



# Carers, Employment and Services in West Sussex

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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.

## Key Findings from the CES survey of carers in England, Scotland and Wales

Demand for care is growing, with more people needing to combine work and care.

In the CES survey, working carers told us that:

- Most had not had their needs assessed.
- Many were supporting someone who was not receiving services.
- Most had help from family and friends.
- Over half had a 'carer friendly' employer.
- Only a quarter had adequate support from formal services to enable them to combine work and care.
- Most named at least one service that was needed but was not currently received.

## Key Findings about carers in West Sussex

**In West Sussex 37,189 people have both a paid job and unpaid care responsibilities, supporting a relative, partner or friend who is sick, disabled or frail.**

**They include:**

**15,690 MEN** (71% of male carers)

**and**

**9,644 WOMEN** (33% of female carers)

who combine unpaid care with **FULL-TIME employment**

**and**

**1,799 MEN** (8% of male carers)

**and**

**10,056 WOMEN** (35% of female carers)

who combine unpaid care with **PART-TIME employment**

**5,957** people (16%) provide 20 or more hours of unpaid care each week

West Sussex's official return to the *Commission for Social Care Inspection* showed that in 2005-6, the county had succeeded in assessing the needs of 1,350 carers of working age. As elsewhere in England, the numbers of carers being assessed has been growing since assessment was introduced, but this figure nevertheless represents only a very small percentage of all carers of working age in the county.

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This report focuses on the situation of carers living in West Sussex. It uses official statistics and new data from the CES survey to explore the extent of unpaid caring among people of working age in the county, and examines the circumstances of employed carers who live in West Sussex and the views of those who took part in the study. There were 154 responses to the survey from carers of working age living in West Sussex: 76% were providing 20+ hours of care per week and 53% were in employment. 10 of the 134 CES in-depth interviews with carers were with West Sussex carers. This report outlines the support available to working carers in West Sussex, highlights innovation and service developments, and offers a contribution to the current policy debate about the role of carers in the delivery of social care in Britain, and about carers' need for support.

# Introduction

## About the study

This report is one of a series<sup>1</sup> relating to the Carers, Employment and Services (CES) study conducted in 2006-7 at the University of Leeds, commissioned by Carers UK.

The CES research team is based in the *Centre for International Research on Care, Labour and Equalities* (CIRCLE) at the University of Leeds. The CES study was funded by the European Social Fund and commissioned by Carers UK, lead partner of the Action for Carers and Employment (ACE) partnership, with funds allocated through the EU EQUAL Community Initiative Programme, 2005-7.

The study<sup>2</sup> included a national survey targeting carers of working age (1909 responses), and an in-depth study in West Sussex and 9 other localities in Britain based on interviews with carers (134), an investigation of local policy and provision relating to carers of working age, and detailed analysis of the 2001 Census<sup>3</sup>.

## 1. Carers and Employment in West Sussex

In this part of the report we consider carers of working age in West Sussex, focusing on the growing demand for care, the characteristics of carers of working age, and the circumstances of those carers who are combining their unpaid caring role with paid work.

### Demand for Care

*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.*

Changes in the age structure of the population and advances in medicine are increasing the demand for care and drawing more people into unpaid caring roles. In West Sussex in 2001 over 97,600 households (30% of all households) contained at least one person with a limiting long-term illness (LLTI). The county's population of people aged 85+ is set to increase by 11,300 people (up 51%) by 2021<sup>4</sup>. In this age group 66% of people already report having a LLTI, and 26% are in poor health. These figures have risen since 1991, when 41% of the 85+ group had a LLTI<sup>5</sup>.

The 2001 Census showed West Sussex had 73,341 carers providing support for their friends and relatives who needed help:

- 116,726 people in West Sussex have a LLTI, among them 42,988 who are also in poor health.
- With age, many older people become frail (23,134 people in West Sussex were aged 85 or older).
- Disability and other conditions have increased.

They included 2,350 parents who identified themselves as carers in households which contained a sick or disabled child<sup>6</sup>.

We estimate that, in West Sussex alone, the care these unpaid carers provide would cost £951million to deliver using paid support<sup>7</sup>. Most carers give their help willingly, and wish to work in partnership with health and social service providers; often they enable those they care for to remain at home where they wish to be. All commentators expect demand for care to increase in coming years.

In 2001, 5% of carers in West Sussex (almost 9,000 carers) belonged to ethnic minority groups

(Figure 1), a percentage a little below their share of the county's total population (6%). This is not surprising, given the younger age profile of ethnic minority groups. Among those of working age, Indian and Pakistani men and Pakistani and Bangladeshi women have higher rates of caring than White British men and women. In CES Report 6 we show that these higher rates of caring are related to higher rates of sickness and disability in ethnic minority households.

**Figure 1 Carers in West Sussex by ethnicity**

Source: 2001 Census Standard Tables, Crown Copyright 2003.

Note: Data in this figure are for carers of all ages.

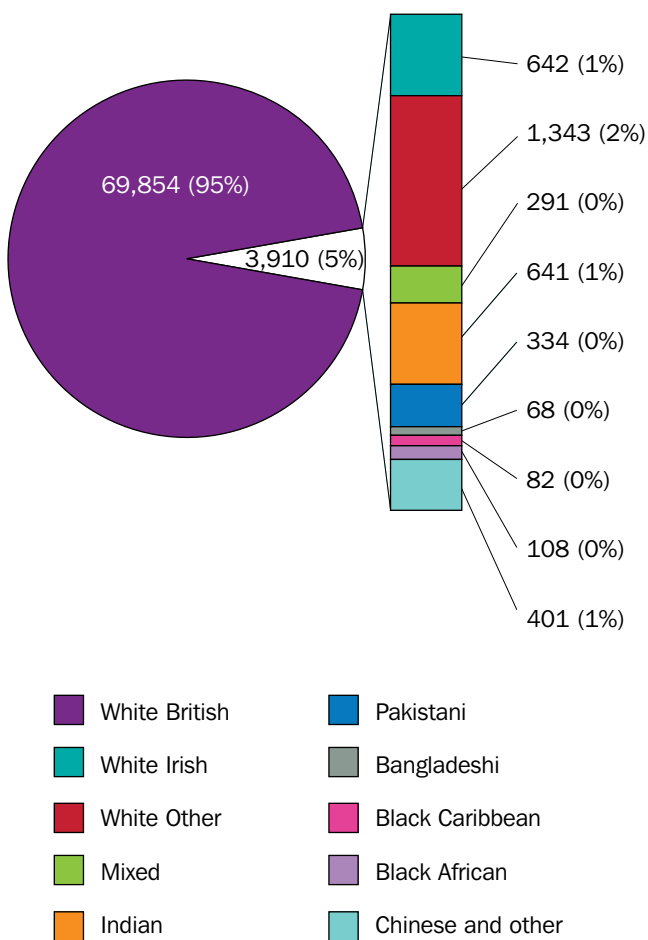
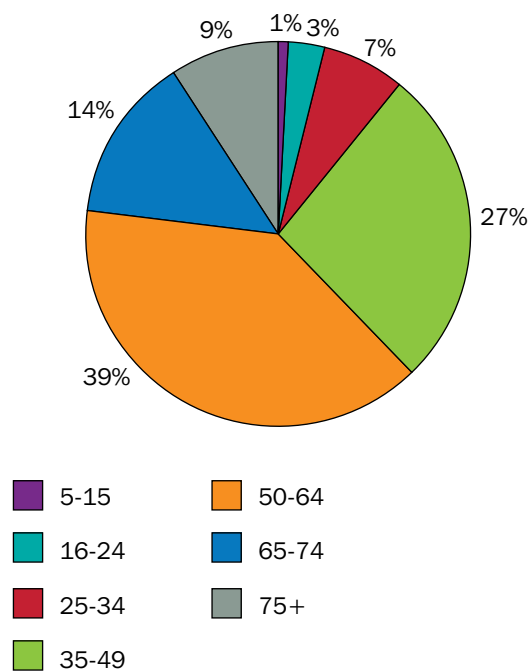


