

Carers, Employment and Services: time for a new social contract?

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

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Carers, Employment and Services: time for a new social contract?

CES Report No. 6, which should be read in conjunction with the other CES reports, presents a summary of the main findings from the CES study about carers in England, Scotland and Wales.

The report highlights the implications of the study findings for the future public policy agenda on carers of working age, setting out the rationale for developing better support for this group of carers at both local and national levels. Key challenges in developing services and provision are identified, and recommendations are made about how they can be tackled by service providers, employers, central/local government and the voluntary sector. The report calls for a 'new social contract' between government, publicly funded agencies, employers, families and individuals, based on the recognition that all parts of society have mutual obligations and expectations about providing and receiving care, and that these are central to the humanity of every citizen.

Executive Summary

This report, *Carers, Employment and Services: time for a new social contract?* sets out a new vision for carers for the 21st century. It draws together the findings of the other reports in the CES Report Series, summarising our analysis of the Carers, Employment and Services (CES) study conducted in 2006-7 at the University of Leeds, commissioned by Carers UK.

It presents an analysis of the findings which are presented in detail in the earlier reports, and a set of policy recommendations based on the evidence collected. The findings are based on: 1,909 responses to the CES national survey (which targeted carers of working age); 134 face-to-face interviews with carers aged 25-64 living in ten selected localities in England, Scotland and Wales; interviews with professionals with responsibility for carer support at the local level; detailed analysis of the 2001 Census; and assessment of a wide range of documentary sources.

The report, which also outlines the focus of the other reports available in the CES Series, is divided into four sections: carers and employment in Great Britain; the main findings of the CES study; the infrastructure of support carers need to assist them in combining their caring roles with paid employment; and a policy-focused analysis and reflection on the CES data, which calls for a new social contract for care and outlines a set of detailed policy proposals.

Background

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

Carers and employment in Great Britain

In Section 1, we highlight the demographic and labour market context which is pushing carers and employment up the social, economic and political agenda in contemporary Britain.

Longer lives and better healthcare, coupled with technological change making care outside hospital and residential settings ever more possible, and the impact of population ageing, which is irrevocably shifting the balance between the young, older people and those (as conventionally defined) of working age, are the root causes of these developments.

An expanding economy, creating many new jobs but faced with fewer young people entering the labour market than are exiting it as they retire, calls for strong policies on employee retention and a high employment rate among both women and men. This means Britain's 4.27 million carers of working age are needed in the workplace. Already two-thirds of them are in paid work, but carers are a stressed and poorly supported group, whose shifting membership means that while in a typical workplace 1 in 9 male workers and 1 in 7 female workers are already caring for someone who is sick, disabled or frail, over time most people will – at some stage in their lifecourse – need to combine work and care. In 2001, the 'snapshot' picture of people aged 45-59 showed that 16% of men and 23% of women were carers.

Stimulated into action by carers' organisations, and supported by an all-party group of MPs some of whom have successfully brought Private Member's Bills to the statute book, carers have secured some recognition and rights in the past decade. But these measures have not yet been strong enough to transform most carers' lives, and carers of working age, especially those combining work and care, often struggle with their complex array of responsibilities with limited support from providers whose services they often find it hard to find out about and to access.

Main findings of the CES study

Section 2 of the report details the methodology used for the CES study, summarises the findings reported in CES Reports 1-4, and presents additional, new analysis based on the 2001 Census.

In outline, this shows that, of the 4.27m carers of working age living in Great Britain, 1.8m of them men and 2.4m of them women, two thirds are in some form of paid employment. 66% of male carers of working age are in full-time paid work (including 12% who are self-employed), while an additional 7% have part-time jobs. Among women who are carers, 32% are in full-time work (including 3% who are self-employed) and a further 30% are in some form of part-time employment.

Confirming our earlier finding that some ethnic groups have higher rates of caring than others, we show that this reflects the greater demand for care which many people in these groups encounter, with Pakistani and Bangladeshi residents of working age twice as likely to live with someone with a limiting long-term illness as White British residents, and with carers in some ethnic minority groups experiencing poorer health themselves as well.

Reinforcing the data in the CES survey, which showed a strong relationship between hours of caring and poverty, our new analysis of the 2001 Census shows that those who care for 20 or more hours per week are very much more likely to live in workless households (the best proxy measure available in the Census for low income) than non-carers or those caring for less than 20 hours per week.

In relation to education and training, the new data presented, again from latest analysis of the 2001 Census, show the negative impact of caring on younger (aged 16-24) carers' likelihood of continuing in full-time education, and (for carers of working age in the older age groups) a strong negative relationship between caring and full-time employment.

A description of all carers of working age who responded to the CES survey (87% of the achieved sample were in the target age group) is presented, showing their weekly hours of care, relationship to the person cared for, the condition/diagnosis of that person, and the length of time they have been caring. The CES dataset is composed mainly of carers with demanding caring roles, and for women especially, provides a good 'fit' with

the profile of carers who care for 20+ or 50+ hours per week revealed by the 2001 Census. However, the CES data under-represents male carers, whose numerical importance is greater than their share of the CES dataset suggests.

In summarising the main findings of CES Reports 1-4, we emphasise that:

- Caring is a normal part of everyday life, which can happen unexpectedly or gradually, and comes to most people at some stage in their lifecourse. At the start of caring, their difficulty in obtaining information, advice and support comes as something of a shock to many carers, adding to their problems at a stressful time. 'New' carers feel the financial and health impact of caring quickly – but these impacts intensify for those whose caring becomes a 'longer-term' commitment. Among 'new' carers in the CES study, 46% of full-time employees, and 62% of part-time employees felt they did not have adequate services to enable them to work.
- Caring should not end a carer's career, damage their education, put their ability to acquire skills and training at risk, or force them to give up work. Although most working carers in the CES study felt they had support from their family and friends in combining work and care, and about half considered their employer was 'carer-friendly', only a minority (about a quarter) believed they had adequate support from formal services – even though 42% were paying privately for these. Very few were getting carer's breaks or respite services, and a large minority felt poorly informed about available support. Many stressed that they were keen to continue in work – yet more than a third had considered giving up because of their caring role. The 400 respondents who had already given up work to care were among the most deprived and dissatisfied in the survey; many of these carers were looking after a sick or disabled child and had been caring for 5 years or more. 500 respondents told us they were currently 'looking after home and family full-time'; of these, 40% said they would rather be in paid work.
- Caring occurs across all groups in our society, in a wide range of diverse situations and circumstances. In CES Report 3, we looked especially at ethnicity, financial position, health status, urban/rural settings, caring relationships and the different conditions and diagnoses of those who are cared for. This report highlights the particular difficulties and special needs of some of these groups, again highlighting the financial and health impacts of caring, but stresses that, across the full spectrum of caring situations and of carers' lives, almost all carers want the same thing: sensitive, tailored support, designed with their own personal and working life, family circumstances, values and beliefs in mind.
- Policy and legislative progress has been made in recognising and supporting carers since they were first defined in law in 1995, and the National Strategies for Carers adopted in England, Scotland and Wales after 1999 represented an important step forward. In the local authorities we studied, we found many examples of creative and innovative solutions which were really benefiting individual carers and their families, including some which were helping them to combine work and care. Nevertheless CES Report 4 stressed that, given the depth and scale of the needs of carers of working age, there is an urgent need to increase support for working carers and to extend the range of services available to them, with greatly improved assistance for those for whom they care high on the list of priorities. Supporting working carers has been peripheral to most authorities' work on carers, with few carers being asked about their need for help in maintaining their jobs and careers, and most engagement with carers focusing on those outside the labour market. In England, in 2005-6, official figures show that only 169,000 carers of working age (out of 3.63 million) had their needs reviewed in a Carers Assessment. Not all received 'services' as a result; fewer than half of all carers who were assessed got breaks or specific services. This support, whilst crucial to those receiving it, is a 'drop in the ocean' in relation to the issues which confront us; now that the needs of carers of working age are clearly visible, we argue, it is time for a step-change in our policy relating to them, and in the design and delivery of our social care system.

Infrastructure of support to help carers combine work and care

This part of the report calls for a radical overhaul of the entire infrastructure of support for carers, and for recognition that the social care system needs to focus much more explicitly on the situation of carers of working age. It argues that although local authority Adults' and Children's services are major and fundamental elements in the infrastructure of support needed, they are far from the only relevant players.

After discussion of wider developments in the welfare state and in the social care system in recent decades, we emphasise that many current public policy agendas are of direct relevance to carers, as recognised by government in the way it set up the Task Forces to review the National Strategy for Carers in 2007.

The report calls for a 'social fabric' approach which recognises the normality and desirability of caring, requires all agencies to involve and consult with carers, shares responsibility for carer support across all public services, the employment system and the voluntary and community sector, and values and integrates carers.

Four main elements of the necessary infrastructure of local level support for carers and the social care system are identified. These are: local providers of social care; local health services; workplace support for carers; and other local infrastructure. The preconditions needed to enable carers and those they support to access this support are indicated in a diagram depicting the most important elements of the infrastructure required.

A new social contract for care

In concluding the report, and drawing on the full range of evidence presented in the CES Report Series, we identify the key challenges for public policy, the economy and the whole social fabric, including its individual citizens and its full range of institutions. These challenges relate to:

Carers' health: a powerful array of evidence now confirms a clear relationship between caring and poor health, which becomes starker with the intensity and duration of the caring role. Carers who have to give up work to care are at particular risk. We argue that:

Our health and social care system must not operate in ways which add to carers' stress and frustrations through poor communications, inadequate information, inflexible arrangements or slowness of response.

Carers need opportunities for flexible breaks from their caring role – both on a regular basis to sustain normal everyday life and citizenship, and periodically to provide a chance for recuperation and a rest.

All carers should have access to training and support in carrying out their caring role, so that carers do not have to take risks with their own health and safety which would not be asked of an employed care worker.

Carers need ready access to occasional and emergency services at times of crisis or in unforeseen circumstances, and need support from local agencies in making appropriate plans for these, to give them peace of mind and readily accessible support when the unexpected happens.

Helping carers to maintain their employment or to access paid work makes an important contribution to their health and wellbeing.

Carers' economic and financial security: the CES study provides strong evidence of the financial penalty carers pay for the care they give. As the contribution carers make is so important for families, the social care system and our economy, this is an unacceptable situation, which must be rectified. We argue that:

Protecting carers' right to work, and sustaining them in combining work and care offers the best protection against poverty and financial hardship for carers. The employment, skills and training system needs to play a much more active and explicit role in supporting carers in combining work and care.

Further pensions reform is needed to ensure that carers' who take a break from work to care, or who change

their working hours or careers, are not penalised in retirement for making the choice to care. Government must take the lead in this and must undertake these reforms as part of a wider review of the way the whole tax, benefits and pensions system works for carers.

Employers and trade unions have a role to play in addressing the design of jobs, creating more opportunities for part-time and reduced hours working at senior levels, and developing appropriate packages of workplace support for working carers.

A new advisory service for SMEs needs to be developed to help smaller organisations give support and advice to carers in their employment, and to explore flexible working solutions which will work to the advantage of their business.

Carers' social inclusion: the social isolation carers often face as a consequence of their caring role prevents them from taking part in their communities as fully active citizens and means that their voice and opinions are often not heard or taken into account. We argue that:

There should be a public sector duty to promote equality for carers, and that carers should be specifically included in all equalities legislation, with the new Equalities and Human Rights Commission playing a key role in representing their interests and ensuring they are protected from discrimination.

The right to request flexible working should be extended to all employees, bringing all carers within the scope of this legal provision, and simplifying its operation for employers.

All strategic developments in local infrastructure need to be 'carer-proofed' at both the planning and implementation stage, with carers fully involved in consultation processes.

Welfare to work policy should be tailored to meet carers' needs, both in the advice given and in the health and social care support provided, to enable carers to engage in training, learning and work.

Government should actively promote combining work and care to employers and trade unions, since this is the most sustainable and desirable way forward for most carers, for the economy and for the social care system.

The evidence base on carers, which has been greatly strengthened by the inclusion of a question on carers in the 2001 Census, needs to be maintained and enhanced. Local level data is crucial for the planning and fair distribution of services and resources, and it is important that the situation of specific groups of carers who may require additional support because of their greater need (such as those in ethnic minority communities) is visible at the statistical level.

In the final part of the report we set out what we mean by the need for a new social contract for care. The 'signatories' to this contract need to be not only the state and its citizens (an arrangement which has underpinned the concept of the welfare state for over 60 years), but to include: individuals and families; neighbourhoods and communities; organisations and businesses; and all the institutions of the local and national state.

We show that all of these already make some contribution to the social economy, and highlight what additional contribution they must be able to make when a need for care arises. Here we emphasise the key role the state should play in providing appropriate frameworks, but stress that social care providers, health services, employers and the agencies responsible for the full range of other local services must work together in an integrated way to deliver a reliable infrastructure of support. Carers need to be able to rely on this infrastructure of support if they are to do what most want to do, which is to continue to provide care, without paying a penalty for doing so. We believe it is of crucial importance that they are not asked to make sacrifices in relation to their health, financial wellbeing or social inclusion.

Our analysis thus calls for a new social contract for care which places the care given by family and friends at its centre, but recognises our shared obligation to put in place an effective and integrated infrastructure of local support, designed to uphold a set of core values, ethics and beliefs, and to ensure the social care system accords to carers dignity and respect, with all agencies recognising and including carers. Underpinning this new social contract for care must be a set of legal and fiscal frameworks which it is the responsibility of the state to put in place. These frameworks must guarantee carers the right to equal treatment and protect them from discrimination and social exclusion, and create a financially secure environment which enables care to be given without asking carers to pay the unacceptable price of low income or poverty in return.

Main recommendations of the CES study

Carers' health

- More responsive services in health and social care.
- Investment in Carers Breaks.
- Improved GP / community health support for carers.
- Information, training and brokerage services for carers.

Carers' economic and financial security

- A new advice, guidance and advocacy service on caring and employment.
- A wider range of jobs available to those working part-time or flexibly.
- Review of the integration of the tax, benefits and pensions system.
- Investment in improving access to education, skills and training for carers.
- A new specialist SME advisory service.
- New support/services for those whose caring changes/ends.

Carers' social inclusion and equal rights

- Carers identified in all equalities legislation.
- A strong statistical evidence base about carers.
- Services which support carers' participation as active citizens.
- Extension of the right to request flexible working to all employees.
- 'Carer-proofing' of local strategic developments and planning processes.
- Welfare to work policy tailored to meet carers' needs.
- Campaign on carers and employment targeting employers and trade unions.

