



# Carers, Employment and Services in Leeds

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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 Leeds

**In Leeds 35,677 people have both a paid job and unpaid care responsibilities, supporting a relative, partner or friend who is sick, disabled or frail.**

**They include:**

**14,799 MEN** (65% of male carers)

**and**

**10,186 WOMEN** (34% of female carers)

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

**and**

**1,542 MEN** (7% of male carers)

**and**

**9,150 WOMEN** (31% of female carers)

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

**6,613** people (19% of working carers) provide 20 or more hours of unpaid care each week

Leeds' official return to the *Commission for Social Care Inspection* showed that in 2005-6, the city had succeeded in assessing the needs of 370 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 city.

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This report focuses on the situation of carers living in Leeds. 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 city, and examines the circumstances of employed carers who live in Leeds and the views of those who took part in the study. There were 107 responses to the survey from carers of working age living in Leeds: 78% were providing 20+ hours of care per week and 55% were in employment. 13 of the 134 CES in-depth interviews with carers were with Leeds carers. This report outlines the support available to working carers in Leeds, 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 (1,909 responses), and an in-depth study in Leeds 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 Leeds

In this part of the report we consider carers of working age in Leeds, 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 Leeds in 2001 over 100,000 households (34% of all households) contained at least one person with a limiting long-term illness (LLTI). The city's population of people aged 85+ is set to increase by 6,300 people (up 48%) by 2021<sup>4</sup>. In this age group 73% of people already report having a LLTI, and 38% are in poor health. These figures have risen since 1991, when 51% of the 85+ group had a LLTI<sup>5</sup>.

The 2001 Census showed Leeds had 70,178 carers providing support for their friends and relatives who needed help:

- 123,347 people in Leeds have a LLTI, among them 56,487 who are also in poor health.
- With age, many older people become frail (13,378 people in Leeds were aged 85 or older).
- Disability and other conditions have increased.

They included over 2,000 people who identified themselves as carers in households which contained a sick or disabled child<sup>6</sup>.

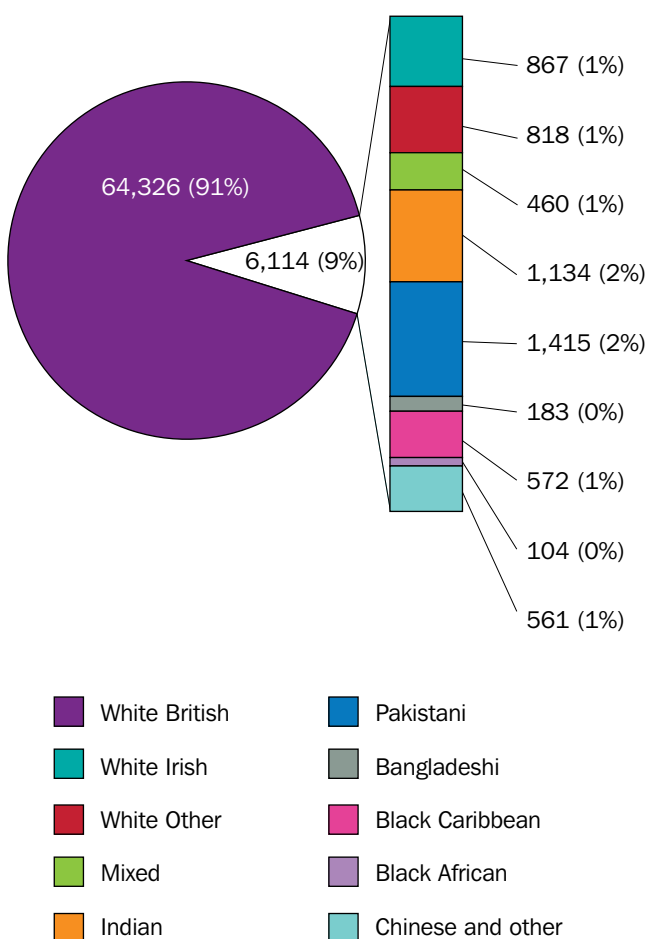
We estimate that, in Leeds alone, the care these unpaid carers provide would cost £1,017 million per year to deliver using paid support<sup>7</sup>. Most carers give their help willingly, and wish to work in partnership with health and social service providers; often they enable those they care for to remain at home where they wish to be. All commentators expect demand for care to increase in coming years.

In 2001, 9% of carers in Leeds (over 6,100 carers) belonged to ethnic minority groups (Figure 1), a

percentage a little below their share of the city's total population (11%). 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.

