services are too expensive (38% compared with 31%); and - perhaps most tellingly - being much more likely to say they do not know what services are available locally (44% compared with 34%). Thus this particularly needy group of carers, a group at significant risk of being unable to continue caring, or of starting to need services themselves, feels that current arrangements are very poorly geared to enabling them to care in a context which maintains their own health and wellbeing, and lack the information they need to access crucial support.

Finally, in this section, we can see how carers' health, their situation in relation to the labour market and paid employment, and their financial circumstances combine to make certain groups of carers particularly needy. In Figure 3.9 we can see that the majority of carers who are unemployed, looking after their home and family full-time, or permanently sick or disabled (as well as in poor health) themselves are struggling to make ends meet (59%, 62% and 67% respectively). This contrasts with carers in good or fairly good health who are in paid employment, early retired or permanently sick/disabled, among whom fewer than a third (and in the case of the early retired only 18%) are in a difficult financial situation.

The relationship between health and caring is thus an important and worrying one, which needs to be the focus of changes in policy, service development and provision. These matters are addressed fully in CES Report 6, which discusses the detailed recommendations arising from the evidence in the CES study.

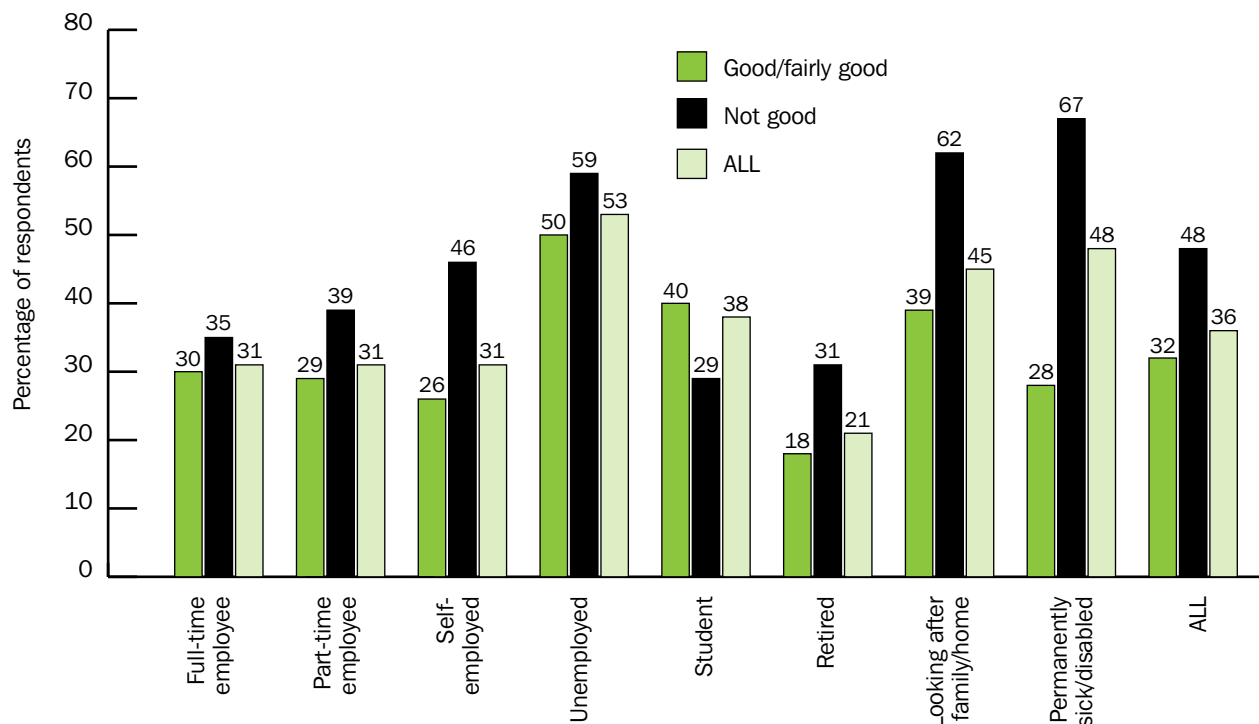
**Figure 3.8 Carers by their own health and by attitudes to services**

Source: CES Survey, University of Leeds, 2007



**Figure 3.9 Carers who are struggling to make ends meet – by economic activity and health**

Source: CES Survey, University of Leeds, 2007



## 5. Caring in its various personal contexts

In this final section of this CES report, we consider some of the other dimensions of the wide range of different caring situations carers experience, looking at both the relationship between the carer and the person they care for, and at the condition or disability of that person<sup>15</sup>.

We show first, in Table 3.9, the numbers of carers in the CES study supporting someone with each of a number of conditions. For those cases where we have at least 200 carers supporting someone with the condition indicated in the study, we present below further analysis of them as a specific group of carers.

### Carers of a sick or disabled child aged 19 years old or younger

Carers of a sick or disabled child aged 19 or younger are typically much younger than other carers (83% are under 50) and in the CES study the overwhelming majority of them are women (91%), 'heavy end' carers (77% provide 50+ hours of care each week) and in a long-term care situation (83% have been caring for 5 years or more), often for a child whose condition includes having a learning disability (81%). They are less likely to work full-time, but more likely to work part-time than other carers,

**Table 3.9 Circumstances/condition of person cared for: carers aged 16-64**

Source: CES Survey, University of Leeds 2007

Number	Condition of the person(s) receiving care	
856	Physical disability	<i>Some carers supported more than one person, or someone with needs in more than one category; respondents could tick as many answers as applied</i>
593	Learning disability	
363	Sensory impairment	
388	Mental health problem	
693	Frail, limited mobility	
208	Dementia	
541	Long-term illness, recovering from illness or terminally ill	
9	HIV/AIDS	
30	Substance abuse/addiction	
119	Other needs (specified in different ways)	

and over a third of them are looking after their home and family full-time. Like other carers in the study, just over half of them have left work to care. Among those who are in employment (excluding the self employed), only a small minority say their caring does not affect their work (16%). Most (80%) say they can rely on family and friends to help them combine work and care, and just over half (53%) say their employer is carer-friendly (slightly fewer than among other employed carers). Only 17% of these carers say they have adequate services to enable them to work (Table 3.10).