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Introduction

This final report in the CES Report Series summarises our findings about carers of working age in Great Britain and sketches out an agenda for change: change in the development and delivery of health and social care services; change in awareness, understanding and respect for carers and their role; change in the design, focus and accessibility of employment, training and advisory services; and change in the adaptability, flexibility, and sensitivity of other local services (including transport, housing and leisure). In its concluding section, and based on an extensive new evidence base, the report calls for a new social contract for care. This new social contract needs to bring together, in a new understanding of their various rights, roles and responsibilities: individuals, their families and friends (the key players in most caring relationships); employers, managers and trade unions (whose attitudes, behaviour and agreements shape working lives); government (which legislates for, funds and designs the public policy context in which caring is delivered); commissioners, providers, assessors and inspectors of public services (whose decisions and actions shape the quality of caring and of carers' lives); and voluntary and community organisations (whose role as advocates, campaigners and supporters of carers has already been pivotal in setting the terms of the debate about caring in contemporary Britain).

Drawing on a major new research study, and on

extensive analysis of the 2001 Census, the reports in the CES Series highlight carers' many different circumstances and caring situations, noting that while caring is part of all our lives, it is experienced in many different ways according to each carer's personal circumstances and situation¹. At the heart of our analysis is recognition and acceptance of the universality of caring, and of an enduring truth about human relationships: that giving and receiving care is a vital component of each person's humanity and connection with others. Ultimately, the labour and love of caring is the expression of our deepest commitments, emotions and values, in relation to our parents, children, partners, friends and other kin. Mediated by culture, biography and experience, (and negotiated by each of us according to our circumstances, obligations and desires²), caring relationships unite and bind couples, families, friends and neighbours, thereby creating the communities we inhabit and value. Caring relationships in Great Britain in the 21st century, far from receding in the face of the much-discussed individualisation³ and 'selfishness' of the age, are in fact ubiquitous, compelling and necessary. Embracing moral, practical and reciprocal dimensions, and in a world where the daily demands on each citizen to communicate, act and relate to others are irresistible – with improved medical technology and treatments not the least reason why demand for care is unprecedented and growing – caring is now a part of all our lives.

In presenting our analysis of the CES study we emphasise carers' common desire for improved services which meet their needs as men and women who wish, also, to lead the kinds of lives which, today, most adults take for granted – lives which include earning a living, time for leisure, community, educational and cultural activities, and space for a personal life. This is why when caring comes to each of us – as to most at some point it will – we need in place social arrangements which ensure that being a carer, whether only briefly or for the longer term, does not make us poor, damage our health and wellbeing, end our careers, or isolate us from ordinary social life.

Most of the findings outlined in this report were presented in detail in Reports 1 – 4 in the CES Series (see below). Our focus is on carers of working age, especially those who combine their (unpaid) caring role with paid employment. Here, in section one of this report, we briefly review the demographic and labour market context in which carers currently seek to combine work and care, and outline the public policy context for the study. In section two we highlight some of the latest evidence available about carers of working age, using both specialist analyses of the 2001 Census and the findings of the CES study, focusing on the themes addressed in CES Reports 1 to 5: stages and transitions in caring (since caring is a journey within a person's biography, rather than a permanent state); managing caring and employment (highlighting both successful experience and the risks which arise when caring cannot be successfully accommodated alongside employment); diversity in caring (emphasising that for all their differences and distinct beliefs, values and behaviours, carers' common needs and experiences are more notable than the divisions between them); carers, employment and local services (highlighting the need for more accessible, flexible and individually tailored provision); and the work of the ACE partnership, led in its two phases between 2002 and 2007 by the campaigning voluntary organisation Carers UK, in a partnership of public, private, voluntary and statutory organisations which has delivered and tested new approaches, promoted new policies and legislation, and created a unique and influential space for dialogue about carers' issues, raising the public profile of carers and taking crucial steps forward in securing policy change.

In sections 3 and 4, we explore the various dimensions of the 'infrastructure' needed, at national, but especially at local, levels, if carers are to combine work and care without undue detriment to their health, finances and wellbeing, and (perhaps most important of all) in ways which respect and dignify the contribution their care makes to the wellbeing of those they care for. In many cases it is carers' support for sick, frail and disabled people which enables those they care for to retain some autonomy and independence in their own homes or family households, where most prefer to be. In concluding the report, we argue that it is through building, maintaining and developing this infrastructure – engaging all parties: individuals and families; employers, managers and trade unions; national and local governments and policy makers; professionals, providers and commissioners – that a new and inclusive social contract can be achieved. We emphasise both the urgency of agreeing this contract, and of taking action to honour it, if damage to individuals, families, businesses and communities is to be avoided, and if the benefits to be gained by all, in recognising, respecting and supporting carers and those they care for are to be secured.

Throughout the CES study and reports, when we refer to carers, we mean those who provide regular, unpaid, support or assistance to another person who needs their help because they are ill, disabled or frail. As stressed in our other reports, many carers support a relative, such as an elderly parent, a sick or disabled partner, or a disabled child. But as carers are not always related to those they care for, we have taken carers' own definition of themselves as our starting point. In using the term 'carer' we have been clear that we are not referring to parents who care for a dependent child (unless that child also has an illness or disability), and that we are not referring to 'care workers' (who are paid to provide the care they give⁴). Our particular focus throughout the study has been on how carers can be helped to care and to have 'a life outside caring' too, with particular reference to a life which involves continuing in paid work or with a career.

The reports in the CES Series draw on the detailed findings of the *Carers, Employment and Services* (CES) study, commissioned by *Carers UK* from a team of researchers at the University of Leeds as

part of the *Action for Carers and Employment (ACE2)* partnership, and funded by the European Social Fund under the *EU EQUAL Community Initiative Programme*. The study was carried out in 2006-7, and included a new questionnaire survey of carers in England, Scotland and Wales (which achieved 1,909 responses from carers), and follow-up personal interviews with a sub-sample of 134 carers. Each of the carers interviewed lived in one of 10 localities⁵ selected for detailed investigation, where we also collected information about the provision of services, and interviewed key stakeholders (see Appendix 1).

Carers, Employment and Services: time for a new social contract? is the final national report in the CES Series. Drawing on the detailed evidence presented in the other CES Reports, it stresses the common disadvantage that carers face, as carers, and the need for radical new thinking and significant policy change to enable carers, in their many different circumstances and situations, to integrate their caring roles with their everyday lives, without compromising their health, finances, jobs or careers. The full range of study findings is reported in the complete series (see below). There is also a set of short, specialised 'CES Local Reports' relating to Scotland, Wales and the six English localities studied, to assist local agencies involved in providing support for carers in their policy development and planning.

No. 1 *Stages and Transitions in the Experience of Caring*

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

No. 2 *Managing Caring and Employment*

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

No. 3 *Diversity in Caring: towards equality for carers*

The different characteristics of Britain's 4.3 million carers of working age – carers in Britain's ethnic minority communities; caring and its challenges for carers in rural and urban contexts; caring in different financial circumstances, and the problems faced by those who are 'caring in poverty'; carers and how caring affects their health; caring in different personal contexts – the relationships between carers and those they support, and the different conditions and needs of those they care for.

No. 4 *Carers and Services in their local context*

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

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

The objectives, design and outcomes of the ACE projects; the role of research in supporting the ACE strategic aims and summary of the findings of the Carers, Employment and Services (CES) study; the work undertaken by the ACE partners in England, Scotland and Wales, and their main achievements; the role of transnational activities in ACE, and their significance for future policy-making at European level.

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

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

1. Carers and Employment in Great Britain

Demographic and labour market context

For the past decade, demographic and social change has been pushing carers' issues up both the social policy and the employment rights agenda – responding to new pressures which are set to continue for some decades. The changes involved affect all areas of Britain, while in the wider European Union too, every Member State expects to see a significant increase in its very aged population in the first half of the 21st century⁶.

Over the next 25 years, it is estimated that the UK will simultaneously need both 2 million more workers and 3 million more carers⁷. The demographic context is clear: the population is ageing, with the balance between older and younger people changing very significantly. Thanks to better healthcare, many sick and disabled people, including babies and children with serious illnesses and disabilities, are also living longer. Furthermore, those who experience serious illness, and others who require hospital care, now find that policies on earlier discharge to the home environment, and the possibility of managing an increasing range of conditions outside of hospital or residential care, also mean more time is spent in a home setting. This often involves the need for significant support, either from domiciliary health and social care staff, from unpaid carers, or, very often, and ideally, a combination of both. While this is (for

most) a welcome development, it is not yet clear that its wider ramifications have been fully grasped by governments, policy-makers or service providers.

Although life expectancy is increasing, for most population groups increased longevity will also involve living for more years in poor health. Experts think even the least deprived men and women are likely to spend about a third of their lives after age 65 in poor health, while among the most deprived group well over half of older age years are likely to be spent with some health problems⁸. Already, living with a disability is a very common experience for both men and women after age 65, affecting over 40% of the later life expectancy of the least deprived men and women, and well over half of the later life expectancy of the most deprived.

With many more people living alone (another growing phenomenon⁹), and more diverse family lives, it is evident that other changes in family structures have also made relationships and commitments more complex than ever before. Taken together, these demographic developments are strong indications that the amount of care and support needed in future years is set to increase very significantly.

Alongside these demographic changes, analyses of future labour market trends make it clear that over the coming decades, the economy will need more skilled and experienced labour, just at the time

Table 6.1 Carers of working age by sex and weekly hours of care

Source: 2001 Census Standard Tables, Crown Copyright.

2001 Census	Women number	Men number	Women %	Men %	All %
All Carers	2,419,957	1,845,754	57	43	100
Caring 1-19 hrs	1,680,528	1,359,269	55	45	100
Caring 20-49 hrs	285,523	192,896	60	40	100
Caring 50+ hrs	453,906	293,589	61	39	100

when the working age population is shrinking – the combined effect of extended education, smaller cohorts of young people starting work, and early withdrawal from the workforce¹⁰. Recent estimates are that 1.3m additional jobs will be created in the UK between 2004 and 2014 alone, with most of the additional demand for labour in the more skilled and higher level occupations¹¹.

The 40 plus age group, where most caring occurs¹², includes many men and women in whom the state and employers have made expensive qualifications and training investments – and on whom employers, managers and co-workers rely for their experience, organisational knowledge and maturity. As shown throughout the CES Reports, among carers of working age, 72% of men and 62% of women already combine work and care – although as demonstrated in CES Report 3, if they are not well supported they pay a significant health penalty as a consequence of the pressures they face in dealing with their multiple responsibilities¹³. Contrary to what is sometimes assumed (and as shown in Table 6.1), this group, in which women predominate, also includes a large number of men (43% of all carers of working age are men); and as carers are distributed fairly evenly across most industrial sectors and occupational groups, in the future employers and organisations in all segments of the labour market will need to face up to the way increased demands for care affect their employees¹⁴.

The reality is that, when caring begins, carers often have 20 or 25 years of working life ahead of them, sometimes more, especially if they are parents caring for a disabled child. Yet as they seek support, and try to adjust to their new caring responsibilities, they

too often find that the alternative care services they need to support them when they cannot themselves be available, often because of their paid jobs, are a costly and limited resource¹⁵. Mass early retirement – leaving the workforce in order to care, as CES Report 2 shows very many people have done – is simply not a practical or affordable future option for most carers, or for society as a whole, as we discuss further below. The 2001 Census showed that 175,800 men and women of working age who had retired early were carers; yet we know from evidence in the CES study that withdrawing from paid work is not always their preferred choice. Furthermore, recent reviews of pensions, demographic change, and skills – and almost all policy-making¹⁶ – call for a future of extended working lives, with older workers encouraged to remain active in the labour market well into their 60s and beyond. Meanwhile alternative care – the services on which those whom carers support rely when their carers are not there – is often hard to obtain, not only because of public spending constraints, but also because of serious shortages of paid caring labour¹⁷.

In the 45-59 age group in Britain, 16% of all men (over 900,000 men) and 23% of all women (over 1.3 million women) are carers. Well over a third of women in this age group, and about half of men, hold managerial, professional or technical positions, where their skills, qualifications and experience are valuable assets on which employers rely. Among carers in this age group, 25% of men (224,000) and 29% of women (384,000) provide 20+ hours of care a week, with 119,000 men and 164,500 women providing their 20+ hours of care on top of their paid duties¹⁸.

These facts about carers show just how essential it is to find ways of enabling people to both work and care. Already in a typical workplace 1 in 9 of all male workers – and 1 in 7 of women – is a carer. In the past decade, a small but growing number of organisations have recognised this situation, and decided to alter their workplace policies and practices, with a view to offering carers in their employment better support and a wider range of options in the decisions they need to take. In earlier research, we examined the experience and motivations of employers in aiming to provide a supportive environment for carers at work, exploring the organisational context for, and response to, carer support. That report, *Who Cares Wins: the social and business benefits of supporting working carers*, focused on the situation of those who combine work and care from the organisational perspective, consulting managers, employees, organisational documentation and senior executives¹⁹. It showed that the organisations studied had turned this apparently challenging situation to their advantage. Indeed, when they took supporting carers seriously, employers found: (i) that it makes very good business sense to have in place effective staff retention strategies; (ii) that employees work more effectively and productively when they are offered flexible working conditions; and (iii) that treating employees who have care commitments with respect, dignity and consideration pays considerable dividends for their business. Our analysis demonstrated that issues of organisational culture, leadership and training are crucially important. Organisations – large or small, in the public or the private sector – can pay attention to efficiency and profitability, can focus on their output and the needs of their clients, and can improve service delivery by introducing a range of flexible working methods and support arrangements which make a significant difference to carers. Nevertheless, employers and managers cannot hope to provide *all* the support carers need; responsible, progressive and flexible management of carers in the workplace is crucially dependent on the existence of effective, responsive local services. These local services ought to provide the main bedrock of support for carers, and need to assist the person cared for in a flexible, person-centred way, with service providers and paid care workers

operating in a close and respectful partnership with both the care user and their unpaid carer(s).

Public policy developments

Carers and their representative organisations²⁰ have been lobbying hard for many years to secure for carers a range of new rights, entitlements and policies, alongside many local voluntary organisations which have developed a range of services for carers at the local level. Over four decades of campaigning, their approach has developed from its initial focus on ‘single women and their dependants’ (the National Council for the Single Woman and her Dependants was formally established in 1965) to the contemporary conceptualisation of carers in all their diversity (with the National Black Carers Network, for example, set up in the late 1990s). Along the way, the carers movement has grown in influence, ambition and impact, with Carers UK (formerly the National Carers’ Association) prominent in the lobbying and campaigning role, but with other carers’ organisations too – principally Contact a Family (first registered as a charity in 1979), Crossroads Caring for Carers (set up in 1974) and the Princess Royal Trust for Carers (formed in 1991), all working to improve the situation for carers at local or national level or both.

During this period, the role of the carers’ movement has been, first and foremost to draw attention to carers and to ‘name’ caring as an activity deserving of policy attention. In recent years, this has been done by a wide range of high profile activities, not least maintaining a profile for carers year on year through nationwide activities and events in Carers’ Week and on Carers’ Rights Day, but initially the task was to draw attention to the ‘isolation’ of carers and to ‘public ignorance’ of their situation²¹.