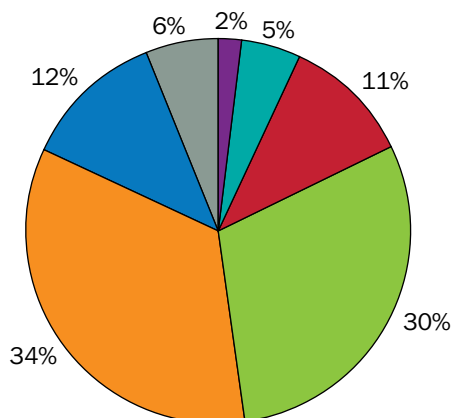
**Figure 1 Carers in Leeds by ethnicity**

Source: 2001 Census Standard Tables, Crown Copyright 2003.  
 Note: Data in this figure are for carers of all ages.



**Figure 2 Carers in Leeds by age**

Source: 2001 Census Standard Tables, Crown Copyright 2003.



Within Leeds, caring is particularly concentrated in areas of socio-economic deprivation (see Figure 3). 18% of carers in Leeds live in workless households (12% of carers providing 1-19 hours of care a week, 24% of carers providing 20-49 hours and 43% of carers providing 50+ hours), compared with 14% of people who are not carers<sup>8</sup>.

### Carers of Working Age

75% of carers in Leeds (52,805 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.

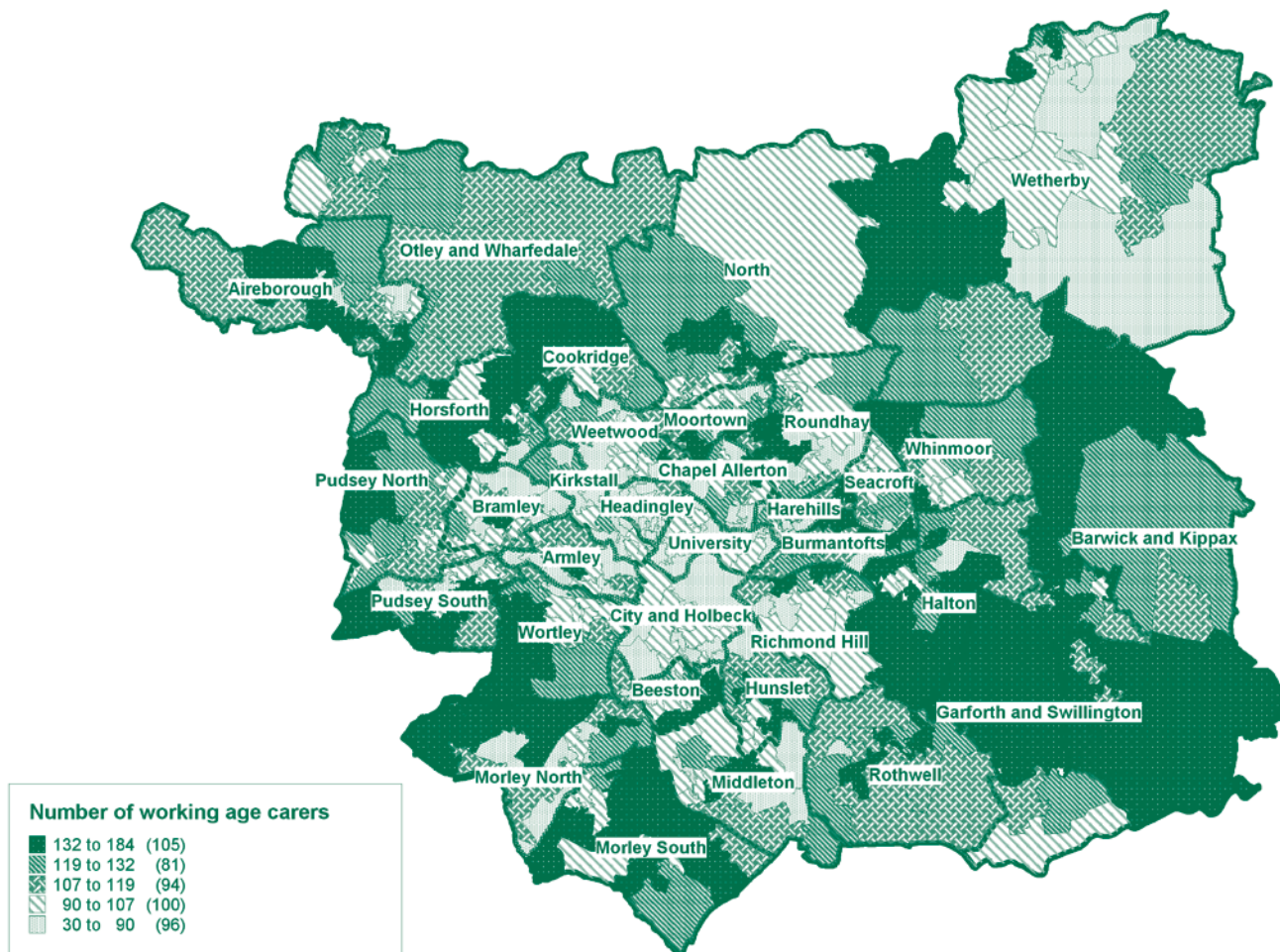
Among people of working age, the likelihood of being a carer rises with age (Figure 4). Among male carers in Leeds, most also hold paid jobs. 56% of men who care for 20-49 hours per week have full-time jobs, 7% work part-time, and 6% are unemployed and seeking work. 9% care for their family full-time, 5% have retired early and 10% are themselves sick or disabled. Even among those men who have very heavy caring roles (50+ hours per week) 40% are in full-time paid work. However these male carers also have high rates of sickness and disability (19%), and a significant minority care for their family full-time (19%).