We can see the factors which carers of a sick or disabled child feel limit their use of services in Figure 3.10, which shows that this group of carers are much more likely than other carers to feel that:

- There are no suitable services in their area (47% compared with 25%).

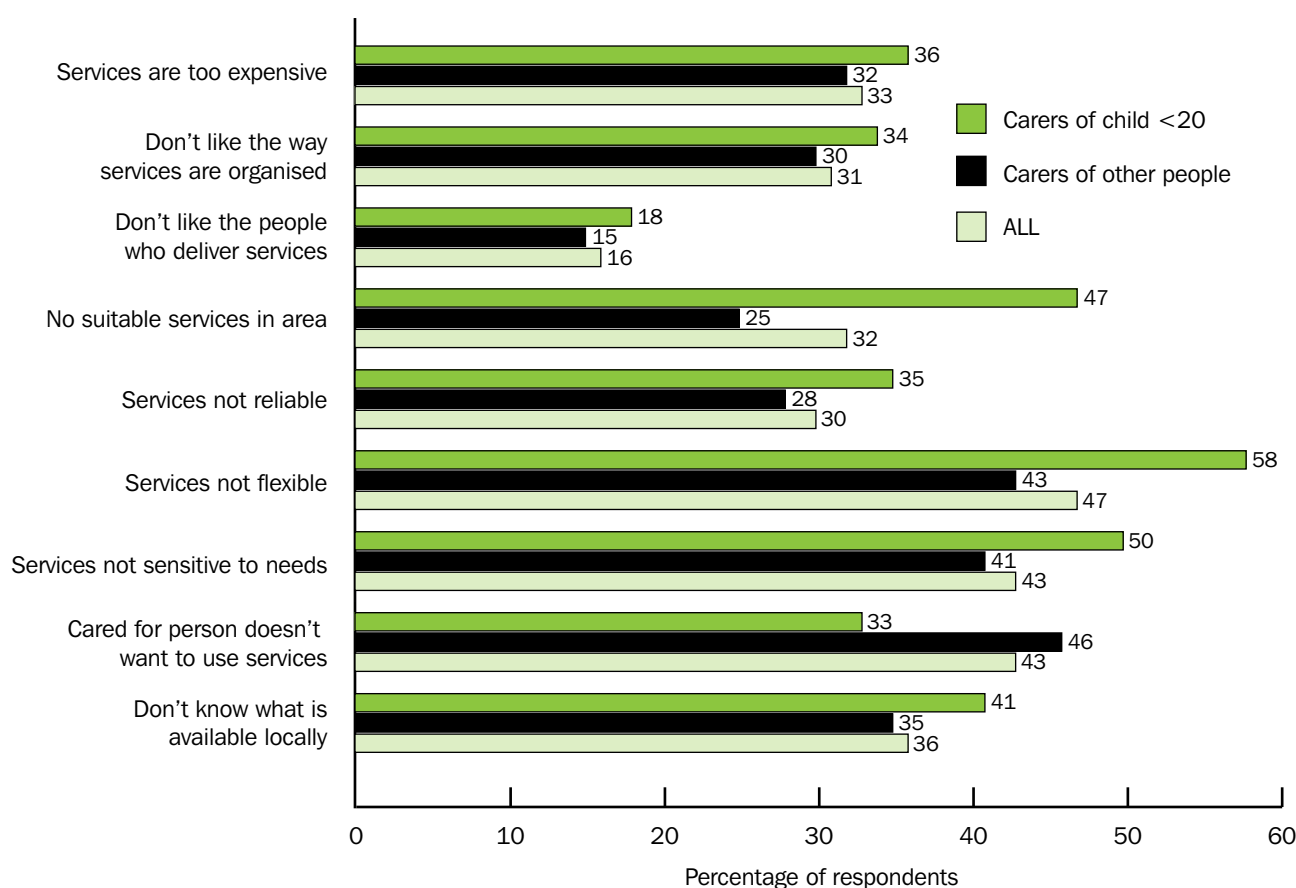
- Services are not flexible (58% compared with 43%).
- Services are not sensitive to needs (50% compared with 43%).
- Services are not reliable (35% compared with 29%).

This group are also a little more likely than other carers to say that their use of services is limited because they are too expensive (36%), they do not like the way they are organised (34%), they do not know what is available locally (41%), or they do not like the people who deliver services (18%). They are less likely than other carers, however, to say that the person they care for does not want to use services (33% compared with 46%).

At the time of the survey, carers of disabled children were less likely than other carers to be using one or more of the services listed in Table 3.11 (56%

**Figure 3.10 Limitations on use of services, by carers of children under 20 and all other carers: carers aged 16-64**

Source: CES Survey, University of Leeds, 2007



**Table 3.10 Carers of a child aged 19 years or younger: carers aged 16-64**

Source: CES Survey, University of Leeds, 2007.