Key issues for the carers’ movement, perhaps especially for Carers UK which has specialised in research, campaigning and lobbying work, have included:

- Identifying the health, financial, social and other penalties carers pay because of the way caring and support for carers and those they care for are organised, and campaigning for policy responses in the form of carers’ benefits and financial entitlements.

- Claiming carers' right to a life outside caring (and to be able to access education, leisure, training and employment).
- Linking the campaigning agenda for carers with other public policy objectives – equalities, social inclusion, work-life balance, social cohesion, human rights.
- Securing substantial resources to deliver innovative projects and pilot different approaches (the ACE partnerships secured £5m of European Social Fund resources in 2002-07, matched 50:50 with UK investments).
- Identifying the need for a solid evidence base, and commissioning external, independent research on carers' situation and perspectives.
- Taking the carers' agenda into EU policy-making, 'naming' carers as a group eligible for funding within European labour market activation programmes, and subsequently working with agencies in the Netherlands, Ireland and elsewhere to found and promote Eurocarers (formally launched in 2007) as a force within EU policymaking on economic and social affairs.

To date, this campaigning has yielded some very significant but (in terms of what carers need) ultimately quite modest results. These include: the right to leave from work to deal with emergencies and caring crises; the right to request flexible working arrangements; the right to a Carers Assessment which respects carers' desire to work as well as to care; and the right to access education, leisure, training and employment²². These developments have enjoyed comparatively widespread support: an all-party group of MPs has been behind some of the key developments²³; new legislation has mostly had all-party support; policy-makers and social care professionals have generally welcomed the shift towards a more explicit focus on carers' situation; and employers' representative organisations (such as the CBI²⁴) now welcome and support the limited rights carers enjoy in the workplace. The carers' lobby has nevertheless continued to call for stronger policies, much more public investment in the services which support carers, and heightened employer and managerial awareness of carers' needs, noting

that the valuable changes and developments so far achieved are very far from an adequate response, given the scale and range of carers' needs²⁵.

As noted in CES Report 4, some aspects of these recent changes move beyond 'enabling' legislation and policies, and give to carers limited but enforceable rights, with statutory obligations on local authorities, employers and others. In reality, nevertheless, delivering new forms of support for carers is held back variously by resource constraints, organisational inertia and blockages, and sometimes, in the workplace and elsewhere, by out-of-date attitudes towards carers, or by ignorance of the ubiquity, importance and necessity of carers' roles.

As a result, only a small minority of carers with significant caring roles have had their needs assessed, as they are entitled (see CES Report 4), and the quality of the assessment process and its outcomes is highly variable²⁶. Some local authorities have been innovative, resourceful and imaginative in developing new support for carers (including in some cases working carers), engaging carers directly in the process of modernising the services they offer (including those involved in the ACE partnerships, whose activities are described in CES Report 5), but these examples of excellence are far from the universal situation. It remains to be seen how effective the recent extension of the 'right to request' flexible working arrangements, available to most working carers only since April 2007, will be for carers²⁷.

Campaigning organisations and service providers all concur that carer recognition and awareness remains a complex issue, not least because self-identification as a carer is extremely variable. Those enacting caring roles do not always wish to describe themselves as carers, sometimes seeing the loving support they offer as simply an expression of a personal relationship (spouse, parent, child, etc.); for others the word itself remains unfamiliar or is confusing (indeed 'carer' continues to be inappropriately used in much popular parlance and some official documentation to describe paid, domiciliary care workers). For some, it is a difficult step to adopt the 'label' of carer – for others it becomes an important, and 'political', identity

imbued with quite specific real and symbolic meaning. The use of the term ‘carer’ in UK legislation (where in 1995 it was legally defined for the first time) and in the collection of official statistics (notably through the question asked for the first time in the 2001 Census) is undoubtedly a significant step in putting carers’ issues ‘on the map’. Two decades ago, scarcely anyone used this term, and few understood its meaning – today it is in widespread policy, legal and professional use and increasingly forms part of the everyday lexicon through which we describe our personal and family lives.

The introduction of National Strategies for Carers in England (1999), Scotland (1999) and Wales (2000) was an important step forward in UK policy-making in this field. Less well resourced than – and perhaps overshadowed by – the National Childcare Strategy (which was set out in the government Green Paper *Meeting the Childcare Challenge* in 1998), it signalled that government was ready to take carers seriously and to acknowledge their need for greater support. It led to the introduction of Carers Grant funding to local authorities (initially in the form of Carers Special Grant), and triggered the development of new support services for carers²⁸. It also created a context in which the Private Members’ Bills which later became the *Carers and Disabled Children Act 2000* and the *Carers (Equal Opportunities) Act 2004* could achieve passage into law, and considerably heightened awareness of carers and their situation across central and local government – with carers’ situation addressed in other legislation too. This included the *Employment Relations Act 1999*, the *Employment Act 2002*, the *Work and Families Act 2006*, and the *Pensions Act 2007*, all of which apply throughout the UK, plus (in England and Wales) the *Children Act 2004* and *Childcare Act 2006* and (in Scotland) the *Community Care and Health (Scotland) Act 2002*.

New inspection, accreditation and regulatory frameworks in social care have also been introduced, with the key agencies – the *Commission for Social Care Inspection (CSCI)*, the *Social Care Institute for Excellence (SCIE)* and different regulatory bodies (the *General Social Care Council* is the social care workforce regulator in England which registers

social care workers and regulates their conduct and training; there is also a *Care Council for Wales* and a *Scottish Commission for the Regulation of Care* and these have similar responsibilities in their different national contexts) all having some specific responsibilities for addressing the situation of carers. The CSCI, which carries out inspections and assessments of social care services and performance and publishes its results, produces an influential annual report on ‘*The State of Social Care*’ in England, drawing particular attention to the role of carers and their need for improved support²⁹.

Across the period since 1998, devolved government in Scotland and Wales has led to a degree of differentiation in the legislative and policy contexts affecting carers, with some variations in outcomes for carers, described in CES Report 4. Perhaps most notably, free personal care for older people in Scotland, introduced in 2002, has changed the situation of carers of some older people living in that part of Britain. During the period of the Carers Employment and Services study, the government White Paper *Our Health, Our Care, Our Say* (2006), which included the New Deal for Carers currently being implemented, CSCI’s annual reports on the state of social care, Sir Derek Wanless’s investigation into the funding of care for older people (published in 2006), and the major review of the *National Strategy for Carers*, which got under way in 2007 and promises to set out new arrangements and plans in 2008 for the following decade, have created a context in which carers and their situation have unprecedented profile in UK public policy.

These developments have made the CES investigation, undertaken as part of the ACE2 partnership led by Carers UK, exceptionally timely. The CES study, focused on the situation of carers of working age, and addressing in particular questions about the factors shaping carers’ ability to combine work and care, sought to explore issues relating to carers and employment in Scotland, England and Wales, focusing on the following research questions:

- Which carers, in what circumstances, access alternative services to enable them to remain in or enter employment or training?

- How do these carers access, choose and pay for the services they use?
- What kinds of alternative services do they use and how do they pay for them?
- How are decisions taken about how and by whom care should be provided?
- What do carers perceive to be the weaknesses of the care available to them?
- What additional services would they value and use?
- What do providers of care services consider to be the strengths and weaknesses of the infrastructure of support for carers in their locality and at the national level?

In the next section of this report, we turn to the findings of the CES study. In addition to undertaking a completely new investigation of carers of working age and their circumstances, through a structured questionnaire distributed in England, Scotland and Wales, and follow-up, face-to-face interviews with a sub-sample of the carers who responded, the study also included examination of the way services affecting carers were being developed in 10 specially selected study localities, and extensive new analysis of the evidence about carers in the 2001 Census. Our work on the Census used both the Census 'standard output' (first released in 2003) and a number of special datasets based on the Census, some of which became available for the first time during the study period. The CES research design, methodology and sources (fully described in Appendix 1), were chosen to provide the most up-to-date possible evidence about carers of working age, and to deepen and enhance knowledge about this very important group of carers. We focused particularly on the way local services provided to carers and those they care for are perceived by carers, and sought to examine how far local services were, or were not, meeting their needs and enabling those who wished to do so to continue in their paid work while caring.

2. Main findings of the CES study

The 2001 Census, which asked a question about carers for the first time in 2001, significantly advanced knowledge about carers, particularly in providing accurate local data about them, and enabling diversity among carers to be properly examined. Neither of these aspects could previously be fully addressed when the only major sources of statistical data about carers were sample surveys³⁰. However, the Census does not provide information about carers' financial wellbeing, their attitudes and experiences relating to formal services, or any assessment of how easy or difficult carers find it to manage work and care, and it was to ensure that these aspects were explored in relation to working carers that the CES study was commissioned by Carers UK in 2005. In this section of this report we outline our study methods, highlight our key findings (based on the 2001 Census, the CES survey, the CES research interviews and our analysis of policy development and implementation at local level), and summarise the material which is presented in much more detail in CES Reports 1-4, which provide the main evidence base underpinning our analysis and recommendations. We also briefly indicate the full range of activities undertaken between 2002 and 2007 through the two *Action for Carers and Employment* partnerships, both led by Carers UK, which included work with 'delivery' partners, 'policy' partners and 'transnational' partners, as well as with

'research' partners, both at the University of Leeds and in other agencies.

Study methods and research context

Conducted in 2006-7, the CES study was designed to explore the caring responsibilities, relationships and experiences of carers of working age, and to assess the adequacy of service provision at the local level as it was experienced by carers. To provide this, the study included the following elements (further details of which can be found in Appendix 1):

- A survey of carers, targeting those aged 16-64; 1,909 carers responded to the survey, 87% of them in the target age group. A wide variety of mechanisms was used to distribute the survey, to ensure that some carers not currently in touch with services were included in the sample.
- In depth, face-to-face interviews with a sub-sample of carers who had completed the survey questionnaire in each of 10 localities, designed to explore their experiences, attitudes and preferences about combining work and care – 134 carers were interviewed in the selected localities in England, Wales and Scotland, providing a rich data-set of carers' views and personal circumstances.
- Personal interviews with staff with professional responsibility for carer support and services in

local authority Adults' Services and other relevant agencies in the 10 selected localities.

- Extensive specialist analysis of the 2001 Census. This included use of special datasets, including the Census SARS (Sample of Anonymised Records) and the Census SAM (Small Area Microdata), which can be explored to identify the relationship between a wide range of variables.
- Documentation relating to local authority policy, provision and strategic aims for carers' support were also examined, and placed in the context of publicly available data on service provision, assessment arrangements and other officially monitored information.

Carers and employment in Great Britain: new evidence from the 2001 Census

By asking every resident about their caring circumstances, the 2001 Census created an extensive resource, making possible new and detailed analysis of carers' situation, both at national level and in every area of the country³¹. Our earlier work analysing the data from the 2001 Census which was first released in 2003 and 2004 has already been presented in other Carers UK publications³². In CES Reports Nos. 1 – 4, we included our additional analysis of the 2001 Census about the specific aspects of carers'

situation explored in each of those reports. The separate CES 'Locality' reports (which cover Wales, Scotland and the 6 English localities included in the study) examine local level data about carers of working age for these specific places. In this report, we summarise some of the key messages arising from these different analyses, and present some additional new material, not included in those other reports, made possible by the release in 2005-6 of the 2001 Census microdata (the Census SARs and Census SAM³³), as well as other Census data specially commissioned by the University of Leeds.

The 2001 Census revealed that there were almost 4.3 million (4,267,129) carers of working age in Great Britain (Table 6.1). These carers include over 1.8 million (1,846,690) men and over 2.4 million (2,420,439) women; thus 57% of them are women and 43% are men. 2.8 million carers of working age (1,322,932 men and 1,507,751 women) combine their unpaid caring role with a paid job (Figure 6.1). Contrary to what is sometimes assumed, therefore, two-thirds of carers of working age are in some form of paid employment. As the CES study shows, however, many of this very large group of carers (despite also being workers and in most cases taxpayers), need more support than they are currently getting to help them manage their dual work and caring responsibilities.

Figure 6.1 Carers of working age by economic activity status

Source for Figures 1.1 – 1.3: 2001 SARs. The 2001 SARs are 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.