Figure 2 shows all carers in Leeds by age: 2% of carers were under 16 and 18% were aged 65+, but most were people of working age. In fact almost two thirds of carers in the city were aged 35-64, for many people years in which their career or earnings are very important.



**Figure 3 Carers of working age in Leeds, by geographical distribution within the city**

Sources: 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 615 households) in the relevant category.



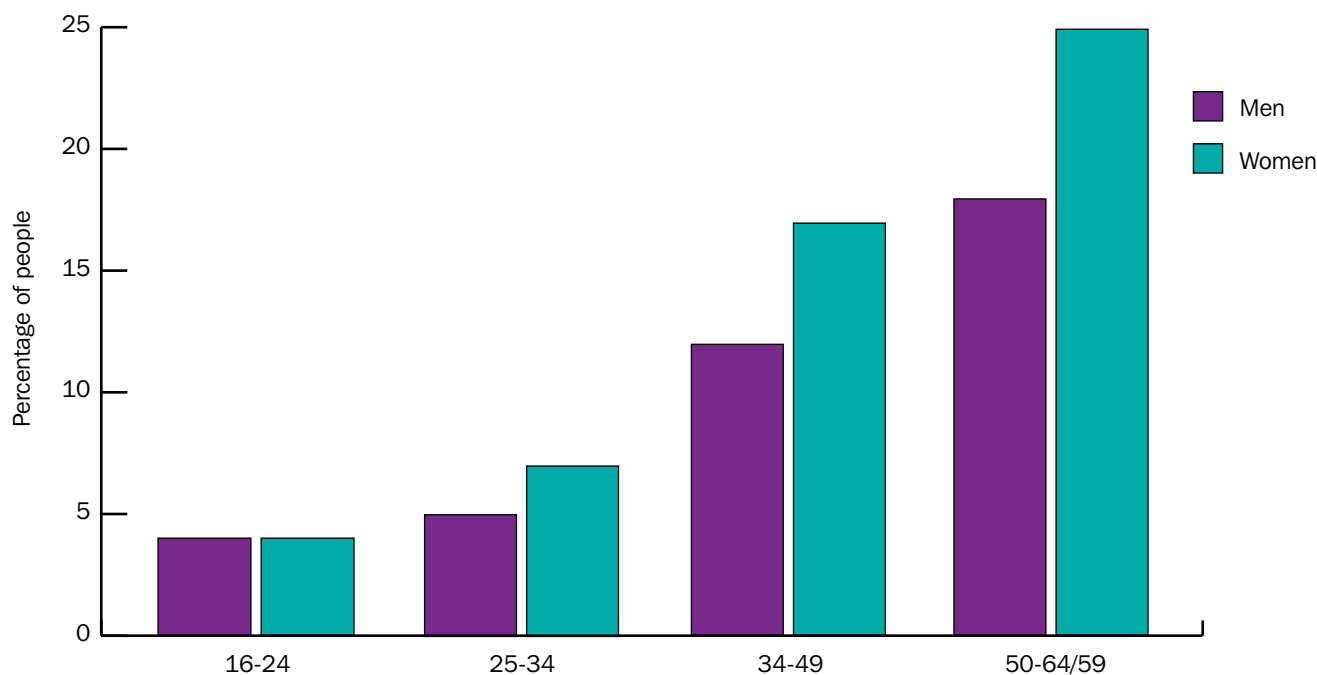
**TABLE 1: Carers of working age in Leeds by sex, employment status and weekly hours of care**

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>	17,033	2,377	3,440	21,377	3,336	5,242
In full-time work	12,093	1,334	1,372	8,569	854	763
In part-time work	1,200	158	184	7,202	896	1,052
Unemployed	726	145	158	542	91	102
Permanently sick or disabled	831	235	637	764	224	540
Looking after home/family FT	163	224	652	2,408	918	2,362
(Early) retired	989	124	254	595	93	115

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

Source: 2001 Census Standard Tables, Crown Copyright 2003.



Over half (53%) 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 (26%) and those in part-time paid work (27%), while 7% are themselves sick or disabled and 28% care for their family full-time. Among women who care for 50+ hours per week, 15% work full-time and 20% part-time, while in this group 45% care for their family full-time, and 10% 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 Leeds (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. 132 respondents were carers living in Leeds. While not fully representative of all carers in the city, 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 city.