	Carer of child aged <20	Carers of all other people	ALL
<b>Number of respondents =</b>	<b>201</b>	<b>1,146</b>	<b>1,647</b>
<i>Age:</i> >50	83	37	51
<i>Sex:</i> Female	91	77	81
<i>Economic activity:</i> Full-time employee	18	32	27
Part-time employee	28	21	23
Self-employed	3	4	4
Looking after home/family	37	24	28
Left work to care	55	53	54
<i>For employees:</i>			
I have adequate services to enable me to work	17	31	27
My employer is carer friendly	53	60	58
My caring doesn't affect my work	16	24	22
I can rely on support from partner/family/friends to enable me to work	80	66	70
<i>Finances:</i>			
Constant struggle to make ends meet	46	32	36
<i>Health:</i> Own health in last 12 months 'not good'	27	25	26
<i>Qualifications:</i> None	15	19	18
Degree or higher	28	29	29
<i>Length of time caring:</i> < 2 years	4	15	11
2-5 years	14	24	21
5+ years	83	62	68
<i>Amount of time spent caring:</i>			
20+ hours a week	95	75	81
50+ hours a week	77	51	59
<i>Condition of person cared for:</i>			
Physical condition	48	54	52
Learning disability	81	16	36
Sensory impairment	29	18	22
Mental health problem	25	23	24
Frail and/or has limited mobility	24	50	42
Dementia	2	17	13
Long-term illness, terminally ill	21	38	33
<i>Fees:</i> Direct payments	16	12	13
Other fees	22	47	40
No fee paid but receives services	53	32	38
No fees paid and no services received	10	10	10

**Table 3.11 Services used and wanted by carers of children aged under 20: carers aged 16-64**

Source: CES Survey, University of Leeds 2007

	SERVICES USED			SERVICES WANTED		
	Carers of children aged <20	Carers of other people	ALL	Carers of children aged <20	Carers of other people	ALL
<b>Number =</b>	<b>501</b>	<b>1146</b>	<b>1647</b>	<b>501</b>	<b>1146</b>	<b>1647</b>
Home/Domiciliary care	14	30	25	18	16	17
Day centre	6	25	19	11	13	13
Specialist nursing	10	12	11	8	9	9
Mental health services	10	14	13	10	7	8
Respite services	26	20	22	28	22	24
Carer's breaks	11	9	9	33	18	22
Sitting services	8	10	9	30	20	23
Residential care	3	5	4	7	7	7
Community Transport	8	11	10	15	16	16
At least one of above	56	66	62	66	58	60
No services	34	33	33	14	22	19
Other services	16	10	12	11	13	12

compared with 66%). They nevertheless had slightly better access to respite and carer's services than other carers (26% and 11%, compared with 20% and 9% for other carers), although these figures of course indicate that the overwhelming majority of carers were not receiving services of this type. Like other carers, about a third of them were coping with no services at all, although 66% (compared with 58% of other carers) said they would like to be able to use at least one service which they did not currently receive.

The new evidence presented here about carers of disabled children adds further detail to a growing body of material relating to the particular needs of this group of carers. As we showed in our report of a separate study<sup>16</sup>, they are a growing group, whose situation is beginning to be addressed in public policy, but who need particular support, because of their age, the length of time they care for, and the heavy demands on them every day. The new evidence in the CES study underscores the importance and urgency of addressing their needs, as discussed in CES Report 6.

### Carers of a partner or spouse

Over 500 carers in the CES study were caring for their spouse or partner. This is thus another important category among carers, and one very often neglected in policymaking and research. These carers are typically older than other carers (60% were aged 50 or older), and in the CES study two thirds were women (see Table 3.12). Two-thirds had been caring for at least 5 years, and about the same number had 'heavy' caring responsibilities (50+ hours per week). Despite this, 58% were in paid work, although 23% reported that they had left work in order to care. Carers in this group are more likely than other carers (34% compared with 25%) to be in full-time employment. Like other carers, most of those who are employees say their employer is carer-friendly (58% in both cases), and two thirds have the support of family and friends (67%). Fewer than one in four (23%) say their caring does not affect their work, yet only 28% feel they have adequate services to support them in combining work and care.

**Table 3.12 Carers of a partner or spouse: carers aged 16-64**

Source: CES Survey, University of Leeds, 2007.

	Carers of a spouse or partner	Carers of other people	ALL carers
<b>Number =</b>	<b>504</b>	<b>1,143</b>	<b>1,647</b>
<i>Age:</i> >50	60	44	49
<i>Sex:</i> Female	66	88	81
<i>Economic activity:</i> Full-time employee	34	25	27
Part-time employee	21	24	23
Self-employed	3	4	4
Looking after home/family	24	29	28
Left work to care	23	26	25
<i>For employees:</i>			
I have adequate services to enable me to work	28	27	27
My employer is carer friendly	58	58	58
My caring doesn't affect my work	23	21	22
I can rely on support from partner/family/friends to enable me to work	67	72	70
<i>Finances:</i>			
Constant struggle to make ends meet	35	37	36
<i>Health:</i> Own health in last 12 months 'not good'	31	24	26
<i>Qualifications:</i> None	22	16	18
Degree or higher	29	28	29
<i>Length of time caring:</i> < 2 years	11	11	11
2-5 years	22	20	21
5+ years	67	68	68
<i>Amount of time spent caring:</i>			
20+ hours a week	86	79	82
50+ hours a week	63	57	59
<i>Condition of person cared for:</i>			
Physical condition	66	46	52
Learning disability	11	47	36
Sensory impairment	19	24	22
Mental health problem	27	22	24
Frail and/or has limited mobility	44	41	42
Dementia	9	14	13
Long-term illness, terminally ill	54	23	33
Problems relating to substance abuse/ addiction	1	3	2
<i>Fees:</i> Direct payments used to provide services	12	14	13
Other (private) fees paid for/towards services	40	40	40
No fee paid, but receiving services	37	38	38
No fees paid and no services received	11	9	10

Many of these carers support a partner/spouse with a physical condition (66%) or with a long-term or terminal illness (54%), far higher percentages than found among other carers. By contrast, they are much less likely to be caring for someone with a learning disability. Like other carers, about 40% are spending private resources on the services they require, while a slightly smaller proportion (37%) receive services for which they do not have to pay. 12% of this group were using Direct Payments, a similar, but slightly smaller percentage than found among other carers.