Figure 2 shows all carers in West Sussex by age: 1% of carers were under 16, and 23% were aged 65+, but most were people of working age. In fact two thirds of carers in the county were aged 35-64, for many people years in which their career or earnings are very important.

**Figure 2 Carers in West Sussex by age**

Source: 2001 Census Standard Tables, Crown Copyright 2003.



Within West Sussex, caring is particularly concentrated in areas of socio-economic deprivation (see Figure 3). 13% of carers in West Sussex live in workless households (9% of carers providing 1-19 hours of care a week, 19% of carers providing 20-49 hours and 32% of carers providing 50+ hours), compared with 8% of people who are not carers<sup>8</sup>.

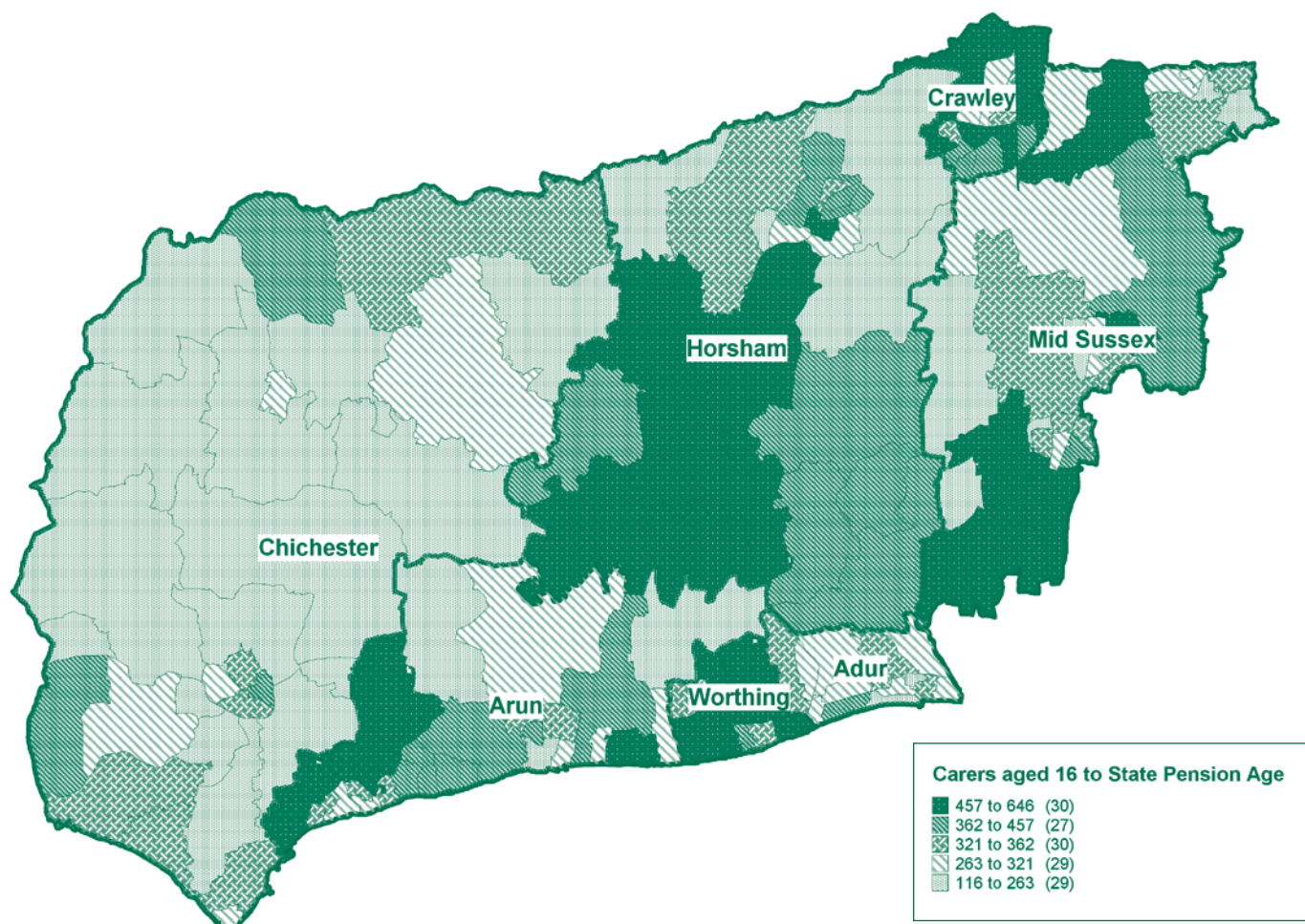
### Carers of Working Age

70% of carers in West Sussex (51,293 people) are of working age; 43% are men and 57% women. Their economic activity status and weekly hours of care are shown in Table 1.