- 29% of Leeds carers told us their health was ‘not good’ (26% of our whole GB sample).
- 77% of Leeds carers had been caring for 5 or more years (68% of our GB sample).
- 81% of Leeds carers provided 20+ hours of care per week (82% of our GB sample).
- 28% of Leeds carers were struggling to make ends meet (33% of our GB sample).

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

- Services are too expensive (26% compared with 33% of our whole GB sample).
- They do not like the way services are organised (32% compared with 31% of our whole GB sample).
- There are no suitable services in their area (35% compared with 32% of our whole GB sample).
- Services are not reliable (39% compared with 30% of our whole GB sample).
- Services are not flexible (56% compared with 46% of our whole GB sample).
- Services are not sensitive to needs (45% compared with 44% of the whole GB sample).
- They do not know what is available locally (33% compared with 31% of our whole GB sample).
- The cared for person does not want to use services (45% compared with 37% of our whole GB sample).

In Leeds, 47 respondents were carers of working age (16-64) who were not currently in paid work. Of these:

- 9 had retired early from a paid job.
- 1 was looking for work.
- 31 were looking after home and family full-time.
- 6 were themselves sick or disabled.
- Over half (55%) would prefer to be working (compared with 39% of all GB carers).

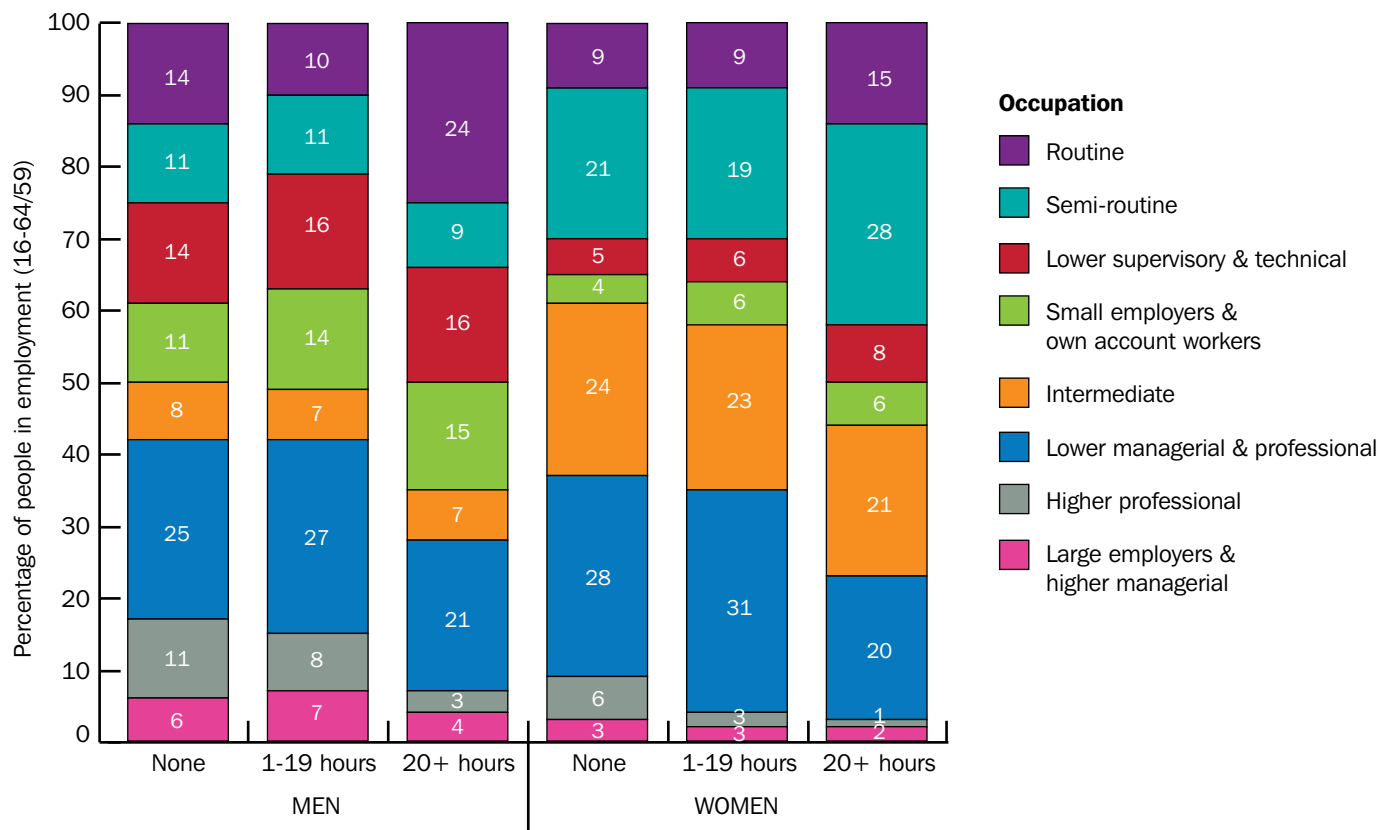
Leeds working carers in the CES survey included:

- 9 men and 48 women.
- 35 people working FT and 18 people working PT.
- 17 people caring for a sick or disabled child.
- 18 people caring for a partner or spouse.
- 23 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 Leeds. A much fuller discussion of all the study findings can be found in the CES national Reports.