### Caring for parents/parents-in-law

Those caring for their parents or in-laws were another large group of carers in the CES study (479 carers). Table 3.13 shows that this group of carers are more likely to be using home/domiciliary care than other carers (36% compared with 20%), but that they have relatively poor access to respite and carers' services, with only 7% getting carers' breaks. One in ten cares for someone with access

(temporary or longer-term) to residential services. Only one in four of these carers said there were no other services they wanted (24%), while well over half (59%) identified at least one service which they did not currently use but would like to have. Respite and sitting services were high on their list, followed by home/domiciliary care, which was wanted (but not received) by 18% of these carers.

Carers of a parent or parent-in-law were slightly better informed about services than other carers (only 31% said they did not know what was available locally), with only one in four (23%) saying there were no suitable services in their local area (Figure 3.11). About a third said their use of services was limited because they were too expensive or they did not like the way they were organised, and almost half (47%) said that the person they cared for did not want to use services (compared with 41% of other carers). A large minority of carers in this group (about 45%) said their use of services was limited because services were not flexible or sensitive

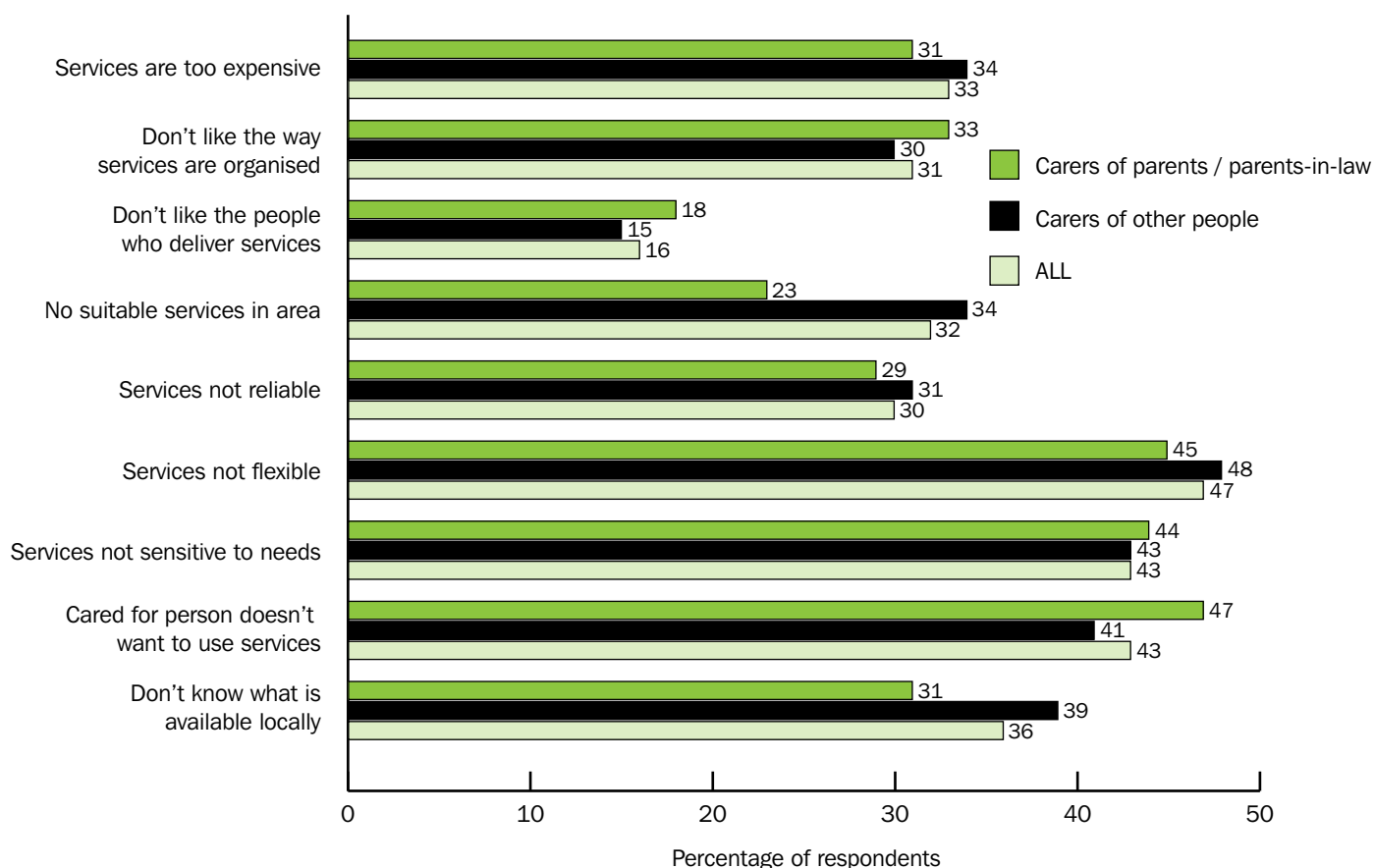
**Table 3.13 Services used/wanted by carers (aged 16-64) of parents/parents-in-law**