Among people of working age, the likelihood of being a carer rises with age (Figure 4). Among male carers in West Sussex, most also hold paid jobs. 65% of men who care for 20-49 hours per week have full-time jobs, 8% work part-time, and 4% are unemployed and seeking work. 7% care for their family full-time, 6% have retired early and 7% are themselves sick or disabled. Even among those men who have very heavy caring roles (50+ hours per week) 49% are in full-time paid work. However these male carers also have high rates of sickness and disability (13%), and a significant minority care for their family full-time (16%).

**Figure 3 Carers of working age in West Sussex by geographical distribution within the county**

Source: 2001 Census Area Statistics, Crown Copyright 2003. This work is based on data provided through EDINA UKBORDERS with the support of the ESRC and JISC and uses boundary material which is copyright of the Crown; 2001 Census, Output Area Boundaries, Crown Copyright 2003. Note: In the key, figures in brackets indicate the number of Super Output Areas (each approximately 637 households) in the relevant category.

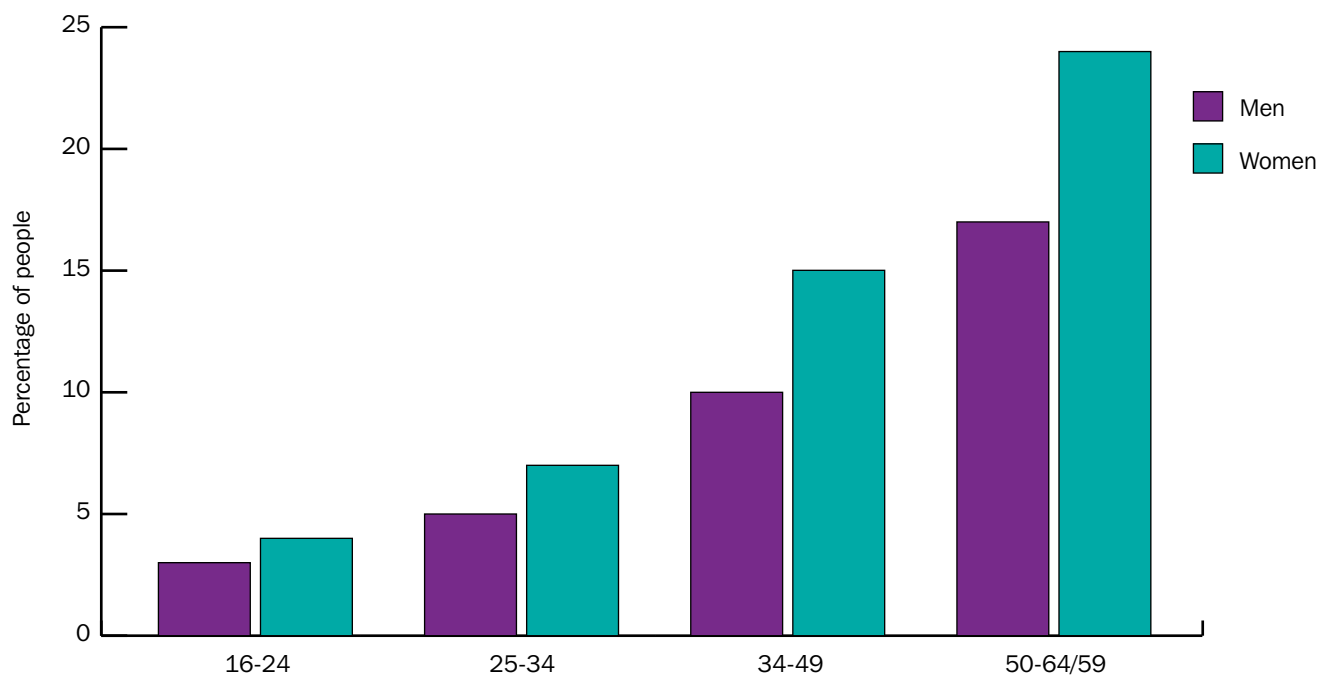


**Table 1 Carers of working age in West Sussex by sex, employment status and weekly hours of care** Source: 2001 Census Standard Tables, Crown Copyright 2003.

	Men (16-64)			Women (16-59)		
	Caring 1-19 hours	Caring 20-49 hours	Caring 50+ hours	Caring 1-19 hours	Caring 20-49 hours	Caring 50+ hours
<b>All of working age</b>	18,001	1,757	2,493	22,299	2,454	4,289
In full-time work	13,333	1,133	1,224	8,171	717	756
In part-time work	1,503	135	161	8,225	766	1,065
Unemployed	450	65	55	416	44	54
Permanently sick or disabled	536	117	334	523	149	310
Looking after home/family FT	153	128	395	3,244	564	1,826
(Early) retired	1,349	106	228	746	78	113

**Figure 4 Percentage of people in West Sussex who are carers by age and sex**

Source: 2001 Census Standard Tables, Crown Copyright 2003.



Three-fifths of female carers who care for 20-49 hours per week have paid jobs too. They are fairly equally divided between those in full-time (29%) and those in part-time paid work (31%), while 6% are themselves sick or disabled and 23% care for their family full-time. Among women who care for 50+ hours per week, 18% work full-time and 25% part-time, while in this group 43% care for their family full-time, and 7% are sick or disabled themselves.

Working carers are thus a very important group, yet, as we will see, many feel poorly supported, suffer impacts on their health and financial position, and feel they need more help from formal services.

### Working Carers

We know from the 2001 Census that across Britain, carers are found in all occupations and in all industries, making working carers an important part of virtually every workforce throughout the whole economy. The occupations of employed men and women in West Sussex (indicating their level of unpaid care responsibility) are shown in Figure 5. Carers who provide 20 or more hours of care per week are more strongly concentrated in lower

level jobs than other workers, a picture also seen at national level. Both male and female carers are more likely to work in 'routine' occupations, and less likely to work in managerial or professional jobs, if they care for 20+ hours per week.

The CES survey was designed to explore the circumstances of working age carers in more depth. It obtained responses from 1,909 carers, including 812 working carers. 224 respondents were carers living in West Sussex. While not fully representative of all carers in the county, the information provided by these carers gives some insight into carers' circumstances and into what combining work and care is like for someone living in the county.

- 21% of West Sussex carers told us their health was 'not good' (26% of our whole GB sample).
- 61% of West Sussex carers had been caring for 5 or more years (68% of our GB sample).
- 79% of West Sussex carers provided 20+ hours of care per week (82% of our GB sample).
- 24% of West Sussex carers were struggling to make ends meet (33% of our GB sample).