**Figure 5 People in employment in Leeds 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 Leeds are working carers: in 2001 14,799 men and 10,186 women were combining care with full-time employment (65% and 34% of male and female carers respectively), while a further 1,542 men and 9,150 women were providing unpaid care while working part-time (7% and 31% 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 Leeds 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. For most, a job was a financial necessity; some also valued their paid work as a break from caring.

*I used to work full time... at first I thought oh yes this will be a doddle, it's just a matter of getting the boys into a routine. But once you become a carer it takes a long time for things to establish, my ideas*

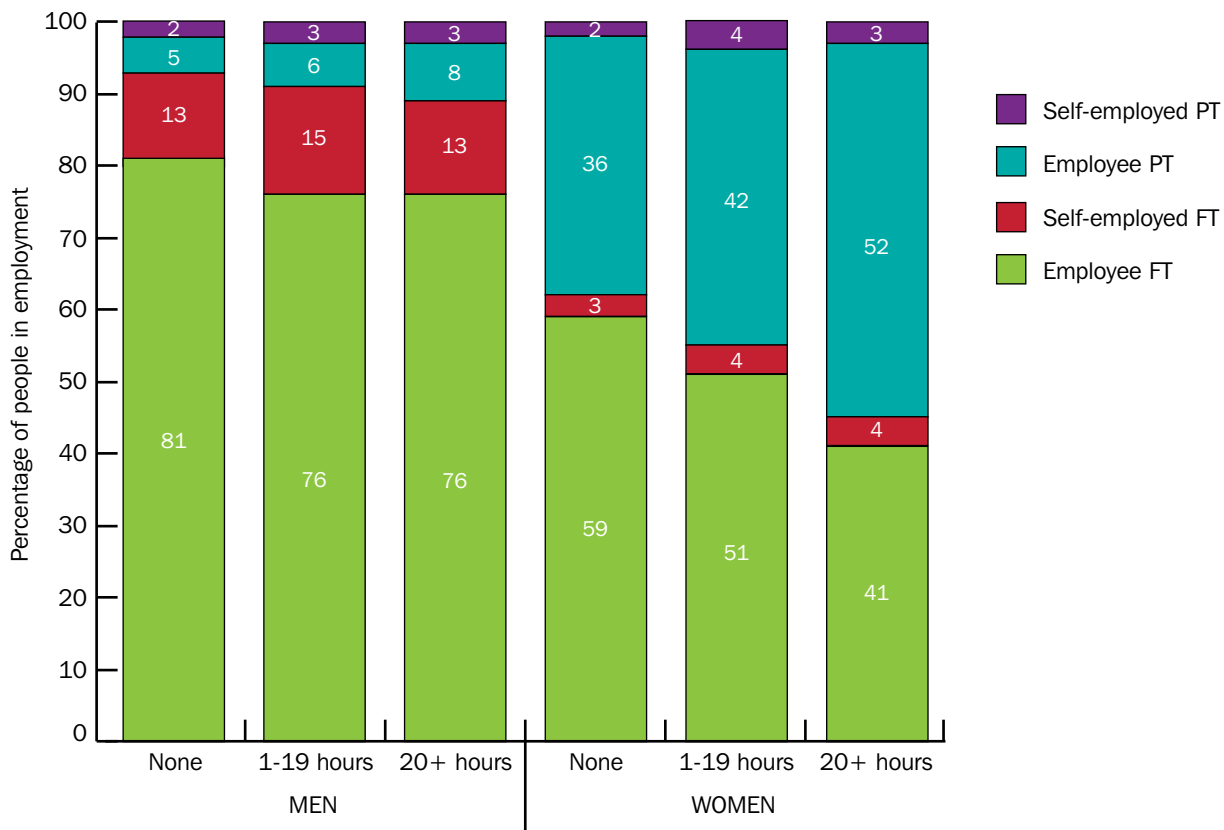
**Table 2 Carers' views on combining work and care**

Source: CES Survey, University of Leeds, 2007.

% in paid work agreeing that: number =	Leeds 53	GB 786
I have adequate services to enable me to work	42	27
My employer is carer-friendly and I feel supported at work	66	58
I rely on family and friends to enable me to work	64	70
I am considering giving up my job	34	39
My caring responsibilities do not affect my job	30	22

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

Note: data in this figure are for men aged 16-64 and for women aged 16-59.