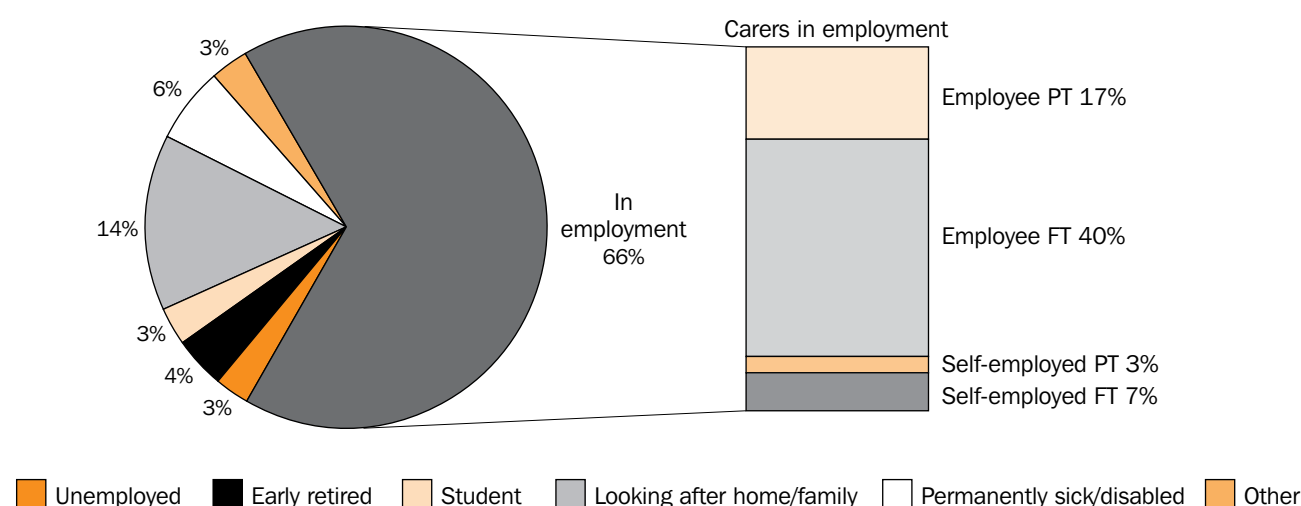


Figure 6.2 Male carers of working age by economic activity status

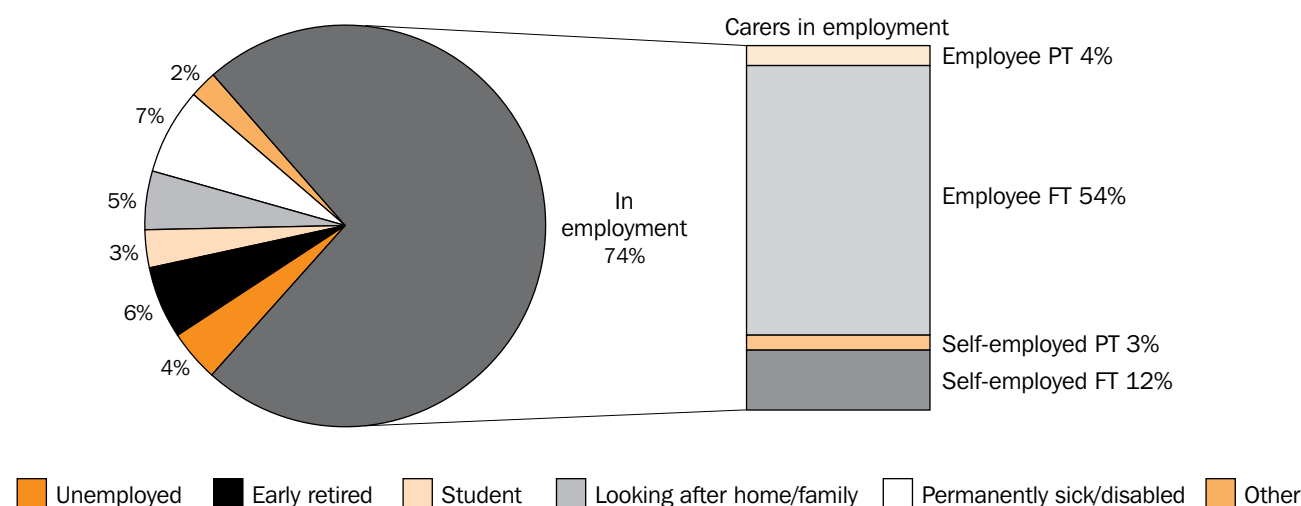
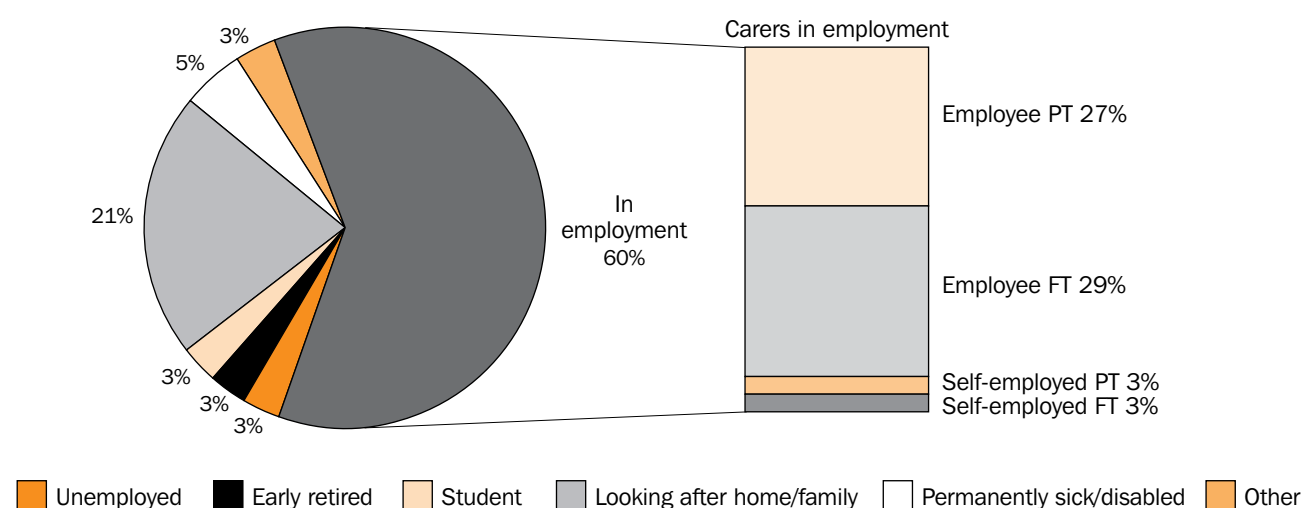


Figure 6.3 Female carers of working age by economic activity status



In Great Britain, over a quarter of a million men (252,474) and almost a third of a million women (304,132) in paid employment combine their jobs with providing very substantial – by which we mean 20 or more hours per week – amounts of regular unpaid care. Perhaps most remarkably, the Census showed that 287,182 people in paid work were carrying out their paid jobs alongside 50 or more hours per week of unpaid care. This latter group of carers is fairly equally divided between men and women (46% are men, 54% women), with the vast majority of men in this group (89%) and almost half of the women (43%) working full-time hours in their paid job. As a result, numerically, there are more men than women coping with full-time employment at the same time as caring for 50+ hours per week. This is an important finding, which both service providers and employers need to

note, as this group of carers, whilst including some of the most pressured members of our society, can be expected also to include some who are successfully combining their different roles. We show the various economic activity statuses of male and female carers of working age in Figures 6.2 and 6.3. (The sources for these figures are as for Figure 6.1. Data in all Figures and Tables are for Great Britain.)

Using the Census it is possible to map the geographical distribution of working carers, and this is shown in Figure 6.4. When we compare this with the geographical distribution of all people of working age who are in employment (Figure 6.5), we see strong comparabilities, indicating that, like others participating in the labour market, carers who want to work are also affected by local labour market trends and opportunities.

Figure 6.4 Geographical distribution of carers of working age in employment

Source: 2001 Census Standard and Commissioned Tables, 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.

Note: In the key, figures in brackets indicate the number of Local Authorities in the relevant category.

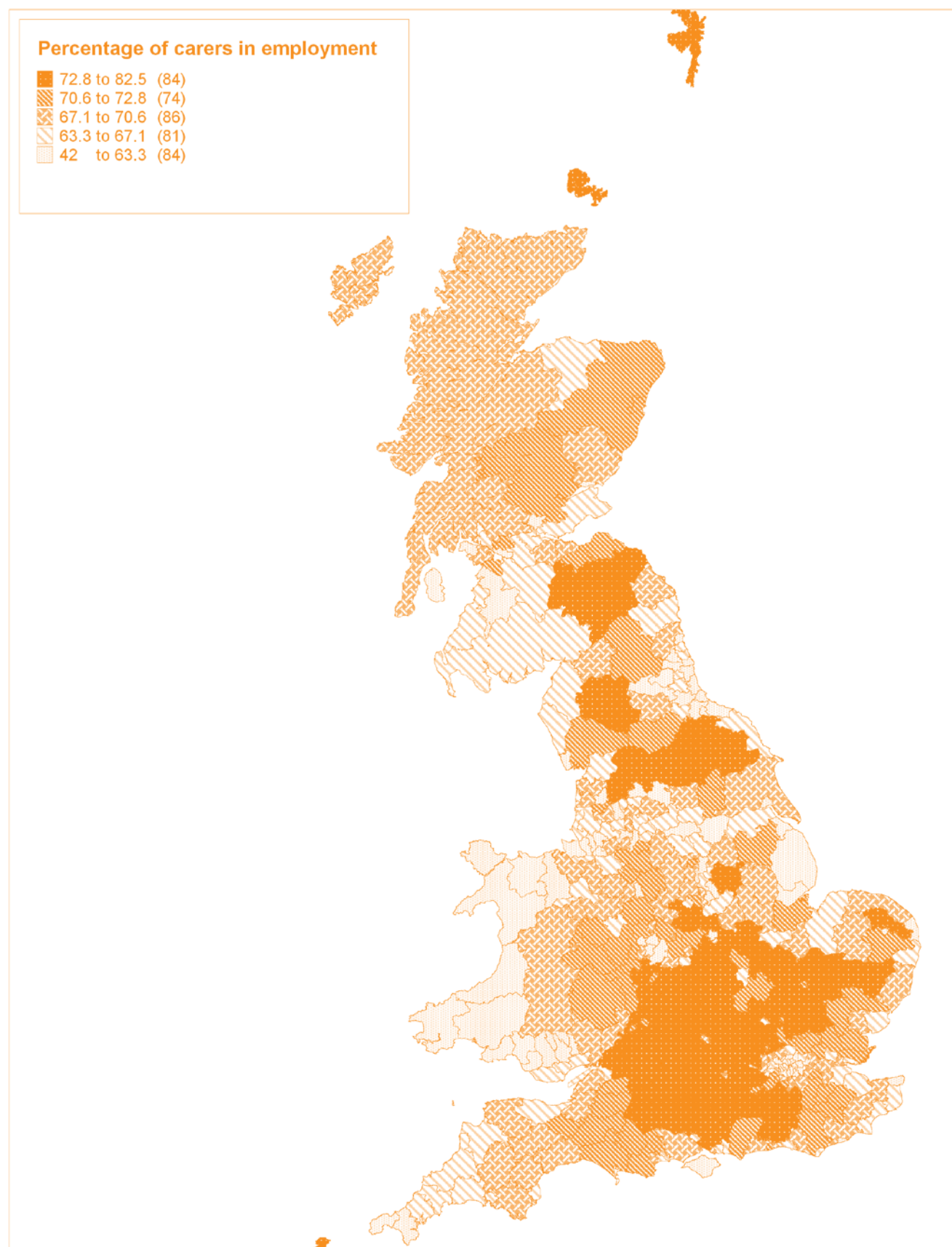
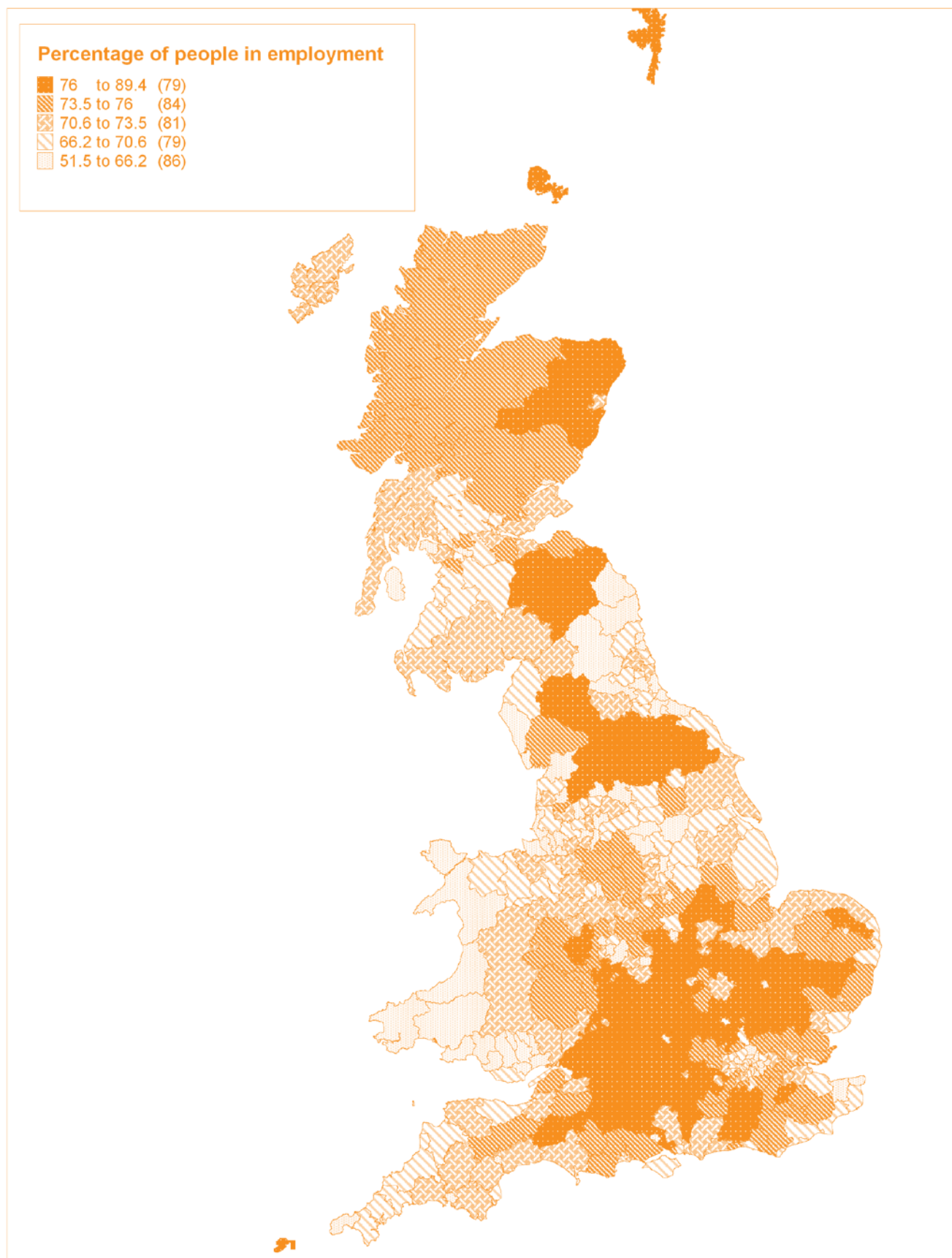


Figure 6.5 Geographical distribution of people of working age in employment (all people including non-carers) Source: 2001 Census Standard and Commissioned Tables, Crown Copyright 2003. This work is based on data provided through EDINA UKBORDERS with the support of the ESRC and JISC and uses boundary material which is copyright of the Crown. Note: In the key, figures in brackets indicate the number of Local Authorities in the relevant category.



The principal differences between male and female carers of working age (shown in Figures 6.2 and 6.3), are that women are much more likely to describe themselves as looking after their home and family full-time (21% compared with 5% of men), and that when in paid work (as most carers of both sexes are), female carers are much more likely to work part-time and are considerably less likely to be self-employed. While this in part reflects differences between men and women in the labour market who are not carers, it also arises (as we show in some of the other CES Reports) because of differences between men and women in the kinds of caring roles they most often occupy.

In providing accurate data about the detailed geographical distribution of caring for the first time, the 2001 Census made it possible to analyse many aspects of carers' circumstances – such as their age, sex, ethnicity, employment status, health, occupations, qualifications, household structure, and weekly hours of caring – by the locality in which they live. This data is especially valuable for planning of local services, and examples of the data available are given in the CES Locality Reports. As Figure 6.4 shows, the geographical distribution of caring responsibility among carers of working age (as for other carers) is not even. As discussed elsewhere³⁴, patterns of caring vary, with areas of greatest socio-economic deprivation showing the highest rates of caring. The fact that the structure of local labour market opportunities plays a significant role in shaping carers' choices and decisions about combining work and care means it is important that the prevalence of caring, and carers' situation vis-à-vis the labour market, is understood and responded to by those responsible (especially at local level) for local economic development, regeneration strategy and economic wellbeing. While there are a wide range of agencies with responsibility in this arena, their role in reaching Local Area Agreements (LAAs, first introduced, on a pilot basis, in 2005³⁵) has been an important development offering new opportunities to address the needs of carers in their local labour markets. The local groups working to draw up LAAs need full information about the potential impact of caring on employment, and on

the barriers carers face in entering employment or maintaining their paid work while caring.