Source: CES Survey, University of Leeds 2007

	SERVICES USED			SERVICES WANTED		
	Carers of parents/parents-in-law	Carers of other people	ALL	Carers of parents/parents-in-law	Carers of other people	ALL
<b>Number =</b>	<b>479</b>	<b>1168</b>	<b>1647</b>	<b>479</b>	<b>1168</b>	<b>1647</b>
Home/Domiciliary care	36	20	25	18	16	17
Day centre	24	17	19	14	13	12
Specialist nursing	13	11	11	10	8	9
Mental health services	12	13	13	7	9	8
Respite services	19	23	22	20	25	24
Carer's breaks	7	10	9	17	25	22
Sitting services	11	9	9	22	23	23
Residential care	6	4	4	7	7	7
Community Transport	11	10	10	16	16	16
At least one of above	65	62	63	59	61	60
No services	36	32	33	24	18	19
Other services	7	13	12	11	13	12

**Figure 3.11 Limitations on use of services: carers (aged 16-64) of parents/parents-in-law**

Source: CES Survey, University of Leeds, 2007



enough, while 18% (compared with 15% of other carers) said they did not like the people who deliver services.

Having reviewed our evidence about carers' experiences in terms of their relationships to those they care for – children, partners, parents - we turn finally to our evidence relating to the conditions of those they care for.

### Living with caring: supporting people with different conditions

To conclude this part of the report, we use examples drawn from our detailed interviews with carers, to illustrate what caring involves and can mean for carers of working age who provide support for people with a range of different conditions. This allows us, using examples from real life, to draw attention to variety and variability in caring and in carers' needs, as well

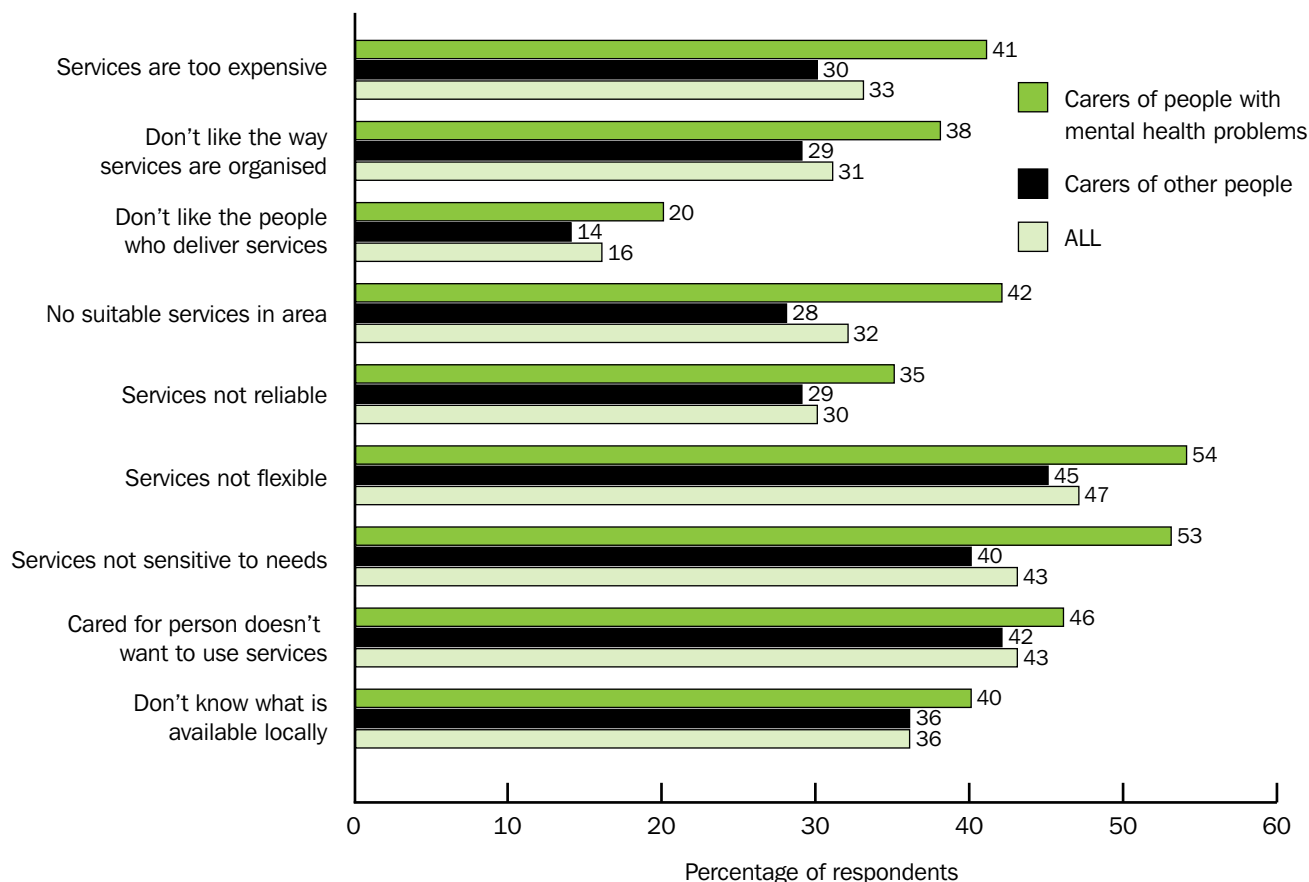
as to highlight common factors affecting carers, particularly in relation to combining work and care.

We begin by looking at those caring for someone with a mental health problem. As our interviewees in this group raised some particular issues, we also present analysis of our survey data on use of services about this group of carers (Figure 3.12).