*were like dreams and ambitions, don't get me wrong I'm still working towards them.*

*I came to an arrangement with my head of department that I would work as much as I could while I was [living away from Leeds with my mother]. They gave me a laptop and I would keep timesheets... so I would try and do my 37 and a half hours a week, which usually meant doing it in the middle of the night and early in the morning.*

Many had found accessing appropriate services a struggle; obtaining support at the immediate point of need was particularly problematic. Some said it had taken years to get a suitable care package.

*At first the times were all over the place. We did agree times, but the care agency never met them and [my mother] did have a lot of different carers.*

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

*I have no time for exercising...it's difficult for me to take any notice of my health as it's difficult for me to take any more time off than I have to. So if I get ill I just try to carry on. I think it's affected my mental health as well. They keep testing for post-natal depression, but it's getting a bit far away to be that now.*

Two carers in the city described their experiences in ways which highlight both what can be achieved when carer support is flexible and responsive, and the problems which carers face when the services received do not provide the carer with appropriate support:

## **IAN'S EXPERIENCE**

*You learn to stand up for what you're entitled to. At first we didn't have a clue and no one told us anything.*

Ian cares for his three adoptive children who have learning difficulties. Ian has had problems in getting social services to acknowledge their needs and to provide care workers, and has since turned to a care agency. However, although he has been allocated 25 hours a week of help, he currently receives only eight hours because the agency is under-staffed. As a consequence, Ian is considering changing his job to work different hours, so that he can do more of the care himself. He would like a definitive source of support and advice, and for social services to spell out exactly what carers are entitled to. He feels that new carers have to fight to discover what their rights are, and that this is burdensome.

## **CAROL'S EXPERIENCE**

*I've stopped getting in touch with them, I'd rather ring friends. They've never actually responded to an emergency.*

Carol cares for her father who is paralysed from the waist down. Her caring role involves coordinating the activities of care workers who help out 20 hours a week. Carol uses Direct Payments as a way of employing this staff, because she also works full-time. Although her employer and colleagues are understanding about her circumstances, Carol finds it hard to take time off and often has to build up a 'bank' of hours to accommodate the demands of her caring responsibilities. She finds life very tiring, and has recently had difficulty finding care workers who have knowledge of the specific care needs of a Caribbean person. Carol would like access to a pool of care workers from which individuals can be selected for their suitability, since she is reluctant to place her father in a care home.

These two examples illustrate the importance of high quality, accessible services – both in improving quality of life for individual carers and their families, and in enabling carers to participate in paid employment, 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 city of Leeds.

## 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 Leeds, this funding allocation, in 2005-6, was £2.65m. 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 Leeds

Table 3 presents recent official data about Carers Assessments and about services provided to carers in Leeds, as collected in formal returns to the *Commission for Social Care Inspection* (CSCI). While this shows that Leeds succeeded in assessing the needs of 370 carers of working age in 2005-6, it should be noted that this figure represents a very small percentage of the city's almost 53,000 carers of working age (almost 36,000 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, however, 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 (as shown in the national CES Reports) 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 Leeds steps have been taken to address these issues, and some of these are outlined below.

**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, Leeds and England**

Source: Community Care Statistics 2005-06: Referrals, assessments and packages of care for adults, England: The Health and Social Care Information Centre. Note: Columns may not sum due to rounding.

<b>1st April 2005-31st March 2006</b>	<b>Leeds</b>	<b>England</b>
<b>Total number of carers assessed and reviewed</b>	1,410	388,000
Number of carers assessed or reviewed separately	630	91,000
Number of carers assessed or reviewed jointly with client	460	247,000
Number of carers who refused assessment	320	49,000
<b>Number of Carers Assessments and reviews undertaken by age</b>		
<18	0	4,100
18-64	370	169,000
65-74	220	66,000
75+	500	100,000
Age unknown	0	0
<b>Number of carers receiving services after assessment or review</b>	1,090	284,000
<i>Carers receiving breaks or carers specific services</i>	860	142,000
<i>Carers receiving advice and information only</i>	220	142,000
<b>Number of carers receiving services after assessment or review by age</b>		
<18	0	3,700
18-64	370	141,000
65-74	220	55,000
75+	520	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>	600	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>	40	18,000
Learning Disability		
<i>Carers receiving breaks or carers specific services</i>	30	16,000
<i>Carers receiving advice and information only</i>	10	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>	50	6,100
<i>Carers receiving advice and information only</i>	20	3,000
<b>% carers receiving services following assessment or review</b>	100	84