Like carers elsewhere in Britain, West Sussex carers often felt their use of services was limited because:

- Services are too expensive (39% compared with 33% of our whole GB sample).
- They do not like the way services are organised (27% compared with 31% of our whole GB sample).
- There are no suitable services in their area (23% compared with 32% of our whole GB sample).
- Services are not reliable (26% compared with 30% of our whole GB sample).
- Services are not flexible (31% compared with 46% of our whole GB sample).
- Services are not sensitive to needs (37% compared with 44% of the whole GB sample).
- They do not know what is available locally (39% compared with 31% of our whole GB sample).
- The cared for person does not want to use services (53% compared with 37% of our whole GB sample).

In West Sussex, 72 respondents were carers of working age (16-64) who were not currently in paid work. Of these:

- 17 had retired early from a paid job.
- 5 were looking for work
- 36 were looking after home and family full-time
- 12 were themselves sick or disabled
- Over a third (35%) would prefer to be working (compared with 39% of all GB carers).

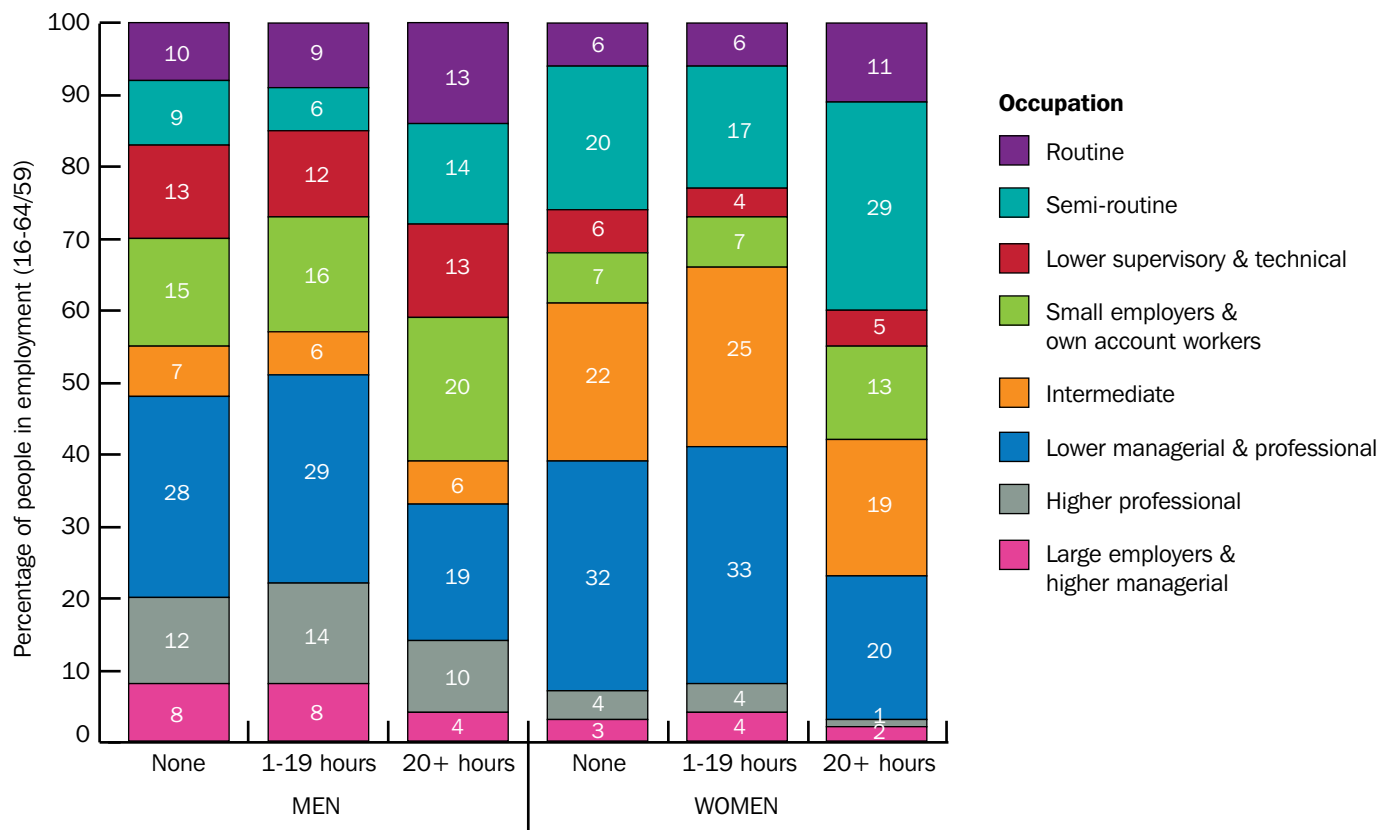
West Sussex working carers in the CES survey included:

- 11 men and 69 women.
- 23 people working FT and 51 people working PT.
- 24 people caring for a sick or disabled child.
- 25 people caring for a partner or spouse.
- 29 people caring for a parent or parent-in-law.

Some of the views expressed by working carers about the way they are supported – by family and friends, in the workplace, and by formal services – are indicated in the next section of this report, which also highlights some contrasting examples of carers’ experiences in West Sussex. A much fuller discussion of all the study findings can be found in the CES national Reports.

**Figure 5 People in employment in West Sussex by caring responsibilities and socio-economic group**

Source: 2001 Census SAM<sup>8</sup>. Note: Data in this figure are for men aged 16-64 and for women aged 16-59.



## Combining Work and Care

Many carers in West Sussex are working carers: in 2001 15,690 men and 9,644 women were combining care with full-time employment (71% and 33% of male and female carers respectively), while a further 1,799 men and 10,056 women were providing unpaid care while working part-time (8% and 35% of male and female carers respectively). Table 2 shows working carers' views as expressed in the CES survey.