We have also learned from the 2001 Census that some ethnic groups have higher rates of caring, at different ages, than others. We now know that the higher propensity to care among some ethnic minority groups (shown in Figures 6.6 to 6.8) reflects the greater demand for care which many people in these groups encounter. People of working age in the Pakistani and Bangladeshi groups are twice as likely to live with someone who has a limiting long-term illness (LLTI) as people in the White British population, and the contrast with some other groups is even more striking (Figure 6.9).

Further analysis of this situation (Figure 6.10) reveals that, across all groups, 79% of people of working age who care for 20 or more hours per week live with someone who has a LLTI, while this is true of only 28% of carers with less demanding caring roles (1-19 hours per week), and of just 15% of those who are not carers. However in the Indian, Pakistani and Bangladeshi groups, carers providing 1-19 hours of care per week are much more likely than virtually all other groups to share their homes with another person who has a LLTI.

In some ethnic groups the health of carers providing 20+ hours of care per week is particularly worrying (Figure 6.11). In the Pakistani, Bangladeshi and Black Caribbean groups, one in four carers aged 45 to state pension age is in poor health (compared with one in five of all carers of this age).

More than half of all Bangladeshi carers in this age group (52%), compared with 33% of White British carers providing 20+ hours of care weekly (and 20% of those caring for less than 20 hours per week) reported that they have a LLTI (Figure 6.12). In most ethnic groups, those who care for 20+ hours per week have poorer health and are more likely to have a long-term limiting illness than non-carers or those with less onerous caring roles³⁶.

Because ethnic minority populations tend to be clustered in particular localities and districts³⁷, it is especially important for local authorities and the service providers with whom they contract, to have access to local level data. Local level

Figure 6.6 Carers of working age by ethnic group and sex

Source: 2001 Census Standard and Commissioned Tables, Crown Copyright 2003.

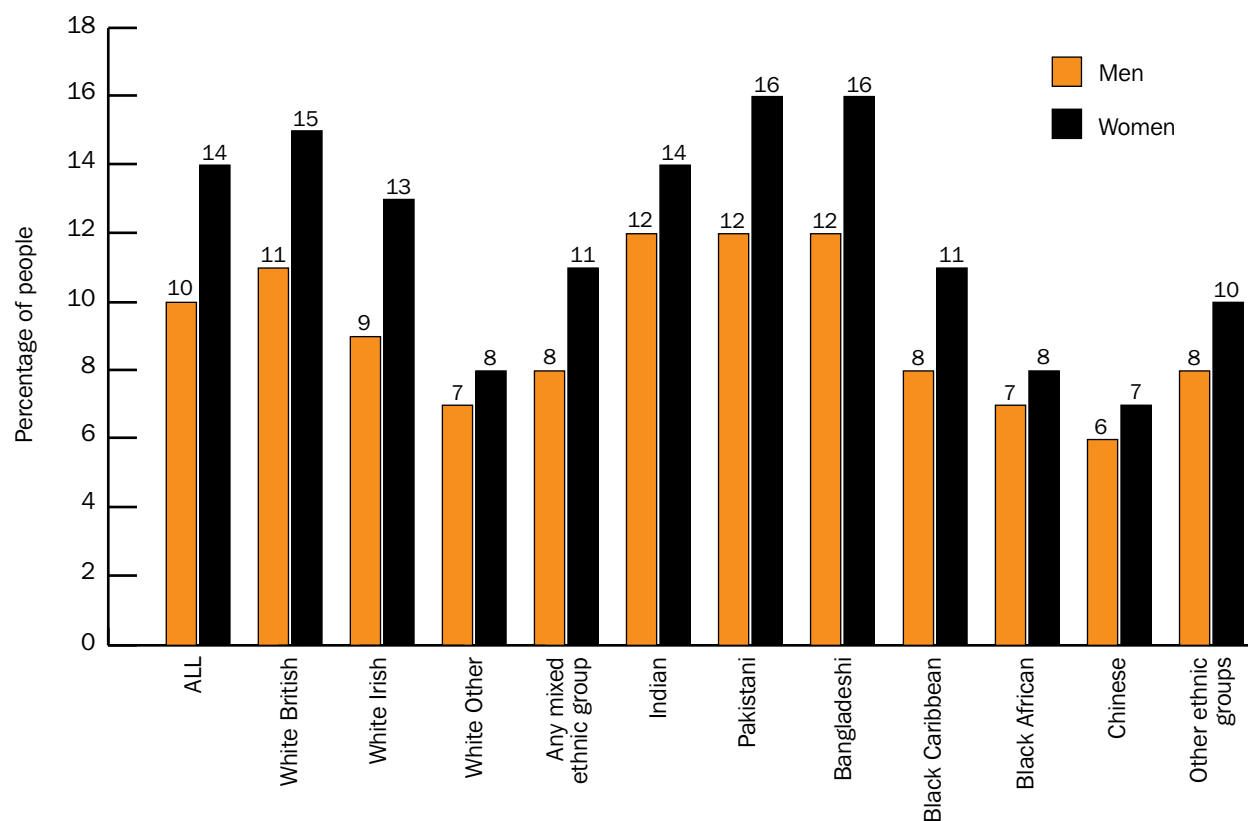


Figure 6.7 Male carers of working age in employment by ethnic group, sex and working hours

Source: 2001 Census Standard and Commissioned Tables, Crown Copyright 2003.

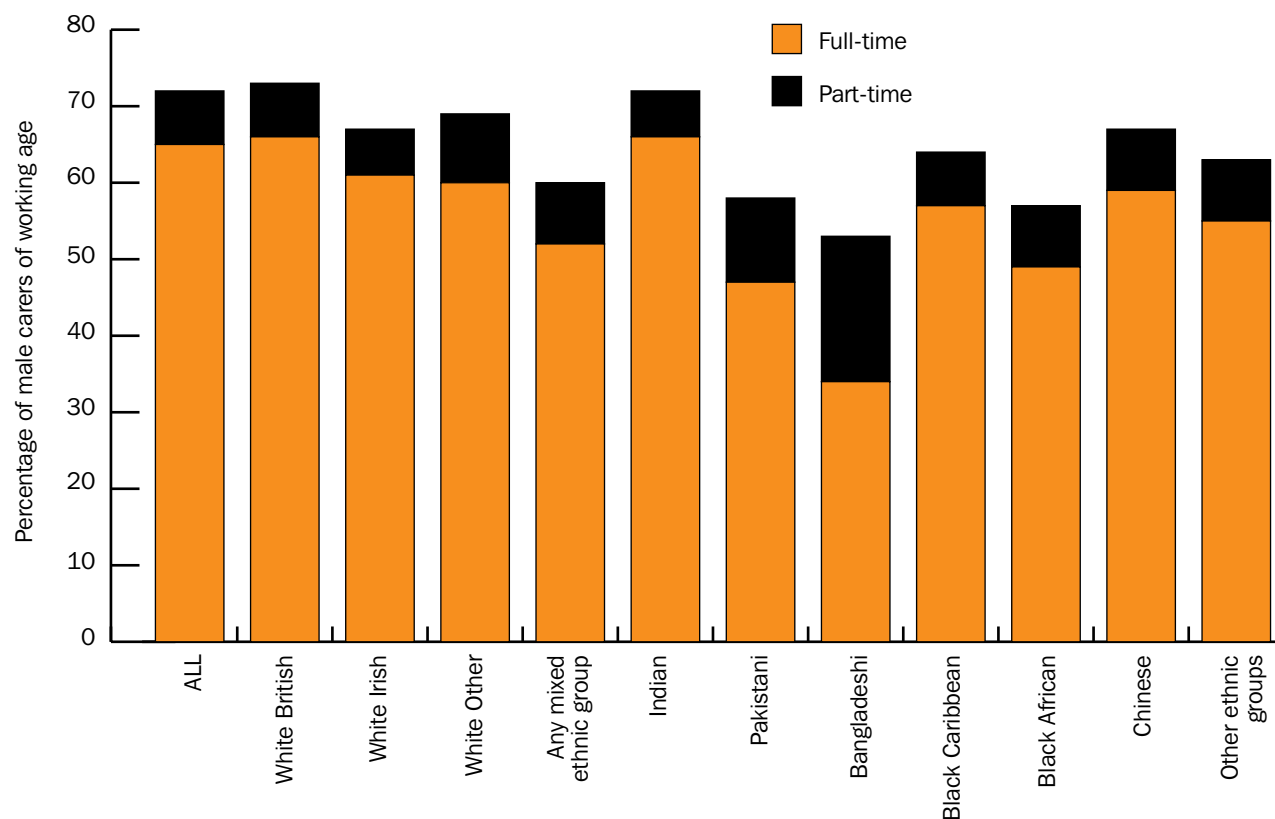


Figure 6.8 Female carers of working age in employment by ethnic group, sex and working hours

Source: 2001 Census Standard and Commissioned Tables, Crown Copyright 2003.

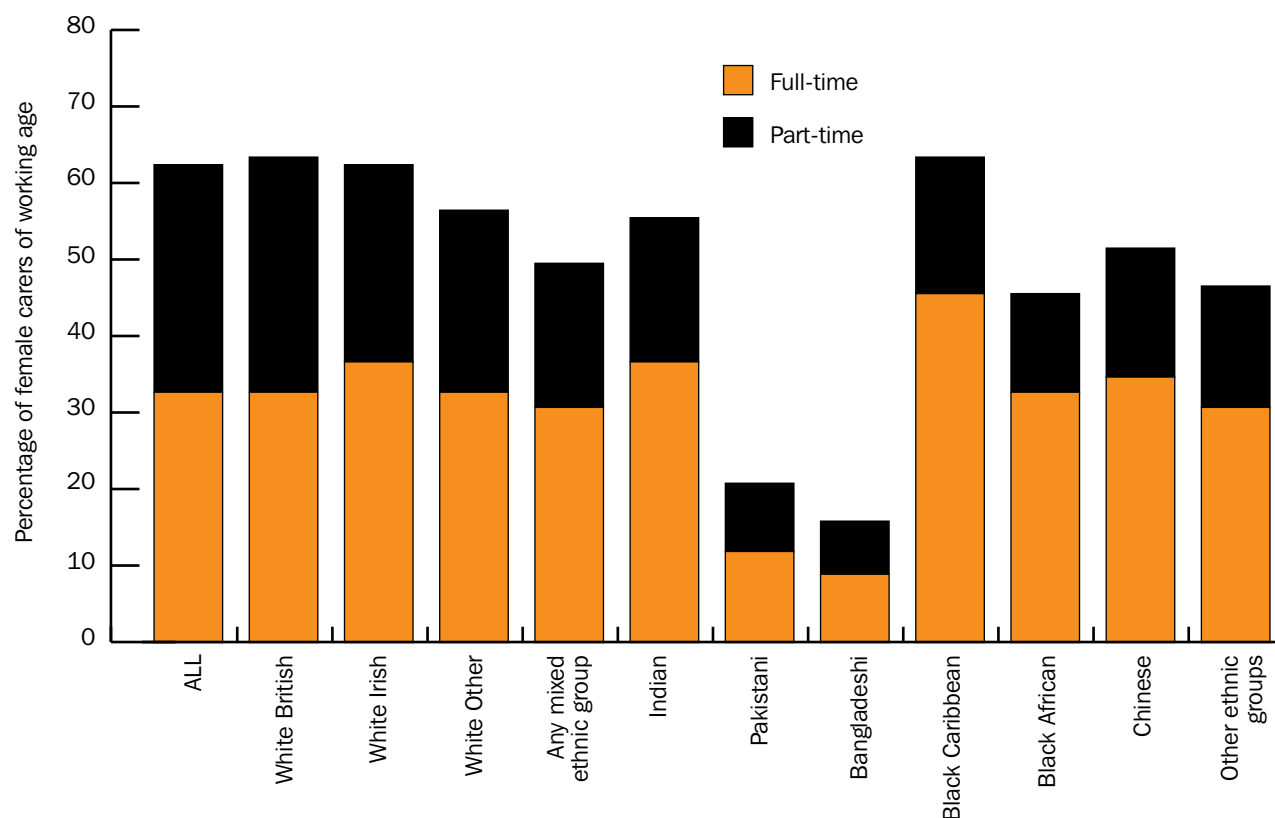


Figure 6.9 People of working age living in a household containing at least one person (excluding themselves) who has a limiting long-term illness, by ethnic group

Source: 2001 Census SARs.

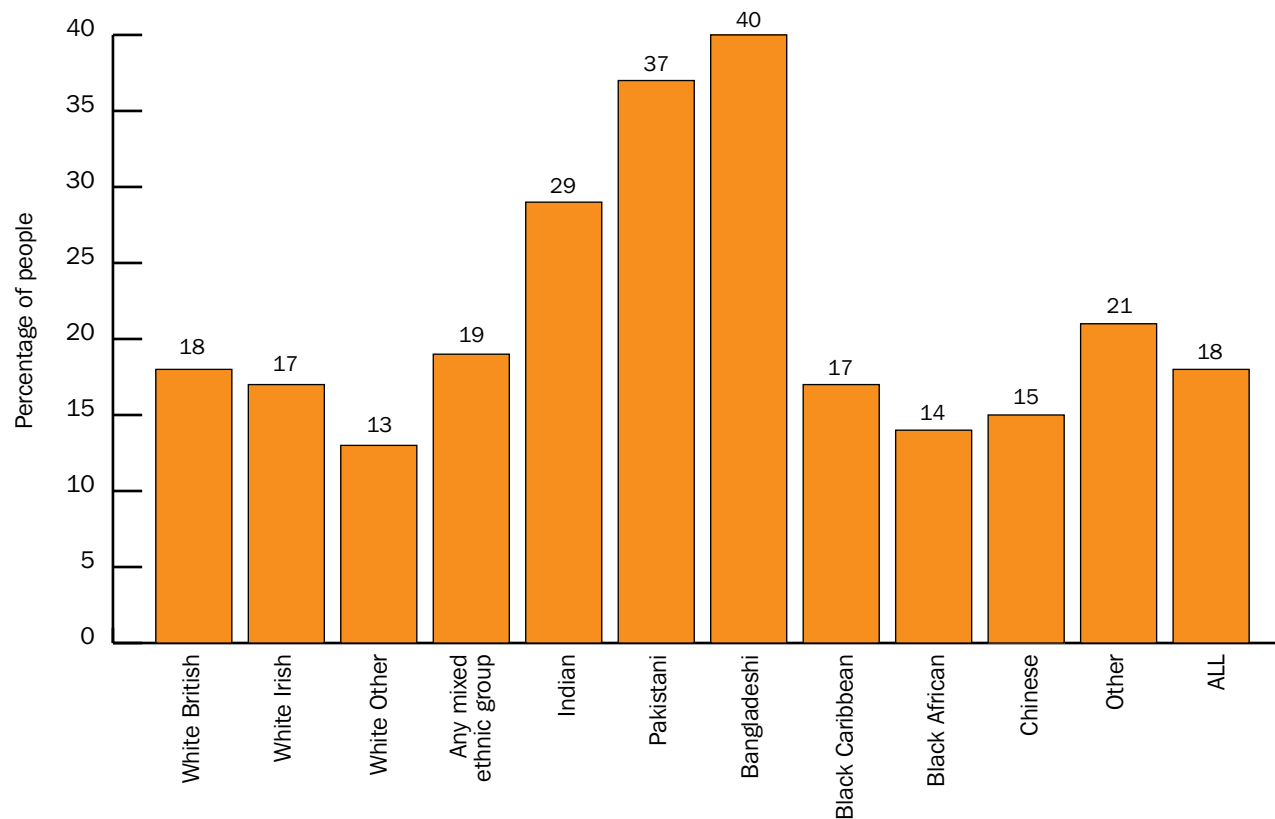


Figure 6.10 People of working age living in a household containing at least one person (excluding themselves) who has a limiting long-term illness by ethnic group and weekly hours of care

Source: 2001 Census SARs.