## Policy developments in Leeds

Leeds Adult Social Services and its partners have been developing the city's services to carers for more than a decade. The first Carers Strategy was drawn up and launched in 1995 and coincided with the establishment of the Leeds Carers Centre. Both these developments were affected by the introduction of the *Carers (Recognition and Services) Act 1995* and the 1997 Social Services Inspectorate report *A Matter of Chance for Carers*, which found that among those caring for adults in local authority areas across the country access to reliable, high quality respite services was a 'lottery of location', particularly for ethnic minority carers<sup>11</sup>. The Centre was supported by the City Council with an additional contribution from Leeds Health Authority through joint finance arrangements. A Carers Development Officer was funded to provide support to the new centre in its development of respite services and to work at a strategic level on the city-wide commitment to carers. The Carers Strategy became the responsibility of the Carers Strategy Implementation Group (CSIG), which also came into being at this time. This group was supported at top level within the Council, and continues to be chaired by the Chief Officer for Adult Social Services. This commitment was shared throughout the organisation:

*Leeds is a big place, and it's got a big social services and welfare services and it was Labour-led for a long time – it's not now – and that certainly must have contributed to a high commitment to service provision to all kinds of disadvantaged groups. And carers were seen as being a disadvantaged group as well as being a valued group, because of the contribution they make. So it's part of the ethic really in Leeds.*

(Senior Officer, Leeds City Council)

With the introduction of Carers Grant in 2000, Leeds Adult Social Services appointed a Carers Lead Officer to manage the grant commissioning process, focusing in the first years on carers' breaks and then, following the relaxation of the guidelines on expenditure, on other types of services for carers, including leisure opportunities and careers advice and training. The main priority for the Council through Carers Grant has been to provide breaks for carers. CSCI noted that 3,319 carers were supported in 2005/6, but identified some 'areas

for improvement' relating to carers<sup>12</sup>. Another part of the Carers Lead Officer's role has been to work closely with over 200 individuals in Leeds' social care teams, to train and support practitioners in carrying out Carers Assessments – from data collection through to data recording, as well as reviewing the quality and outcomes of the Carers Action Plans which arise from the Assessments.

In Leeds, the local health sector has been more involved in carers' initiatives as a funding than as a delivery partner. Its infrastructure is complex and undergoing considerable change. However, the *'Making Leeds Better'* partnership initiative has been operating in Leeds since 2004 to redesign hospital provision and the 'patient pathways' associated with pre- and post- hospital admissions. During a period in which local primary care provision has been reorganised under a single Trust, Leeds Adult Social Services has worked to safeguard and promote its long- standing approach of working with the city's carers as equal and valued partners.

*There are about 70,000 carers in Leeds who devote themselves to giving the kind of care that professional care workers could never replace. The council supports carers in a number of ways, such as support for emergencies and special support for older and young carers. But we are also the first to recognise that without family carers, the quality of many older, ill or disabled people's lives would be much poorer.*

Councillor Peter Harrand, Executive Board Member for Adult Health and Social Care<sup>13</sup>

Carers themselves are involved in the delivery and planning of services in a number of ways. As already mentioned, the CSIG is the key strategic group for carers, with responsibility for producing the annual delivery plan for the Carers Strategy 2003-2006 and monitoring its implementation<sup>14</sup>. CSIG membership includes carer representatives, carers' organisations and the main health and social care organisations which fund services in the city. The Carers Lead Officer also plays a pivotal role in the Adult Social Services Department's mechanisms for consulting with and involving carers. (The creation of a Standing Carers Reference Group for the Learning Disability Partnership Joint Commissioning Service is a recent example of this.)



Leeds Adult Social Services adopted the 'Better Care, Higher Standards, Partnership Long Term Carer Charter', launched by the Department of Health in 1999. This tells anyone who needs long-term care or support what standards of service they can expect from local housing, health and social services, and what to do if these expectations are not met. One of the seven standards is 'to support carers in caring'. Working with carers and users and the other main health and social care organisations since 2000, Leeds Adult Social Services has produced progress reports on carers' level of satisfaction with services and on gaps in services which have been addressed or newly identified<sup>15</sup>. CSCI's *Record of Performance Assessment for Adult Social Care in Leeds 2005-2006* noted the Council's performance in this area:

*The council reports on its strategy to engage carers. It has formed the multi-agency employment and training working group and established a group of carers to inform their work on carer assessments and creating further opportunities for carers.*

Rising to the challenge of modernising social care delivery, Leeds Adult Social Services has placed its emphasis on developing more effective ways of delivering social care in people's homes or in supported settings. Examples include: the Council's 'digital pen and paper initiative' for its Social Services and Home Care workers (which allows staff to file information about service activity directly from clients' homes, and was awarded the Socitm 2005 *Excellence in IT* award<sup>16</sup>); and the 'Home Not Alone' strategy (the first housing and support strategy for older people in Leeds, creating integrated housing and social care to allow a greater number of older people to live independently for longer<sup>17</sup>). Adult Social Services has also been decommissioning part of its home-care services to incorporate more specialist voluntary sector organisations in the provision of recovery and long-term care services (up to a 25% share), concentrating its own 'in-house' provision on short-term intensive interventions<sup>18</sup>.