The carers who gave us face-to-face interviews in West Sussex highlighted a number of important issues. As elsewhere, they often found maintaining paid work a challenge, and some had been forced to leave their jobs:

*I can't see how they [employer] could have kept me on, on those terms, because caring for someone with mental health, you never know what the day's going to bring.*

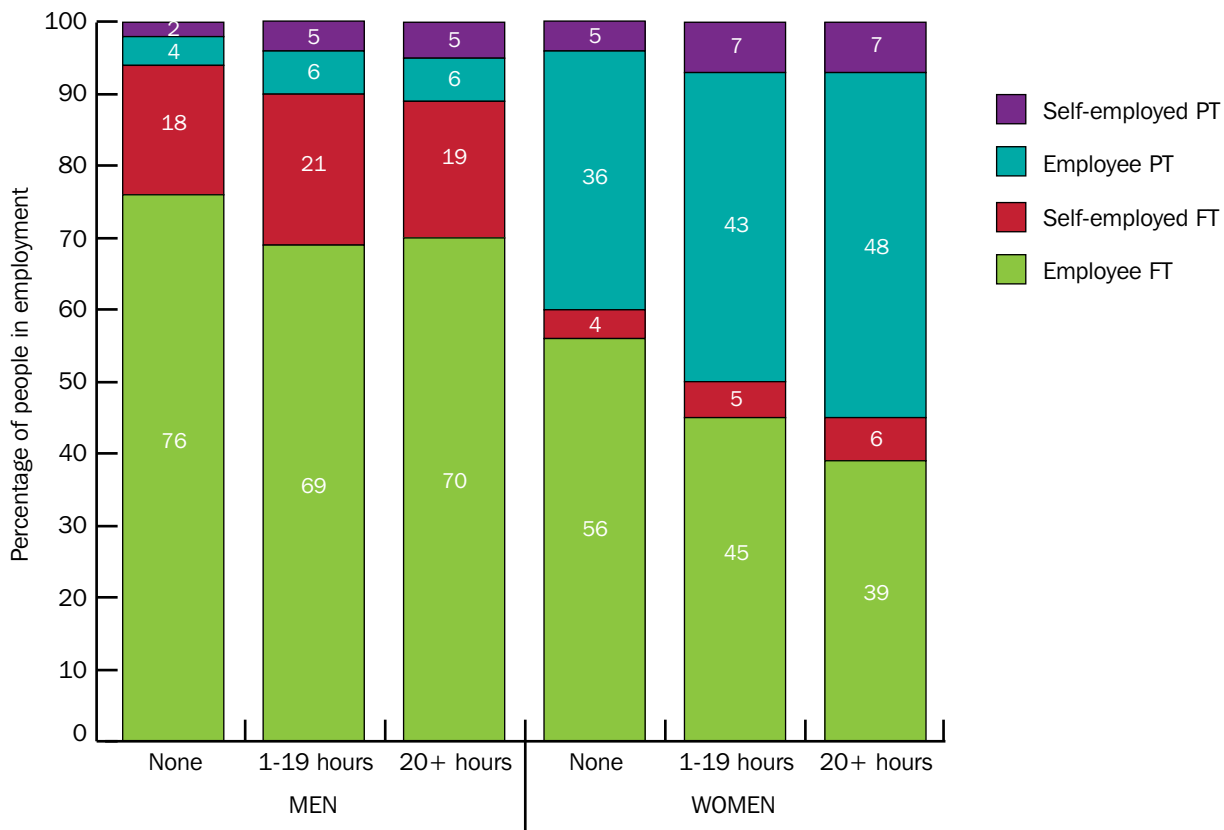
**Table 2 Carers' views on combining work and care**

Source: CES Survey, University of Leeds, 2007.

% in paid work agreeing that: number =	West Sussex 80	GB 786
I have adequate services to enable me to work	27	27
My employer is carer-friendly and I feel supported at work	53	58
I rely on family and friends to enable me to work	61	70
I am considering giving up my job	30	39
My caring responsibilities do not affect my job	28	22

**Figure 6 People in employment in Hertfordshire by caring responsibilities and employment status**

Source: Census Standard Tables, Crown Copyright 2003. Note: Data in this figure are for men aged 16-64 and for women aged 16-59.





*I had to gradually give up working, the more and more I couldn't leave him.*

For most, a job was a financial necessity; some also valued their paid work as a break from caring. Many had found accessing appropriate services a struggle; obtaining support at the immediate point of need was particularly problematic.

*I foolishly thought there might be something in the benefits system which might help me.*

Many reported that the demands of caring left little time for other aspects of life:

*I'm a father (too) 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.*

Two carers in the county described their experiences in ways which highlight what can be achieved when carer support is flexible and responsive, and tailored to their particular circumstances.

### **NORMAN'S EXPERIENCE**

*"Basically, you're not depressed, basically you're a carer, and you don't realise it."*

Norman cares for both his wife who has muscular problems and his daughter who suffers from ME. After a spell of illness, Norman visited his GP and was told that he was doing too much while caring alone. Norman was referred to social services, and through this he and his family were provided with assistance from paid care workers who now help with domestic chores.

Norman's paid work is located outside his home district and he has found his employer very unsympathetic to his caring circumstances. Although he appreciates the help now received through social services, Norman is looking for a new job because he feels he lacks the flexibility – either at home or in the services received – to cope when the demands of caring fall outside the scope of the services received.

He would like a little more assistance from care workers, but he feels other people have even greater caring needs than his own, and he refuses to apply for anything else.

**Norman** has been able to maintain his employment, despite the demands of caring for a two members of his family, because of the support he has secured. The pressure he faces now comes in maintaining his routine of work and care in the face of his employer's negative attitude and the level of services his family receive.

**Luke** has also been able to carry on working full-time and caring. He has invested considerable effort into making Direct Payments work for his family; shortages of care workers have meant that it has taken several years to put satisfactory arrangements in place.

### **LUKE'S EXPERIENCE**

*"Finding carers is a big problem in this area because there's nil unemployment and it has been for many years because of the airport – you know, there's plenty of work."*

Luke cares for both his wife who is registered disabled and his daughter who has learning difficulties. Luke uses Direct Payments as a way of employing suitable care workers, a system which works well for him as it allows him to continue working full-time. However, a related difficulty is that appropriate staff are hard to find in an area with alternative job opportunities. He has had to pay high rates to get properly qualified staff, though he feels that this is a good thing because the care workers have grown close to his family and are thoroughly dependable. Luke also regards himself as fortunate to have recourse to flexible working hours.

Although he claims that Direct Payments are demanding on account of all the paperwork involved, he also considers himself lucky in the sense that he knows exactly what he is entitled to and how to go about getting it, even though it has taken several years to reach this position.

These examples highlight weaknesses in current arrangements, but also illustrate the transformative power of high quality, accessible services. These can improve the quality of life for individual carers and their families, enable carers to participate in paid employment and contribute to the support of their

families, and put their skills to work in the formal economy – where securing an adequate labour supply is an increasing problem for local employers.

In England, Wales and Scotland, many carers in the CES study lacked confidence in the ability of statutory agencies to respond quickly and appropriately to their situation, and, because of this

and other problems in securing support, some were at risk of giving up work.

We turn next to arrangements for supporting carers of working age, especially those who are in paid employment, both nationally and in the county of West Sussex.