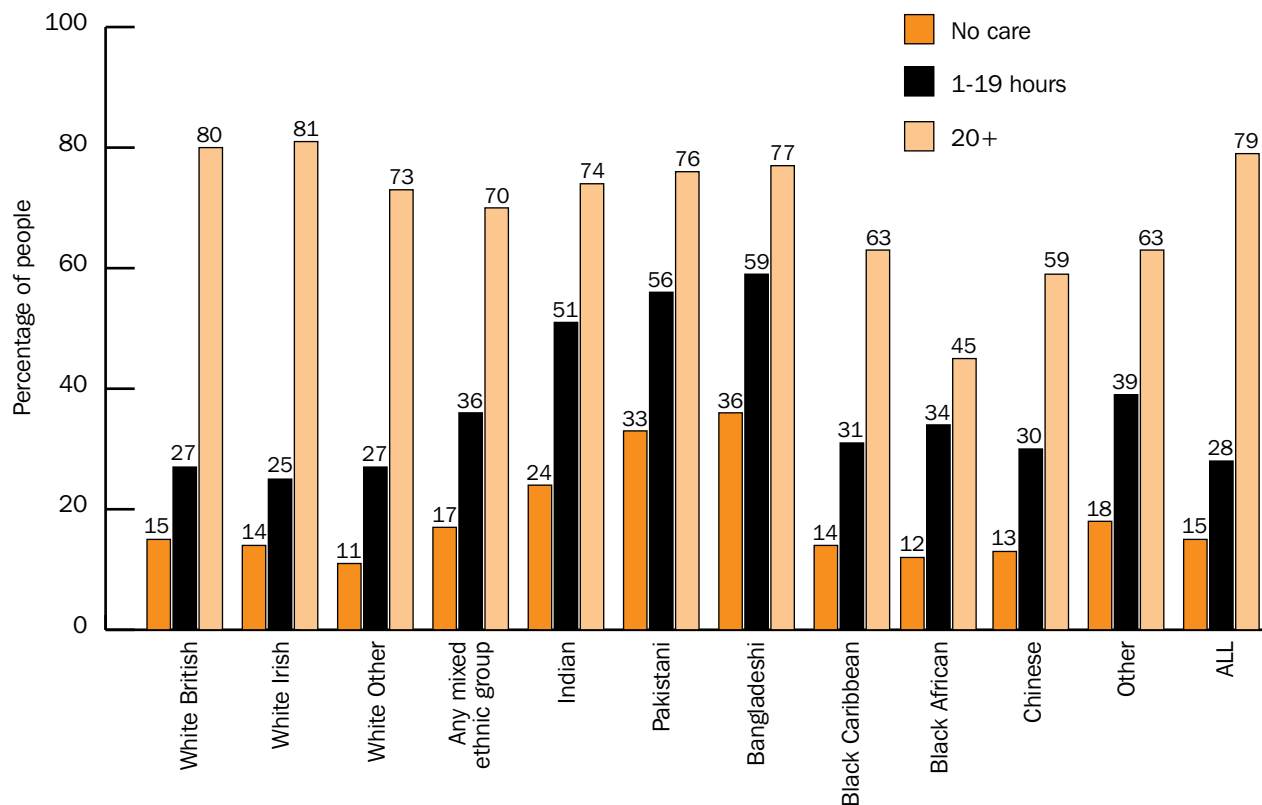


Figure 6.11 Poor health among people aged 45 to state pension age by ethnicity and caring situation

Source: 2001 Census SARs.

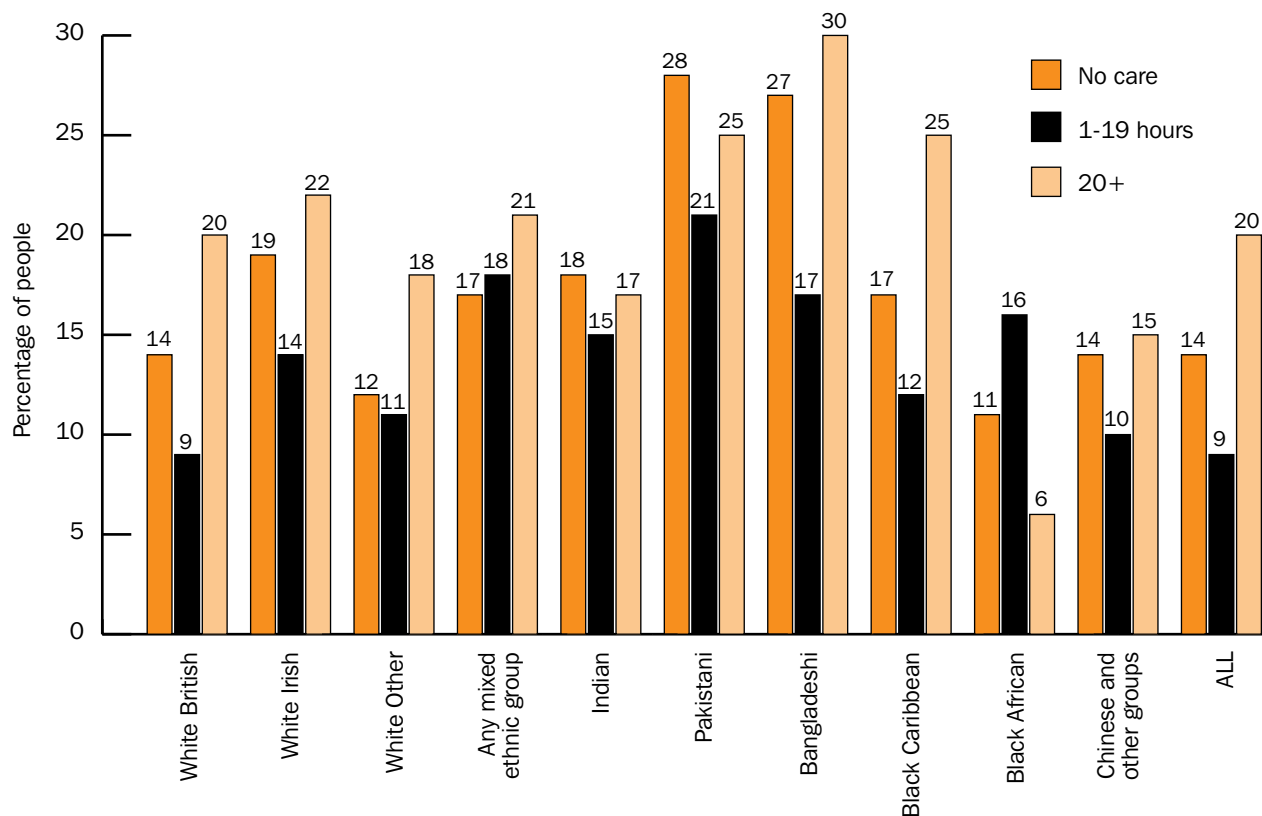


Figure 6.12 Limiting long-term illness among people aged 45 to state pension age by ethnicity and caring situation

Source: 2001 Census SARs.

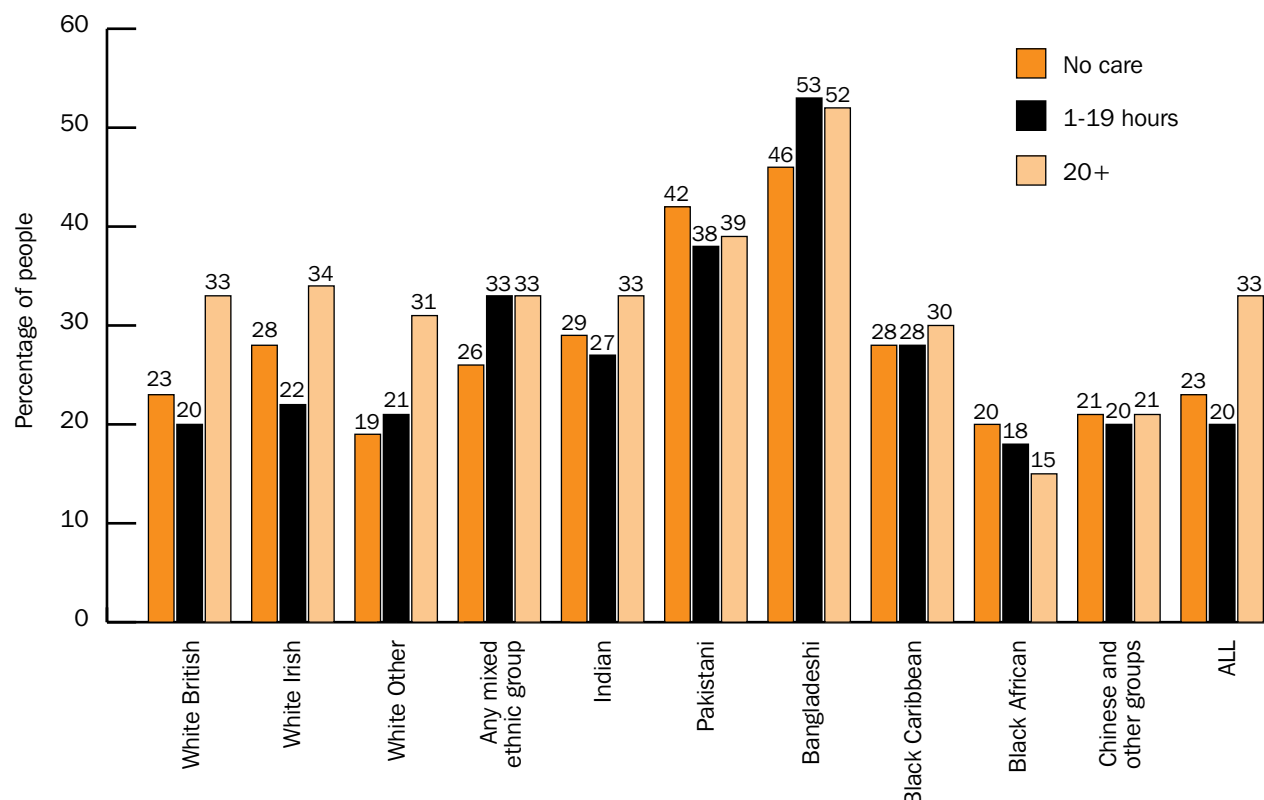
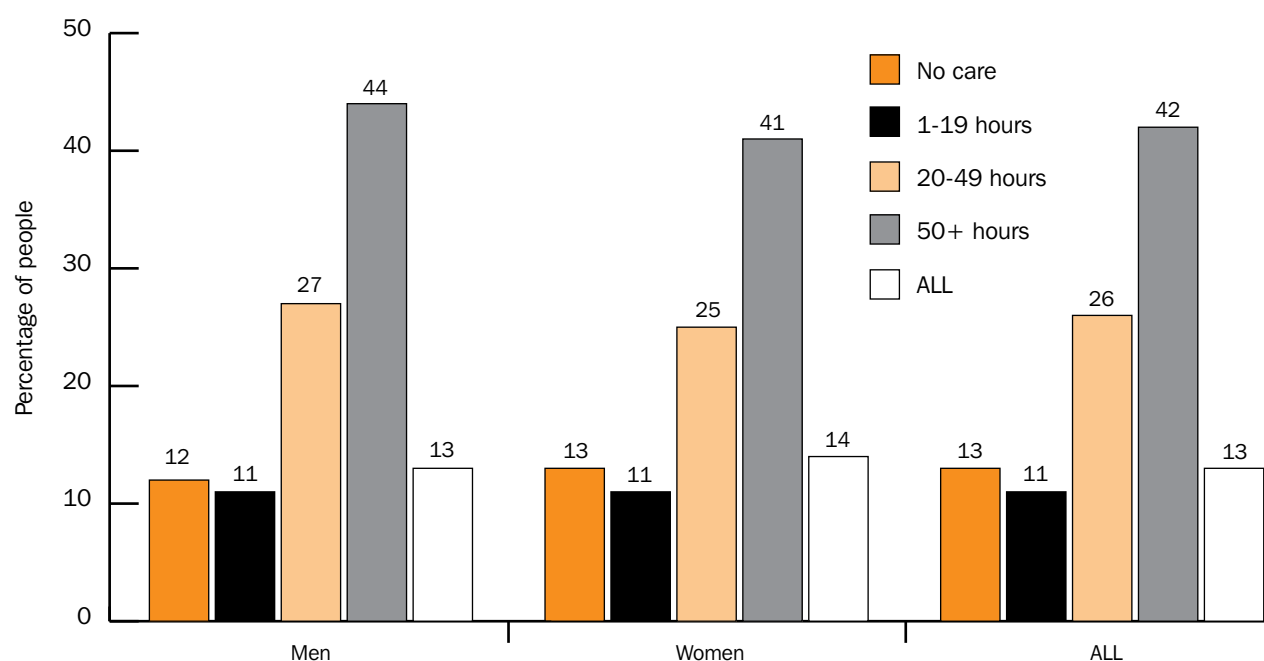


Figure 6.13 People of working age living in a household with no working adult, by amount of care and sex

Source: 2001 Census SAM. The 2001 SAM 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.



information about carers is crucial for planning and commissioning services for people who are ill, disabled or frail, and their carers. Disparities between localities are sufficiently large for this to be a factor which should also inform decisions about allocating public resources. The CES Locality Reports present information about carers at this level of geography, designed to assist local providers, service planners and commissioners in carrying out their work, and contain information about ethnic minority carers and other details of carers' characteristics³⁸.