To address the diversity of needs of carers and users among its resident population, Leeds Adult Social Services produces a number of guides, in a wide variety of formats and languages, advising carers about their choices. These include 'Choices for Carers'<sup>19</sup> which has been compiled since 1993. Initially a catalogue of respite care facilities and how to access them, this is now an exhaustive guide of relevant services and systems. There are also shorter leaflets about: getting a break, carers' services in Leeds, Carers Assessments, and caring in black and ethnic minority communities. To begin to tackle the low take-up of services by black and ethnic minority communities, Carers Grant money is used to support a carer development worker, based in the Carers Centre, who speaks a range of Asian languages including Urdu, Bengali and Hindi<sup>20</sup>. This worker holds outreach surgeries in different parts of the city and arranges visits to people's homes. As in other authorities which participated in the CES study, engagement with ethnic minority carers continues to be difficult to implement. One approach has been to promote Direct Payments (DPs), which offer different users and their carers greater flexibility; in 2005-6 black and ethnic minority users accounted for 9% of all DP recipients<sup>21</sup>. One factor affecting take-up is the tight local labour market, in which recruiting social care workers (whether by individuals using DPs or by organisations such as the City Council) is affected by competition from other employment sectors.

To meet its obligations under the *Carers (Equal Opportunities) Act 2004* the authority has funded a range of initiatives using its Carers Grant allocation. Led by the Carers Lead, these include a survey of working age carers about their aspirations and work experiences, and a careers fair targeting carers and involving a range of education and training providers. In its role as an employer, Leeds City Council has also developed its own internal policies to improve the options available to its own 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 Leeds, 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 city's 52,000 working carers have had their needs assessed.

In Leeds, as elsewhere, restrictions on Adult Social 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; 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, Leeds Adult Social Services has responded to this challenge by undertaking a number of innovative measures to support carers and those they care for, and to ensure that carers can feed back their views about current service provision and inform social services of unmet needs. The City Council's work on increasing the take-up of Direct Payments and its commitment to piloting an 'individual budgets' model in 2008<sup>22</sup> are further steps forward in offering greater flexibility in service provision.

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. Leeds Adult Social Services, through the Carers Grant and in partnership with voluntary sector partners, has provided targeted support including employment related advice, courses to accredit caring skills and to support entry to employment and education, and outreach to carers in work (beyond those working as local authority employees). Its work in this area has nevertheless mainly been delivered through pilots, special projects and short-term initiatives.

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. There are emerging opportunities in the areas of local regeneration and local strategic planning into which a focus on carers' employment could be inserted. There is also more work to be done with colleagues in health through '*Making Leeds Better*', to ensure that working carers are able to participate as equal partners in the reorganised patient pathways.

Leeds Adult Social Services has had a multi-agency Carers Strategy in place since 1995. A cornerstone of its approach has been to put carers' employment on to the agenda of other local agencies and partners. Examples include work undertaken by the Carers Lead Officer to:

- Support Care Managers to help them signpost carers to other agencies which can provide employment services or access to training opportunities.
- Promote carers' access to adult learning through collaboration with the Learning and Skills Council.
- Highlight working age carers as a hidden yet potential workforce to Jobcentre Plus and other local employers.

Carers Grant, introduced in England in 1999 as an additional resource allocation to local authorities 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 involved 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.

## 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; 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 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> 'Kings Fund Calls for Support for all Carers' British Medical Journal (1998) 317:1410 <http://www.bmj.com/cgi/content/full/317/7170/1410/a>.
- <sup>12</sup> CSCI *Record of Performance Assessment for Adult Social Care in Leeds 2005-2006*.
- <sup>13</sup> Leeds City Council press release, *Thanking Leeds Carers in National Carers Week*, 6th June 2007.
- <sup>14</sup> As this report went to press Leeds City Council was preparing to publish its next Carers Strategy.
- <sup>15</sup> Leeds City Council, Leeds NHS, *Better Care Higher Standards Leeds Long term Care Charter Annual Report 2004*.
- <sup>16</sup> 'Leeds City Council Scoops Technology Oscar' [http://www.theregister.co.uk/2005/10/19/tech\\_oscars/](http://www.theregister.co.uk/2005/10/19/tech_oscars/).
- <sup>17</sup> Leeds City Council, *Home Not Alone 2005-2010: A strategy to meet the housing and support needs of older people in Leeds*, Executive Summary.
- <sup>18</sup> Leeds City Council Plan 2006-2007, p54.
- <sup>19</sup> Leeds Adult Services, *Choices for Carers: Information for Leeds Carers and the people they care for, about how to get a break, or share the care*.
- <sup>20</sup> Leeds Carers Centre Staff Pages <http://www.carers.org/local/north-east/leeds/staff.html>.
- <sup>21</sup> Leeds City Council Scrutiny Board (Health and Adult Social Care): Report on Direct Payments, 22 January 2007, Agenda Item 12.
- <sup>22</sup> op. cit.

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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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