## 2. Support for Working Carers

### National Policy Context

Over the past decade, professionals and practitioners have been working in closer partnership with carers of those using social care services. Underpinning their approach has been an emerging understanding of the key role carers play in the delivery of health and social care, and a growing recognition of the importance of acknowledging their contribution and treating them with dignity and respect. Since 1995, carers have been recognised in law, and new legislation has been passed which provides carers with a limited range of rights and entitlements.

The legislation and policy now in place (Figure 7) secures: carers' right to 'emergency leave' from work to deal with caring crises; the right to request flexible working arrangements (since April 2007<sup>9</sup>); and a right to an assessment of their own needs which takes their wishes with regard to education, training, employment and leisure into account (since 2005<sup>10</sup>).

These recent changes have placed new statutory obligations on local authorities, employers and others. Since 1999, government has also allocated special funding (Carers Grant) to local authorities to help them deliver better support for carers. In West Sussex, this funding allocation, in 2005-6, was almost £3.5m. Across the country, many local agencies have been innovative and resourceful in their response. However, delivering new forms of support for carers, and in particular to employed carers, has in many localities been affected by resource constraints, organisational blockages, and difficulties in building genuine partnerships. In

the workplace, and elsewhere, developments have sometimes been affected by out-of-date attitudes towards carers, or by ignorance of the ubiquity, importance and necessity of carers' roles.

### Services relevant to carers in West Sussex

Table 3 presents recent official data about Carers Assessments and about services provided to carers in West Sussex, as collected in formal returns to the *Commission for Social Care Inspection* (CSCI). While this shows that West Sussex succeeded in assessing the needs of 1,350 carers of working age in 2005-6, it should be noted that this figure represents a very small percentage of the county's over 51,000 carers of working age (over 37,000 of whom have paid jobs as well as caring roles) – a situation also seen in other parts of the country). Thus only a small minority of carers had had their own needs assessed or had received services in their own right as carers.

Evidence presented elsewhere in the CES Report Series indicates that it cannot be assumed that carers not in touch with the assessment and service provision process have only very light caring duties, or do not need or want support. Many working carers need and want better support. Their needs include more suitable services for those they care for, and information about how to secure these; information about what is available locally, and guidance about managing caring and employment.

In West Sussex steps have been taken to address these issues, and some of these are outlined below. More information about the activities and

**Figure 7 Main legislative/policy developments affecting carers in England since 1995**

\*This column highlights selected provisions, and does not aim to summarise all aspects of the development indicated.

Development	Key change for carers*
<b>Carers (Recognition and Services) Act 1995</b>	Introduced the concept of a Carers Assessment.
<b>Caring About Carers: a national strategy for carers</b> Policy statement, Department of Health (1999)	Stressed that enabling carers to combine paid work and care was a priority for government.
<b>Employment Relations Act 1999</b>	Gave employees the right to 'reasonable time off' to deal with emergencies.
<b>Carers and Disabled Children Act (2000)</b>	Gave carers the right to an Assessment (carers of adults and carers of disabled children). Allowed carers to receive services in their own right, and introduced Direct Payments to purchase these. Direct Payments offered to parents of disabled children to manage on their children's behalf.
Changes to <b>Invalid Care Allowance</b> (now known as <b>Carers Allowance</b> ) (2000)	Amendment to the <i>Social Security (Contributions and Benefits) Act 1992</i> , which included extending carers' benefits to people aged 65 and over.
<b>Employment Act 2002</b>	Gave employed parents of disabled children under the age of 18 the right to request flexible working arrangements.
<b>Children Act 2004</b>	Required local authorities to lead on joined-up service delivery through multi-agency Children's Trusts. Strong emphasis on supporting families and carers, described as ' <i>the most critical influence on children's lives</i> '.
<b>Carers (Equal Opportunities) Act 2004</b>	Placed a statutory duty on local authorities to inform carers of their rights, and to consider carers' wishes in relation to education, training and employment when conducting Carers Assessments.
<b>Every Child Matters: change for children</b> Policy document (2004)	Indicated that disabled children and children with long-term health conditions should ' <i>receive co-ordinated services which allow them and their families to live as ordinary lives as possible</i> '.
<b>Work and Families Act 2006</b>	Extended the right to request flexible working arrangements to all carers in employment, from April 2007.
<b>Childcare Act 2006</b>	Placed a duty on local authorities to provide sufficient childcare for working parents ' <i>which includes provision suitable for disabled children</i> '.
<b>Our Health, Our Care, Our Say: a new direction for community services</b> , Department of Health White Paper (2006) <b>New Deal for Carers</b> Policy announcement (2007)	Outlined an expectation that local authorities and Primary Care Trusts would identify a Carers Lead. Recommended the introduction of funds for emergency respite care, and development of an Expert Carers Programme and a national Carers Helpline. Initiated a consultation on a 'New Deal for Carers'. Package of measures relating to respite, emergency planning and help-lines for carers.
<b>Pensions Act (2007)</b>	Recognised carers' situation, and reduced the number of qualifying years carers need for a full basic state pension; introduced a new Carers Credit for those caring 20+ hours a week for someone who is severely disabled.
Revised <b>National Carers Strategy</b> (due 2008)	The UK government's consultation process on this began in 2007.

**Table 3 Carers Assessments and services provided directly to carers, West Sussex and England**

Source: Community Care Statistics 2005-06: Referrals, assessments and packages of care for adults, England: The Health and Social Care Information Centre. \* Denotes number less than 10, therefore not reported.

<b>1st April 2005-31st March 2006</b>	<b>West Sussex</b>	<b>England</b>
<b>Total number of carers assessed and reviewed</b>	5,210	388,000
Number of carers assessed or reviewed separately	500	91,000
Number of carers assessed or reviewed jointly with client	4,540	247,000
Number of carers who refused assessment	180	49,000
<b>Number of Carers Assessments and reviews undertaken by age</b>	5,030	339,000
<18	10	4,100
18-64	1,350	169,000
65-74	560	66,000
75+	3,110	100,000
Age unknown	0	0
<b>Number of carers receiving services after assessment or review</b>	1,610	284,000
<i>Carers receiving breaks or carers specific services</i>	1,290	142,000
<i>Carers receiving advice and information only</i>	330	142,000
<b>Number of carers receiving services after assessment or review by age</b>		
<18	*	3,700
18-64	460	141,000
65-74	160	55,000
75+	1,000	84,000
Age unknown	0	0
<b>Number of carers receiving services or information, by client group of cared for person</b>		
Physical disability, frailty and sensory impairment		
<i>Carers receiving breaks or carers specific services</i>	800	95,000
<i>Carers receiving advice and information only</i>	200	110,000
Mental Health		
<i>Carers receiving breaks or carers specific services</i>	200	23,000
<i>Carers receiving advice and information only</i>	0	18,000
Learning Disability		
<i>Carers receiving breaks or carers specific services</i>	100	16,000
<i>Carers receiving advice and information only</i>	40	10,000
Substance Misuse		
<i>Carers receiving breaks or carers specific services</i>	0	1,900
<i>Carers receiving advice and information only</i>	0	500
Vulnerable People		
<i>Carers receiving breaks or carers specific services</i>	200	6,100
<i>Carers receiving advice and information only</i>	70	3,000
<b>% carers receiving services following assessment or review</b>	32	84

services developed through *Action for Carers and Employment* partnership (ACE2) between 2005 and 2007, in which West Sussex County Council was a partner, are provided in CES Report 5, *Action for Carers and Employment: Impact of the ACE partnership 2002-7*.