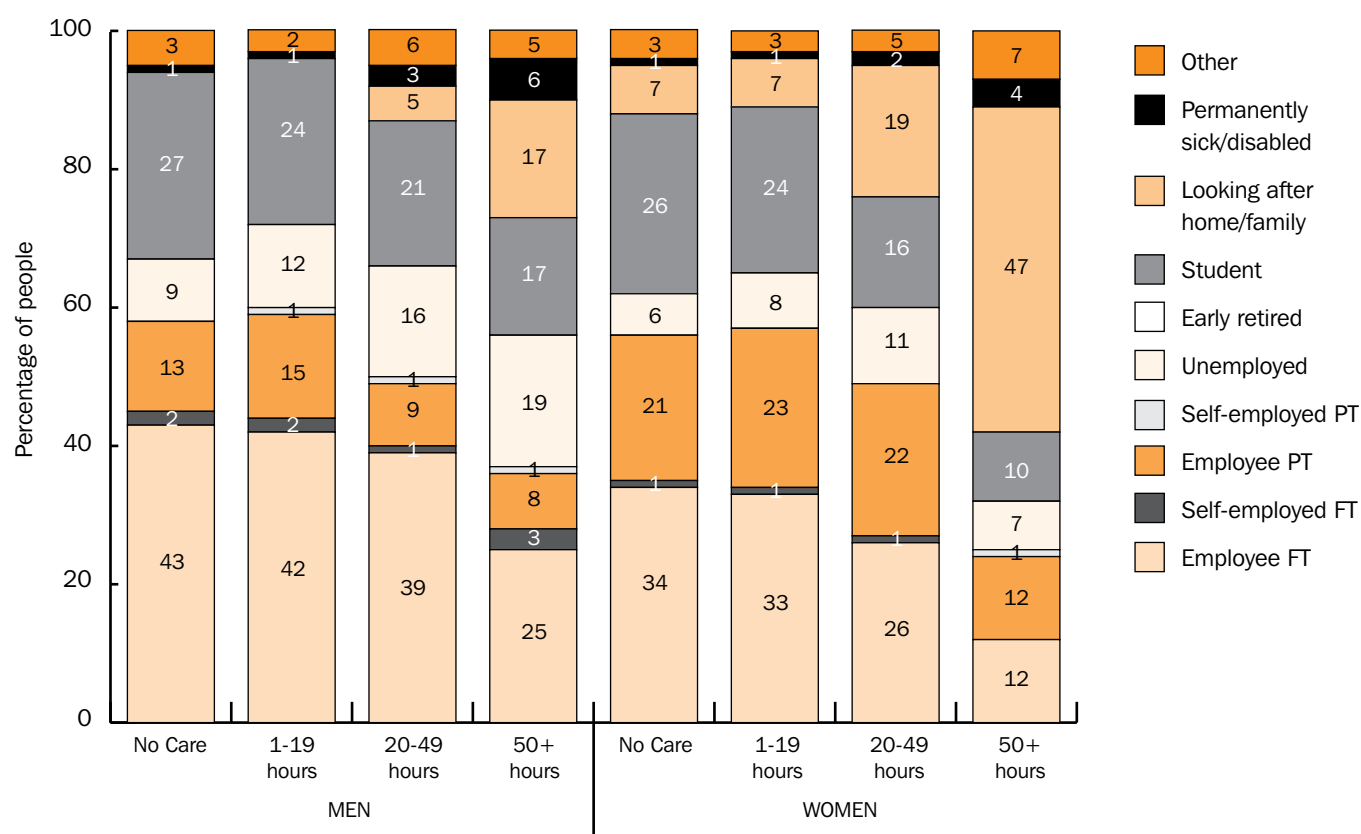
In common with other research³⁹, the CES study confirms that many carers experience significant financial hardship as a consequence of their caring role. While the 2001 Census did not ask people to disclose their incomes, it can be used to identify households in which no-one has paid work, a reasonable proxy measure for poverty. Here the evidence shows a strong correlation between caring and being in a workless household (Figure 6.13).

It is sometimes assumed that the impact of caring is felt only by people who have reached middle age, and it is true that caring is more concentrated in the 45+ age group. However, examination of age, economic activity and caring, possible using the 2001 Census SARs, shows how caring affects economic activity status at different ages. Among young adults (aged 16-24) caring reduces the likelihood of being a student and thus of participating in further or higher education for young men, and, especially, for young women (Figure 6.14). It also reduces their chances of being in either full or part-time work. The data in Figure 6.14 relate to 280,000 young adults who have caring responsibilities (across all three categories of hours of caring shown).

In the 25-44 age group, caring roles also have a significant effect on the economic activity of men and women (Figure 6.15). Here the impacts of caring on health and full-time employment are

Figure 6.14 People aged 16-24: economic activity by amount of care provided and sex

Source: 2001 Census SARs.



very clear for both sexes. Already in this age group, a quarter of men who care for 50+ hours per week, and half of women, are outside the labour market, and while women with moderate (1-19 hours) caring roles are more likely than non-carers to work part-time, those with more demanding caring responsibilities have lower rates of part-time employment than non-carers. Here we see the situation of a very large number of people, as there are 1.63 million carers in the 25-44 age group.

The circumstances of Britain's 2.38 million older working age carers (those aged 45 to state pension age) are shown in Figure 6.16. For both men and women at this stage in their lives, caring for 20 or more hours per week reduces employment significantly, while also increasing poor health and the likelihood of looking after home and family full time. Among those who care for 20 or more hours per week, there is also a notable impact on men's self-employment, and on women's part-time employment.

This additional analysis of the 2001 Census, supplementing the analyses presented in the other CES Reports and elsewhere, provides robust evidence of carers' need for better support. We turn now to the additional evidence collected in the CES study, which provides the opportunity to explore in much more detail carers' experiences, attitudes, needs and aspirations.

The Carers, Employment and Services Study: exploring the circumstances of carers of working age

Commissioned in 2005, the Carers, Employment and Services study was conceptualised as part of the ACE partnership and grew out of the earlier research, undertaken within ACE1 (2002-5), which concentrated mainly on how a forward-thinking group of 'carer-friendly' organisations were responding to carers' situation in their own workplaces. That research highlighted the scope

Figure 6.15 People aged 25-44: economic activity by amount of care provided and sex
Source: 2001 Census SARs.

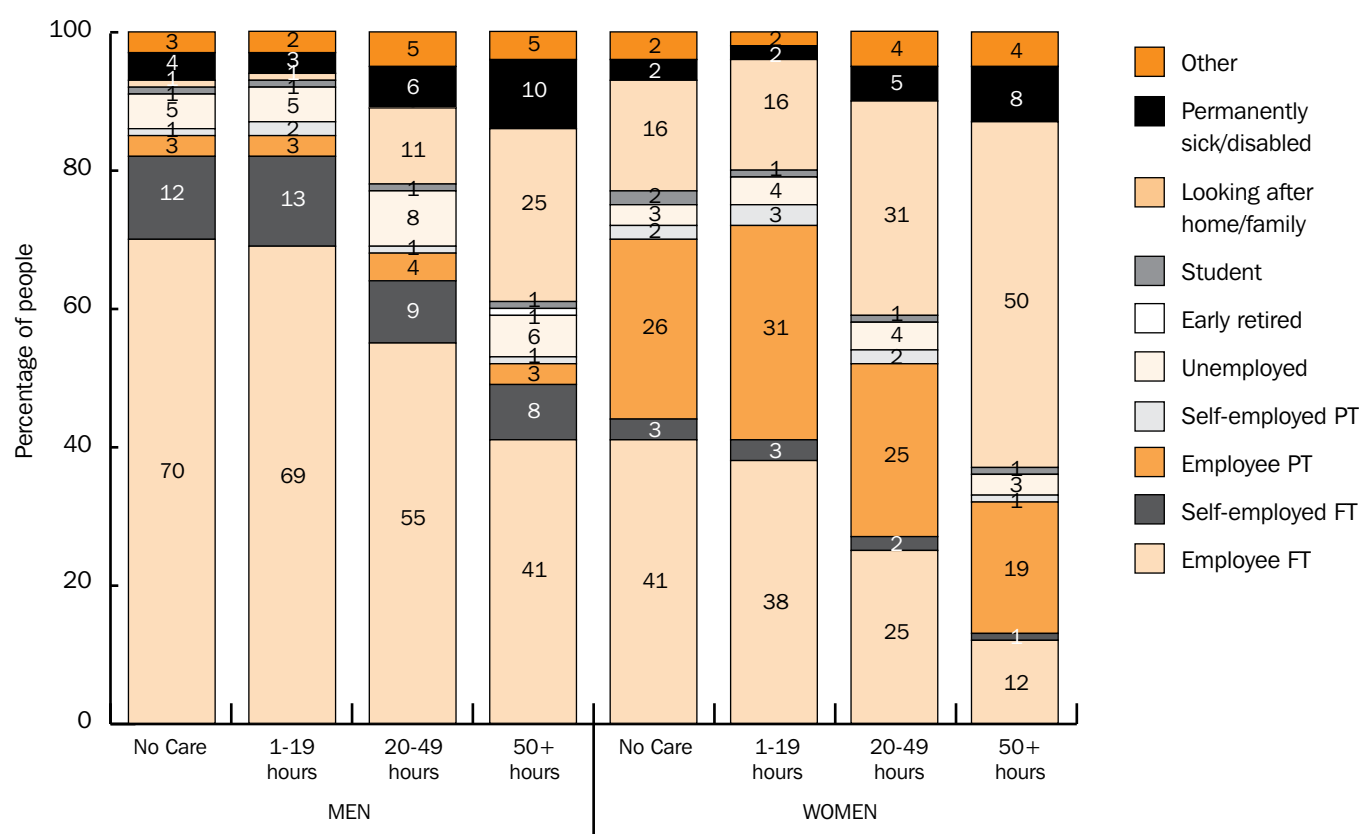
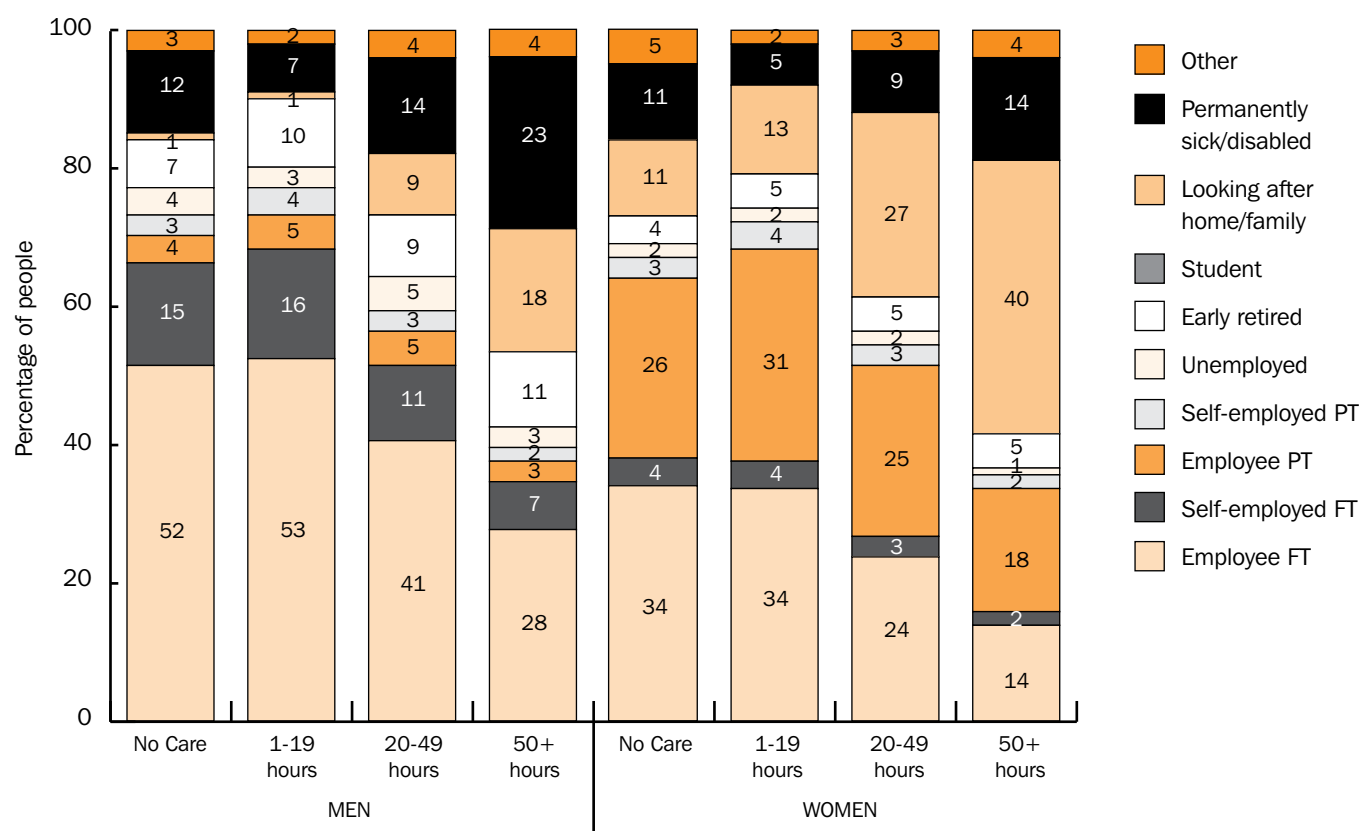


Figure 6.16 People aged 45-64/59: economic activity by amount of care provided and sex

Source: 2001 Census SARs.



for positive responses to carers at work, and the benefits organisations can gain through supporting their employees who are carers, but also exposed the fact that, however positively employers respond to carers, without suitable local services, particularly for those they care for, but also sometimes for carers themselves, organisations and businesses cannot, on their own, provide the right infrastructure of support for carers. This shifted the research questions away from what works for carers in their places of work, to a consideration of how carers who wish to combine work and care find out what local services are available and access support, and to how far the assistance they get helps them in managing their caring role alongside their job or career. The research design chosen was selected to explore the situation of carers of working age, and to maximise our chances of identifying not just those carers who were already 'in touch with services', but also 'hidden carers' who might be coping

without support. This aim lay behind our strategy in distributing the survey questionnaire, which included accessing carers directly through employers, health service settings and general publicity, as well as through carers' organisations and local authority social services contacts (see appendix 1).

As discussed in CES Report 2, the carers who responded to the CES survey were mostly carers with demanding caring roles (about half of both men and women respondents were caring for 50+ hours per week). Our achieved sample of survey respondents over-represents women carers in the general population (and under-represents men who are carers): we think this is probably a feature of much other research on carers, too, and explains why male carers have so often been neglected in discussion about carers' situations⁴⁰. As discussed in CES Report 2, we have compared the characteristics of our survey respondents with data on all carers in the 2001 Census. On the measures we examined,

female CES survey respondents were reasonably representative of all female ‘heavy end’ carers of working age, particularly in their patterns of economic activity (although our respondents were a little less likely to be in paid work). The CES survey drew fewer responses from men than women, and, as we noted in Report 2, our sample of male carers of working age under-represents male carers in full-time employment, and over-represents male carers working part-time.