**Mental illness:** Our interviews showed that common concerns among carers who care for someone with mental health problems include the unpredictability of the condition, the stigma attached to it, the danger sometimes involved in this form of care, and a reliance on health services rather than social services. Some carers in this group had experienced difficulty in having their role acknowledged and being involved in decisions about care, particularly where dealings were primarily or exclusively with health professionals.

**Figure 3.12 Limitations on use of services by carers of people with mental health problems: carers aged 16-64**

Source: CES Survey, University of Leeds, 2007



### ARNOLD

Arnold cares for his wife who recently suffered a mental breakdown involving depression, and now experiences bouts of suicidal behaviour. Arnold has been forced to quit his full-time job to care for his wife, and now struggles to pay his mortgage and bills; he works as an 'odd job' man in his locality, and cannot earn more than is allowed under the Carers' Allowance system. Arnold has experienced feelings of worthlessness and incompetence as a carer, as well as guilt because he cannot provide for his two teenage sons who currently attend university and have to work during their summer breaks, often to provide money for the family. Arnold is extremely disappointed by the little help available from social services for carers: he believes that mental illness lacks a sufficient criterion for assessment, and that treatment is focused only on stabilisation, and not on recovery. He also believes that social services would

benefit from better organisation at an institutional level, and he has recently become involved in campaigning to this effect.

Male, 50-59 age group, self-employed

**Dementia:** Common issues among those caring for someone with dementia included a difficulty in leaving the cared for person alone for anything other than very short spells of time, and a need for almost constant supervision. Relative to other carers, however, carers in this situation seemed to have rather more support from specialist/voluntary organisations, and often commented on the benefits of their help and advice. Some carers reported conflicts of values between the generations, and often carers of relatives with dementia found the person they cared for was reluctant (or refusing) to use services. Margaret's case shows how access to Direct Payments can help in this situation.

## MARGARET

Margaret has cared for her mother for seven years since she developed Alzheimer's Disease and Margaret's father died. Margaret currently works for her brother-in-law, who is very supportive of her caring situation. However, because of the number of hours she works, Margaret cannot claim Carer's Allowance. She uses Direct Payments as a way of arranging care while continuing to work – without Direct Payments, this would not be possible, as her mother requires 24-hour care. Margaret only found out about Direct Payments through her own independent research on the Internet; social services had not informed her of this option, despite her own uncertain health (high blood pressure). Margaret has been using this service for only a few months, and hopes it will make her caring, working and personal life more manageable. Female, 35-49 age group, full-time employed

**Frailty/limited mobility:** Common issues among carers who care for someone who is frail or has limited mobility include the fact that day care centres tend to cater primarily for older people who lack mental alertness (and are thus perceived as unsuitable by frail older people who do not have this problem). These carers, too, were quite likely to comment on inter-generational conflicts about how care should be provided, and often said that those they cared for were reluctant to use services – sometimes because they were determined to retain as much independence as possible, and found it hard to accept the need for support.

## SHEILA

Sheila cares for her husband who suffers from severe arthritis. Before the onset of his condition, Sheila's husband ran a business, but since then he has been unable to work. Sheila and her husband have existing debts and are currently functioning on a minimum of social benefits. Sheila cannot seek full-time work because she knows she will lose what little financial assistance she is receiving from social services. She is currently also caring for a neighbour for several hours each week for a small fee. Sheila's husband's condition has resulted in their living in a sheltered bungalow, and this is a source of unhappiness for them both

– they believe they should now be enjoying their lives, having worked so hard in the past. They feel they do not have the strength to fight for what they need from social services, since previous experience has taught them how demanding this process can be.

Female, 50-59 age group, unemployed

**Physical disability:** Carers supporting someone with a physical disability often reported difficulties related to moving and lifting the cared for person, and their concerns about associated risks to their own health. Some wanted relevant training, while others felt they needed assistance, equipment, or home adaptations. Some felt they had not been provided with suitable equipment through social services, and felt the equipment they did have was of poor quality. Carers also observed that some cared for people (particularly children) did not like change, making continuity in the care workers visiting the home particularly important. Other concerns raised included fears for the future (after the carer has died or has become infirm, issues discussed in more detail in CES Report 1); that day care centres are often not age-sensitive (with children sometimes inappropriately attending with adults); and the view that care workers of appropriate age should work with disabled children (especially teenagers).

## BELINDA

Belinda cares for her 26-year old daughter who has suffered from a physical disability since birth. Belinda works part-time at a pharmacy, and can do so because her daughter accesses both day care and respite facilities. In the past, Belinda had a career in a bank, but she had to give this up when her daughter was born; she believes women's careers are ended by the demands of such caring roles. Although Belinda feels there are far more services available now than in the past, she feels there are few provisions in place for crises: for instance, her husband cannot easily get time off from his own full-time post, so the onus of care would fall on her. She is also resentful of the fact that as she approaches state pension age, she will soon lose her Carer's Allowance. However, she is generally happy with the services she receives. Female, age group 60-64, part-time employed

**Learning disability:** Those caring for someone with a learning disability were particularly likely to mention a lack of understanding among social services (including a lack of recognition of certain conditions), and their need for better respite services. They emphasised the importance of being able to spend time with other members of the family, including (among carers of disabled children) with their other children. While some in this group felt both they and their disabled children were well supported, others claimed that services arranged through the schools their children attended were not sensitive or responsive to their child's individual needs. In these cases, this caused many problems and considerable distress.