## Policy developments in West Sussex

West Sussex County Council has played an important role in the modernisation of social care delivery, at both the local and national level, and has placed considerable emphasis on developing new ways of giving service users and their carers greater control in deciding how and where available resources are spent.

Through its involvement in the ‘individual budgets’<sup>11</sup> national pilot, West Sussex Adults’ Services is aiming to transform the way its department operates – moving away from an assessment process led by practitioners whose role is mainly to ration services, to a new system which allocates a budget to individual users and carers, enabling them to purchase the services they need.

In 2004, the CSCI noted in its ‘Inspection of Social Care Services for Older People’ in West Sussex that “users and carers were involved both in strategic planning and in planning of service development at a local level, with strong partnerships with voluntary sector and user groups”. West Sussex has a very well developed Carers Network which is a member of the Princess Royal Trust for Carers (PRTC). Corresponding to the size and geography of the county (which includes coastal, rural and commuter belt towns and villages) three carers projects operate in Chichester and Bognor, in Worthing, and in Mid-Sussex<sup>12</sup>. In the 1990s, engaging carers was accomplished through an information project using a touring bus. This approach has recently been replaced by outreach workers, employed and based at each of the three projects. The West Sussex Carers Network has been involved in both strategic planning (discussed below) and in the delivery of services funded by Carers Grant and other resources. Advocacy work has been a key element of the three carers projects, and has recently been expanded to offer information, and emotional specialist support.

*If we’re to make headway around individual budgets, self-directed support – particularly around older people – whatever we have in place needs to have the confidence of carers. Involving the voluntary sector [is very important], so that carers feel there are things in place to help them, for their benefit.*

(Senior Manager WSCC)

The county’s Carers Strategy has been drawn up through a number of interlinked structures, and based on systematic consultation with carers and carers’ organisations. At ‘grass roots’ level, a Carers Advisory Forum, open to all carers and their representative organisations, feeds views about service provision and unmet needs to the Carers Strategy Group, which is chaired by a senior manager of WSCC Adult Services and attended by practitioners in the local authority, health trust and voluntary sector. Together, this group devised the ‘Joint Strategy and Action Plan’ for carers in 2000, drawing on feedback from two county-wide carers’ conferences, run in collaboration with the Health Authority. This plan formed the basis for the ‘West Sussex Carers Strategy and Action Plan 2002-2005: Working Together to Support Carers’, recently updated and replaced by the ‘Carers Strategy 2006-2009’, following a similar process of consultation. At the political level, implementation of the county’s Carers Strategy is scrutinised by the WSCC Policy and Development Group, chaired by an Elected Member. This group also takes reports from carers’ representatives who are members of Partnership Boards within Adults’ Services (such as the Learning Disabilities Partnership Board) and the Carers Advisory Forum, or who take part in West Sussex’s Best Value Review (Carers)<sup>13</sup>.

Through these processes, West Sussex Adults’ Services has set out its ambition to increase awareness of local carers’ issues among statutory agencies and managers within the authority and to encourage them to adapt their services to better suit carers’ circumstances. Thus carers were a high priority group in the Local Area Agreement<sup>14</sup>, signed in March 2006, through which senior managers have been given specific responsibility for the development of carers’ services. The Health and Social Care NHS Trust has also been a notable partner, and despite pressure on health funding, has

worked to raise local awareness of carers' issues, using the Patient and Public Involvement (PPI) Forum (an initiative introduced nationally in 2004), and GPs' surgeries to improve referral processes and signposting to carers' services.

West Sussex also has a number of specialist posts with a 'carers remit', which the local authority sees as important in the delivery of these systems and initiatives. A member of the Adult Services senior management team (the Carers Lead) has specific responsibility for the carers' agenda, including the county's Carers Strategy and the commissioning of services using Carers Grant. A Carers Policy Officer has also been appointed, to support the Carers Lead, and plays a key role in maintaining and operationalising consultative structures and in sustaining and developing relationships with health and voluntary agencies.

Through these arrangements, West Sussex's Carers Grant resources have been allocated mainly to voluntary sector service providers. The local authority feels this is the best way of delivering a greater range of services, with greater flexibility and less bureaucracy; their approach in this was noted and approved by the CSCI inspection team in 2004.

In 2006 the West Sussex Delivery and Improvement Statement (DIS) relating to Adult Social Care

recorded some of the key outcomes achieved in the county in the area of carers' services:

- Number of breaks provided increased from 23,040 to 28,300, exceeding planned growth, however the focus on this area remains to raise the levels to that of similar councils.
- The council spends a higher proportion than similar councils on ensuring access to breaks for carers from black and minority ethnic groups.
- Considerable experience has been gained in the development of tailored respite and of the lead time for hard-to-reach groups of carers.
- Direct payments to carers have been promoted as a means of increasing carers' and users' choice and control.<sup>15</sup>

Through its involvement in the ACE2 partnership, WSCC set up the RISE project (Respite, Independence and Supporting Employment) in 2005, to support carers in remaining in or returning to work. These specialist services for working carers are discussed in more detail below.

In its role as an employer, WSCC has developed its own internal policies to improve the options available to its employees who are or who become carers, placing particular emphasis on raising their awareness of their entitlements as carers.

### 3. Issues and Challenges

Despite these achievements, reaching working carers, providing them with information and encouraging them to use carers' services is still 'work-in-progress' for West Sussex, as for all local authorities. At present the number of Carers Assessments, as a 'gateway' to services, is capturing only a small minority of all local carers – and as most of the carers receiving support were not in paid work, very few of the county's more than 37,000 working carers have had their needs assessed.

In West Sussex, as elsewhere, restrictions on Adults' Services budgets and the eligibility criteria used in identifying those who can receive support

through social services mean that it is mainly carers at the 'heavy' end of caring who get support; local experience is that many of those who are in touch with services are a long way from the labour market. Evidence in the CES study at national level suggests that it is important not to assume that such carers cannot or do not want to work; as carers' experience, up and down the country, is that they are rarely asked about their preferences, or if they need support in accessing a paid job. Carers Assessments are one vehicle for identifying ways of improving the support available to working carers – both by identifying direct help for carers

(e.g. through respite and breaks) and by delivering services to those they care for in more flexible, sensitive and situation-specific ways.

As already indicated, West Sussex Adults' Services has responded to this challenge by undertaking a number of targeted initiatives to investigate alternative ways of delivering its services – based on the rationale that improving the way in which care services are delivered to users has a positive effect on the wellbeing of the carers involved. One example is the council's collaboration with the Independent Living Association as part of its ACE project, which has focused on service users who receive Direct Payments and use this resource to employ Personal Assistants. This initiative has created a consultative network of Personal Assistants, which is developing alternative models of service delivery, including care co-operatives, and aiming to achieve the continuity of care which users and carers require.

A second challenge is delivering the changes required by the *Carers (Equal Opportunities) Act 2004*. It is recognised that promoting the right of carers to a life outside caring by safeguarding their employment and training opportunities is moving forward only slowly. As with all the CES authorities, its work in this area has mainly been delivered through pilots, special projects and short-term initiatives.

West Sussex County Council now hosts and funds a website, 'West Sussex Carers Online', which provides signposting to paid jobs in the care sector, training courses to build people's skills in undertaking a caring role, and information on carers' rights as employees. In its Carers Strategy 2006-2009, 'Carers, Employment and Training' is one of seven priorities identified. Here the approach aims to ensure that carers obtain maximum financial advantage in relation to their own individual circumstances and that they are

supported to remain economically active. Actions due to be undertaken include: training social care staff about the council's obligations under the *Carers (Equal Opportunities) Act 2004*; and, as part of the development of individual budgets to users, piloting outcome-based Carers Assessments which meet carers' educational, training, employment and leisure needs.

Carers Grant, introduced in England in 1999 as an additional resource allocation to local authority social services departments has been a very important and effective catalyst for service development, yet these funds represent a 'drop in the ocean' in achieving the transformation of services needed by working carers. Some local authorities included in the CES study were concerned about whether funding of this type would continue and about how to protect such funds as core budgets were affected by other pressures. Some argued that until a carers' perspective was adequately embedded in the thinking of all social care and health staff, core funding which supported services for users would not necessarily be allocated in ways which best support carers. As both carers and service providers told us, high quality services to users, funded out of local authorities' Adults' Services and Children's Services core budgets, are extremely important in supporting carers.

To mainstream responsibility for supporting carers in employment to all relevant local agencies – those responsible for job creation, recruitment and the supply of skilled labour, as well as local employers – is a major challenge. West Sussex County Council recognises that there are emerging opportunities in the areas of local regeneration and local strategic planning into which a focus on carers' employment could be inserted, and has used Local Area Agreements as the mechanism to bring this to council officers' attention across the council.

## Notes

- <sup>1</sup> The *CES Report Series* includes 6 titles presenting national level analysis: 1.Stages and Transitions in the Experience of Caring; 2.Managing Caring and Employment; 3.Diversity in Caring: towards equality for carers; 4.Carers, Employment and Services in their Local Context; 5. Action for Carers and Employment: impact of the ACE partnership 2002-7; and 6.Carers, Employment and Services: time for a new social contract? Separate reports relating to Scotland and Wales and to the English localities studied are also available.
- <sup>2</sup> Details of methods used are given in CES Report 6.
- <sup>3</sup> Data on carers' characteristics are from the 2001 Census Standard and Commissioned Tables, Crown Copyright 2003 and the 2004-based Sub-national Population Projections, except where the indicated source is the CES survey 2007.
- <sup>4</sup> 2004-based sub-national population projections, ONS, Crown Copyright.
- <sup>5</sup> 2001 Census Standard Tables and 1991 LBS, Crown Copyright. The question about general health used in 2001 was not asked in the 1991 Census.
- <sup>6</sup> Figure estimated using 2001 Census Standard Tables with data on households with a resident aged 0-15 with a LLTI and the number of carers in the household.
- <sup>7</sup> Buckner, L and Yeandle, S (2007) *Valuing Carers: calculating the value of unpaid care* London: Carers UK.
- <sup>8</sup> Source: 2001 SAM. The 2001 SAM (Small Area Microdata) is provided through the Cathie Marsh Centre for Census and Survey Research (University of Manchester), with the support of the ESRC and JISC. All tables containing Census data, and the results of analysis, are reproduced with the permission of the Controller of Her Majesty's Stationery Office and the Queen's Printer for Scotland.
- <sup>9</sup> Under the *Work and Families Act 2006*, which came into force in 2007. This right had previously been granted to carers who were parents of a disabled child aged under 18 in the *Employment Act 2002*.
- <sup>10</sup> Under the *Carers (Equal Opportunities) Act 2004*, which came into force in 2005, and applies in England and Wales but not in Scotland.
- <sup>11</sup> [http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Socialcare/DH\\_4125774](http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Socialcare/DH_4125774).
- <sup>12</sup> Carers Liaison Project, Regis, Chichester, and rural; Carers Liaison Service Worthing; Carers Support Services, North and Mid Sussex.
- <sup>13</sup> Each council undertakes a Best Value Review of its services. These are carried out by independent council officers, and members who evaluate a service in terms of its cost, effectiveness and efficiency against national performance indicators. Best Value reviews are then inspected by the Best Value Inspectorate which produces an independent report.
- <sup>14</sup> Local Area Agreements (LAAs) set out the priorities for a local area agreed between central government and a local area (the local authority and Local Strategic Partnership) and other key partners at the local level. They outline funding arrangements and joint service delivery.
- <sup>15</sup> West Sussex Delivery and Improvement Statement (DIS) relating to Adult Social Care (2006). In 2006/07, the *Commission for Social Care Inspection (CSCI)* has introduced changes in the performance assessment process for English local authorities, replacing Delivery and Improvement Statements (DIS) with a Self-Assessment Survey (SAS – document no. 038/07, published Feb. 2007) in order to work 'towards a set of indicators that reflects outcomes for service user/carers' CSCI *Social Carer Performance 2004/05*.

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## 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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