#### **PAUL**

Paul cares for his wife, who has a number of debilitating medical problems, and for his ten year-old son who has Attention Deficit Disorder, Tourette's Syndrome and panic attacks. Paul would like to seek work, but finds it impossible to do so, since his caring role takes up all his time; he is also suffering from stomach cancer. Paul has access to Crossroads and has a good care worker involved in his son's care. However, Paul wishes social services were not involved in his care situation because he believes they are poorly organised and have little understanding of its demands. His experience of social services has involved their blaming him and his wife for his son's anti-social behaviour; Paul believes that social services are inconsistent and self-serving.

Male, 35-49 age group, unemployed

**Long-term illness:** Our interviewees who were caring for someone with a long-term illness often noted their 'lack of choice' about having to leave paid work to care, sometimes noting that this was something they were very willing to do. Some in this group commented on what they felt was poor practice among service providers (sometimes making them extremely wary about using services again), and the need to 'build up' services over the months and years - starting with whatever they could get, and gradually, often with much effort, developing the full range of support they needed.

#### **JOHN**

John has cared for his wife for five years, since she developed MS. Although John enjoys a flexible working relationship with his employer, he nevertheless has to rely on his mother-in-law to care for his wife so that he can continue to work. John says he is unable to access any Home Care services because he earns more than is allowed to qualify for free support. His wife cannot claim incapacity benefits because she was not in paid work before the sudden onset of her condition. John is frustrated by this situation, and has contacted his local MP to see if the system can be changed; but finds it cannot. As John's mother-in-law is now getting old, he is uncertain about whether she will be able to continue caring, and although John wishes to remain in work until retirement, he is unsure if this will be possible. He fears he may be forced to quit his job in order to care, a step which he thinks will reduce him to poverty, and make him eligible for appropriate Home Care services.

Male, 35-49 age group, full-time employed

**Terminal illness:** Those who were dealing with the terminal illness of a loved one were often doing all they could to keep life 'as normal as possible' until the cared for person died, and many were caring during a relatively short but very intense period of care; in these circumstances everything else in the carer's life tended to be pushed aside to focus on care. Among our sample, experiences of palliative care services varied; some carers were full of praise and felt the services they received enhanced their lives at a difficult time; others lacked adequate support and found this extremely difficult and upsetting. In one case, a carer in relatively affluent circumstances, paying for services from family resources, had a particularly poor experience, highlighting the fact that financial wellbeing does not solve all problems for carers. Within their workplaces, too, carers supporting someone who was terminally ill also had mixed experiences: some found their colleagues and managers unhelpful, causing them great stress and further worry, while others noted, and greatly valued, the consideration and flexibility they were receiving at work.

## **BRENDA**

Brenda cared for her mother who died from breast cancer two years ago. Brenda had a good working relationship with her employer and was allowed to work from her parents' home during significant periods of the care, even though she was located in Cambridge and her parents lived in Jersey.

Brenda often had to travel back and forth from her own home, and found this a very demanding time, as her father suffered a mental breakdown during his wife's terminal illness. Brenda did not access social services, because a private hospice was able to provide sufficient support.

Female, 25-34 age group, full-time employed

**Sensory impairment:** When the cared for person's needs related primarily to a sensory impairment, carers often commented on that person's desire for autonomy and independence. Here the independent living agenda for disabled people was especially important, and many of these carers indicated that they did not really consider themselves to be, or to think of themselves as a 'carer'.

## **BRIAN**

Brian cares for his 17-year old daughter who has been completely deaf since contracting meningitis at three years old. Brian works full-time, and says his caring role does not affect his job. Nevertheless, there are other challenges, including the additional attention his daughter requires, sometimes to the neglect of Brian's two other children. Additionally, Brian's wife has suffered depression as a consequence of their daughter's condition and the demands of care; Brian has had to provide emotional support for his whole family. Social services have not provided much support, and Brian has contacted independent organisations for help and advice. The whole situation is now stable.

Male, 50-59 age group, full-time employed

# Conclusion

This report has explored five issues to do with diversity in the experience of being a carer: carers and ethnicity; caring in rural and urban areas; carers in different financial circumstances; carers and their own health; and caring in its various personal contexts. Our original objectives for this part of the work also included exploration of the situation of carers in the gay and lesbian community, a group we worked hard to access and research<sup>17</sup>, but from which we were not able to achieve more than a very small number of responses. Using evidence from the *Carers, Employment and Services* study, also discussed in further depth and detail in the other reports in the CES Report series, we have shown in this report that many of the key issues which matter to carers are common concerns across different groups.

Like other carers, most carers in ethnic minority groups willingly give care to those in their families who need support, and wish to integrate their caring roles with other aspects of their lives. They believe good, reliable local services should be available to assist them in doing this, and feel that their employers should respond to their changed circumstances flexibly and with consideration. They take pride in the care they give, but do not accept that caring should carry the penalties of social isolation, inadequate income, damaged health or foregone jobs, careers or work roles. They want and need better access to information, to have more of a say in the way services are designed and delivered,

and to be respected and acknowledged for the caring contribution they make.

These concerns are also shared by carers in both rural and urban settings, and are important to carers across the full spectrum of wealth and poverty. Sensitive, tailored support, designed with their own personal and working life, family circumstances, values and beliefs matters to, and would be welcomed by, most carers. It has particular significance where needs relating to a different language, customs or traditions exist, or differ from mainstream practices - but the principles which need to guide service development, practices and standards are the same. Wherever they live, whatever their cultural background, whatever their standard of living, what carers really require is to be supported in ways which empower them, and those they care for, to live their lives as others can. This means being able to participate in work, social activities and family life; having a voice in the health and social care arrangements which affect them in their everyday lives, and being able to make their own choices, to take a break when they need it, and to find support quickly in a crisis or when their caring role changes or becomes especially difficult or demanding.

Carers' health has emerged as a key issue in this report, for poor health is strongly associated with caring, especially over a long period, or when caring

demands are intense. It seems that caring without good support is bad for carers' health, a situation which inevitably carries a range of further risks, including the likelihood of additional demand for healthcare and social services. Those in poor health report greater dissatisfaction with service provision, and when health is poor or declines, other problems – poverty, access to information, frustration and stress as problems mount – become more acute too.

There are major challenges here for public policy, for government, politicians, public servants and local agencies, at a time when, although the need for care is increasing, the resources and staffing available for paid care at home continue to be tight and under pressure. As we argue in more detail in Report 6 in the CES Series (*Carers, Employment and Services: time for a new social contract?*), fundamentally, the issues at stake are about equality for carers; about their right to have equal opportunities for work, family life and personal wellbeing, and to have access to responsive support and services which treat them with dignity and respect for the contribution they make. We judge that to achieve this, carers need specific rights protecting them from discrimination and giving them entitlements to equal opportunities and fair treatment, and that to achieve this, changes to equality legislation are needed. Our full range of recommendations for addressing these issues, based in the analysis presented here and in the other CES Reports, can be found in Report 6.

## 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. 3). 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. Translated versions of the questionnaire were available to those respondents requiring them. 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. 19% of the carers interviewed face-to-face (25 of 134 interviewees) were from ethnic minority groups. 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

- <sup>1</sup> 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.
- <sup>2</sup> A full description of the study methodology is available in CES Report 6. Appendix 1 to this report provides an outline of the main elements of the study relevant to the analysis presented here.
- <sup>3</sup> The 10 localities selected were all areas where a single local authority had responsibility for the provision of social care services: Hertfordshire; West Sussex; Southwark, Leeds, Sheffield, Sandwell, Falkirk, East Ayrshire, Anglesey and Swansea.
- <sup>4</sup> The question asked 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?'
- <sup>5</sup> Salway, S, Platt, L, Chowbey, P, Hariss, K and Bayliss, E (2007) *Long-term ill health, poverty and ethnicity* Bristol: Policy Press/Joseph Rowntree Foundation; Platt, L (2007) *Poverty and ethnicity in the UK* Bristol: The Policy Press and Joseph Rowntree Foundation; Palmer, G and Kenway, P (2007) *Poverty rates among ethnic groups in Great Britain* Bristol: The Policy Press and Joseph Rowntree Foundation.
- <sup>6</sup> Harper, S and Levin, S (2005) 'Family Care, Independent Living and Ethnicity' *Social Policy and Society* 4:2, pp157-169.
- <sup>7</sup> The 'White Other' category includes Romany Gypsies, Turkish Cypriots, people from the former Yugoslavia, and other people of Eastern European origin, as well as people from other European countries, South Africa, USA, Canada, Australia and New Zealand.
- <sup>8</sup> In a sample of this size, statistical analysis is not meaningful at a more detailed level of analysis. We therefore present data about the non-White group together. 216 carers from ethnic minority groups (11.6% of all respondents who reported their ethnicity) responded to the survey: Indian (32); Black Caribbean (28); Black African (24); Pakistani (14); Chinese (10); White Irish (32); White Other (50); Mixed groups (14); Other Black (2); Other Asian (3); Other ethnic groups (7). 23 carers chose not to report their ethnicity.
- <sup>9</sup> *Real change, not short change: time to deliver for carers*, London: Carers UK 2007.
- <sup>10</sup> Both of the latter involve asking for very detailed information about incomes, complicated by the situation with regard to benefits and outgoings (such as mortgage repayments) in each case - details which they might not wish to disclose, would be difficult to interpret, and might reduce their willingness to take part in the research.
- <sup>11</sup> Power, C, Atherton, K, Strachan, D P, Shepherd, P, Fuller, E, Davis, A, Gibb, I, Kumari, M, Lowe, G, Macfarlane, G J, Rahi, J, Rodgers, B and Stansfeld, S (2007) 'Life-course influences on health in British adults: Effects of socio-economic position in childhood and adulthood.' *International Journal of Epidemiology*, Vol.36 (3):532-9.
- <sup>12</sup> Buckner, L and Yeandle, S (2006) *Who Cares Wins: the business and social benefits of supporting working carers: statistical appendix* London: Carers UK.
- <sup>13</sup> Buckner, L and Yeandle, S (2006) *Who Cares Wins: statistical appendix* London: Carers UK, p. 11.
- <sup>14</sup> MacKenzie, CS, Smith, MC, Hasher, L, Leach, L & Behl, P (2007) 'Cognitive Functioning under Stress: Evidence from informal caregivers of palliative patients' *Journal of Palliative Medicine*, Vol.10, no.3, 749-758.

- <sup>15</sup> While most carers in the study were caring for only one person at the time of the survey, a minority were caring for two or more persons who were frail, sick or disabled. This, and the fact that some of those cared for suffer from more than one condition, should be borne in mind in interpreting the tables in this part of the report.
- <sup>16</sup> Stiell, B, Shipton, L and Yeandle, S (2006) *Caring for Sick or Disabled Children: parents' experiences of combining work and care* London: Carers UK.
- <sup>17</sup> In this part of the work, despite intensive efforts and the support and co-operation of a range of local and national organisations in the GLBT community, which publicised the study, we were not successful; only a handful of respondents were from, or chose to identify themselves as belonging to, these groups. These difficulties in accessing gay and lesbian carers, and other incidental evidence, lead us to believe that this may be a group of carers who are not accessing the services they need, and may be in particular need of specialist support.







## 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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