1,909 carers responded to the CES survey by completing the survey questionnaire. Of these, the majority (1,489) were of working age (16-64 for men, 16-59 for women⁴¹). Their characteristics in terms of hours of caring (Table 6.2), their relationship to the person cared for (Table 6.3), the condition/diagnosis of the person cared for (Table 6.4), and the length of time they had been caring (Table 6.5) are shown in the tables indicated. Most were ‘heavy end carers’, supporting someone living

in the same household. The majority of the men who responded were caring for a partner or spouse, while many of the women were caring for a parent or for a disabled child. The men were proportionately more likely to be caring for someone with a long-term or terminal illness; the women were proportionately more likely to be caring for someone with learning difficulties. Male carers were proportionately more likely to have been caring for between 2-5 years, whereas female carers were relatively more likely to be new carers, or to be in very long-term caring situations.

So far in this section we have emphasised the scale and extent of caring, its distribution among the population according to age, sex and ethnicity, and our data on caring and health. We have also outlined the main characteristics of the CES survey respondents, as this information is important in interpreting the new quantitative data we have collected. In the remainder of this section we

Table 6.2 Carers of working age in the CES survey by weekly hours of care

Source: CES Survey, University of Leeds 2007.

CES Survey	Women number	Men number	Women %	Men %
All Carers	1,137	306	79	21
Caring 1-19 hrs	216	61	78	22
Caring 20-49 hrs	255	71	78	22
Caring 50+ hrs	666	174	79	21

Table 6.3 Carers of working age by relationship to person cared for

Source: CES Survey, University of Leeds 2007.

	Women number	Men number	Women %	Men %
All in survey	1,177	312	79	21
Caring for a child aged 1-19 years	434	41	91	9
Caring for a child aged 20+	150	32	82	18
Caring for a partner or spouse	269	170	61	39
Caring for a parent or parent-in-law	358	72	83	17
Caring for person in own household	834	259	76	24
Caring for person outside household	247	41	86	14
Caring for persons in and outside household	80	6	93	7

Table 6.4 Carers of working age by condition/diagnosis of person cared for

Source: CES Survey, University of Leeds 2007.

CES Survey	Women number	Men number	Women %	Men %
Condition/diagnosis of person cared for	1,177	312	79	21
Physical condition	588	186	76	24
Learning Difficulties	504	54	90	10
Mental Health problem	275	76	78	22
Long-term or terminal illness	370	124	75	25
Dementia	133	38	78	22
Sensory Impairment	278	53	84	16
Frail/Limited mobility	492	123	80	20

Table 6.5 Carers of working age by length of time caring and sex

Source: CES Survey, University of Leeds 2007.

CES Survey	Women number	Men number	Women %	Men %
All in survey	1,177	312	79	21
Up to 2 years	140	30	82	18
2-5 years	225	88	72	28
5-9 years	292	76	79	21
10+ years	513	115	82	18

summarise the CES study findings, as reported in CES Reports 1 - 4. The data and analysis in those reports also drew on other aspects of the study, including face-to-face interviews with 134 carers in the ten selected localities, interviews with key stakeholders involved in delivering services to support carers, and documentary sources. A much fuller presentation of the evidence can be found in the other CES Reports. In each case, as we outline the material in the four reports, we start by highlighting the key issues which emerge from the analysis, before presenting a sample of the detailed evidence underpinning our assessment.

Stages and Transitions in the Experience of Caring

In CES Report 1, on stages and transitions in the experience of caring, we emphasise that caring is part of normal human relationships and of everyday

life, with caring happening to most people at some point in their lives. As we discuss in more detail later, giving and receiving care are both crucial dimensions of each person's humanity, yet despite the centrality and ubiquity of caring, when caring 'happens to us' it is often unexpected and unanticipated. The fact that caring can 'creep up on us' and can also 'land on us' when we least expect it is an important aspect which distinguishes caring for an older, sick or disabled person from the demands of looking after a new baby or healthy young child. As the data in our report shows, the onset of caring can be sudden or gradual – in either case its impact is often upsetting. Whether someone close to us has a major accident, serious diagnosis or sudden illness, or by contrast very gradually loses their mental or physical faculties or experiences declining health and strength, it is natural for the experience to be distressing, with impacts on other parts of family, working and

personal life. What carers in the CES study often found destabilising and shocking, however, was that at this time, getting information, accessing services and negotiating flexibility at work were often so very difficult. Carers told us that the health and financial impacts of caring are often felt very quickly, and that when caring becomes a longer-term commitment, these effects intensify. Our report drew particular attention to the fact that many longer-term carers support a disabled child (often into that child's adulthood) or a partner with a serious long-term illness or major disability.

The 214 'new' carers in the CES study (carers who had been in their caring role for less than two years) had entered caring in different ways, some gradually becoming carers, while others had caring suddenly thrust upon them. Two thirds were caring for 20 or more hours per week, and almost 60% were in paid employment. Most were caring for someone who was living with them, usually an older person or another adult. 41% were supporting someone who was not receiving any services. 28% of 'new carers' were struggling financially, and 42% said the person they cared for had not had their needs assessed. A key problem for these carers was a lack of information and inadequate responsiveness and accessibility on the part of service providers. Many felt confused, frustrated and unsupported, and 41% did not know what services were available locally. Early information was needed about benefits, assessment, services, respite and breaks, and rights and options at work, but had often not been given, or was not easily found. Many recounted problems in communicating with health and social care services which had caused them great distress and frustration. 'New carers' often reported problems in combining work and care and although most did not want to give up work, 46% of full-time employees, and 62% of part-time employees, felt they did not have adequate services to enable them to work. A small majority (56%) felt their employer was carer-friendly and supportive. 42% said the person they cared for did not want to use services, sometimes because they wanted a relative to provide the care they needed, and sometimes because they felt services were unsuitable, inflexible or expensive.

1,675 carers in the study had been caring for two

years or longer. Of these, 76% were living with the person they cared for, and 84% were caring for 20 or more hours per week. Less than half were in paid employment: 45% of those caring for 1-19 hours per week; but only 21% of those with the heaviest caring roles; for over a third of the 'heavy end' carers, caring was their full-time role. The caring responsibilities of this group of carers were varied: 29% cared for a sick or disabled child under 19, and 12% looked after an older child (aged 20+); 24% supported a spouse or partner, and 13% were caring for a parent or parent-in-law. Almost a third of those caring for 20+ hours per week were caring for someone who was not receiving any services, and a third said the person they cared for had not had their needs assessed. Over a quarter said their own health was 'not good', and a third were struggling to make ends meet. Thus impacts on their own health, financial situation and ability to work were major issues for 'longer-term' carers. While some were satisfied with the services received, many reported problems in arrangements and dealings with service providers, often saying they had reached 'crisis point' or felt poorly supported by service providers. Over the years, many felt they had become 'experts' in their caring situation (in terms of their detailed knowledge of the condition and needs of the person cared for, their role in providing the specific care needed, and in co-ordinating support arrangements), but they did not always feel this was recognised by the agencies they dealt with.

CES Report 1 also dealt briefly with the 'end of caring', considering the different circumstances in which caring can come to its conclusion, and the different kinds of assistance carers may need when this happens.

Managing Caring and Employment

CES Report 2, on managing caring and employment, complements our earlier study *Who Cares Wins: the social and business benefits of supporting carers*, which investigated the way organisations can use flexible employment and support to retain in employment carers who might otherwise have to leave their jobs⁴². By assisting them in doing what they wish to do – managing their caring responsibilities alongside their paid job or career – the organisations studied had achieved benefits in

terms of better retention of skilled and experienced employees, lower recruitment costs, improved productivity, and enhanced staff motivation. Complementing that research, the new CES report turned to the services available to support working carers, and to carers' experiences of accessing that support. The report stressed the importance of this issue, since there are 4.27 million carers of working age in Britain, 66% of them – representing 2.8 million people – combining their caring role with paid work.

In the report, we stress that at the societal level, giving up work to care – something which about 400 carers in the CES study had done – is not an acceptable or sustainable solution. This response does not work for the economy or for employers, it does not (and cannot) work for the pension system, it does not work for families and communities, and it does not work for most individuals. There are of course some circumstances when a full-time commitment to caring is necessary or is what those involved – during the last months of a terminal illness, for example – may want. But almost always, those who become full-time carers while of working age need a 'way back' from such intense and demanding caring situations, which often leave them socially isolated or excluded, into ordinary life and everyday opportunities – so that caring does not end their career or damage their education, does not put them at risk of long-term poverty, and does not jeopardise their own health and wellbeing through social isolation and exhaustion.

The CES survey included 812 working carers, 93 of whom were also interviewed face-to-face. They comprised 654 women and 156 men; among them 21% were in poor health, and a third (both among employees and the self-employed) were 'struggling to make ends meet'. About three quarters had help from family and friends which helped them in combining work and care, and two thirds (but only about half working in the private sector) said their employer was supportive and 'carer-friendly'. Only a quarter felt they had adequate support from formal services to enable them to combine work and care; most needed at least one service they were not currently receiving; 42% were paying privately for services. Very few were getting carer's breaks, and less than a quarter had access to respite services.

Almost half felt a lack of flexibility and sensitivity in the delivery of services was hampering them in obtaining support, and a large minority felt poorly informed about available services. Many stressed that they were keen to continue in work, yet more than a third had considered giving up work because of their caring role. Almost half of those working part-time were only in this type of work because of their caring responsibility.

400 carers in the CES survey were under 65 but had given up work to care; compared with working carers, they were more likely to be struggling financially and to be in poor health. Most were 'heavy end' carers who had been caring for 5 years or longer; many were caring for a sick or disabled child, who had often now reached adulthood. These carers were more dissatisfied with available services than working carers, and despite their relatively intense and long experience of caring, a third felt they lacked information about what was available.

Those carers who were unemployed and actively seeking work were finding it hard to find jobs that were flexible enough to meet their needs, and lacked support in returning to work; some felt they had lost confidence. Among over 500 respondents who were looking after their home and family full-time, 40% said they would rather be in paid work, but could not return to employment because the services available did not make a job possible. More than two thirds of carers outside employment said their caring responsibilities had caused them to leave paid work.

Diversity in Caring: towards equality for carers

In CES Report 3, on diversity in caring, we focused on the many different situations and circumstances in which caring may arise, and on the fact that caring occurs across all groups in our society. We placed particular emphasis on ethnicity, financial circumstances, urban and rural settings, and health, and also looked at the relationships between carers and those they care for, and at the conditions experienced by those who need their help.

Our data make it clear that the health impacts of caring are significant, and worsen with both the length and intensity of caring. In the report,

however, although we recognise the special needs and requirements of carers in some situations and circumstances, our main message is that across the full spectrum of caring situations and of carers' lives, almost all carers want the same thing: sensitive, tailored support, designed with their own personal and working life, family circumstances, values and beliefs, in mind. This means that it is not so much 'special' services for 'different' groups which is needed – although some groups of carers and users of services have particular needs, including language requirements – as that all carers need: better information, communicated to them effectively; more say in how services are designed and delivered to them and those they care for; respect and acknowledgement for their caring contribution from all the agencies and individuals they deal with; and to be treated as equal partners in the delivery of social care.

204 ethnic minority carers, 130 from non-White groups, responded to the CES survey. Non-White carers in the CES study were more likely than White British carers to be 'struggling' financially. Ethnic minority carers were especially likely to be caring for a sick or disabled child or for someone with a mental health problem, and proportionately more ethnic minority carers were caring in circumstances where Direct Payments were being used to arrange services. Ethnic minority carers were especially likely to say they felt restricted in using services because they lacked information, or because services were too expensive, lacked flexibility, or were not suitable for their individual needs. Our interviews with ethnic minority carers raised some issues about the skills of paid care workers, especially where service users spoke languages other than English, and about culturally appropriate provision. In general, however, common issues were more important than differences.

424 carers in the CES survey provided care for someone living in a rural area. Urban and rural carers in the study cared for very similar kinds of people, with few differences between urban and rural carers. Particular issues raised by rural carers in detailed personal interviews included: travelling to and from services, which was time-consuming and costly; difficulty in finding appropriate services; and limited choice about services. Carers who

provided care for someone living at least half an hour's travelling distance away (a separate, small, group of carers) were better qualified, more likely to be in full-time employment, and relatively 'new' to caring, compared with other carers. Their caring responsibilities also tended to be lighter in terms of hours of care per week.

36% of carers of working age were 'struggling to make ends meet'; only 26% said they were 'reasonably comfortable financially'. Carers who were struggling financially were more likely to be: in poor health themselves (34%), unqualified (21%), or caring for 20+ hours per week (88%). They were also more likely to be caring for a child under 19 (37%), someone with a learning disability (42%) or someone with a mental health problem (27%).

Analysis of respondents' employment circumstances showed that 40-50% of carers in the unemployed, sick or disabled and 'looking after home and family full-time' categories were struggling financially, compared with just under a third of carers in full or part-time work.

61% of carers wanted at least one service which was not currently received: this figure varied only very slightly with financial circumstances. Carers in financial difficulties were a little more likely than other carers to lack information about service provision, or to say that the person cared for did not want to use services. Better off carers were slightly more likely than other carers to say their use of services was restricted by cost, or by their perception that services were not sufficiently reliable, flexible or sensitive to individual needs. Overall, when carers were compared according to their financial situation, the similarities in their views about services were more striking than the differences; in detailed interviews, however, poorer carers particularly noted worries and concerns about managing their day-to-day situation.

484 carers in the CES survey reported poor health; we found a clear link between the length of time carers have spent caring and poor health. Among those in employment, men were slightly more likely to report poor health than women, with unemployed carers especially likely to report health problems. Carers in poor health were considerably more dissatisfied than

other carers with the services available. Our interview data indicate that carers' frustrations in accessing services, and the limited support they receive, contribute to their poor health. Carers in poor health, whether in paid work or not, are more likely to be struggling financially than other carers.

Carers, employment and services in their local context

CES Report 4, on the local context of support for carers, highlighted the policy and legislative progress that has been made in Britain since 1995 in terms of recognising carers, responding to their needs and aspirations, and providing them with new rights and new forms of support. The report is illustrated with examples of good practice and innovation in supporting carers, and these include some inspiring projects which have been transformative in their impact on the lives of the individuals and families affected.

But the report also notes major weaknesses in support for carers, with those who are in paid work particularly neglected and unsupported. It stresses that at the local level, where support needs to be delivered, even the best agencies and authorities are merely 'scratching the surface', with only a tiny minority of carers, even among those with heavy caring roles, having their needs assessed or receiving a service. Another important issue identified in the CES study is the significant minority of carers who report that the person they care for does not want to use formal services. This was not reported only by those new to caring or who had only light caring roles, but was often an issue for those who had been caring for a long time and committing many hours each week to their caring role. This highlights the need to further explore why this is, and why the services currently available are considered so unattractive by so many potential service users.

Devolution of power from Westminster to the Scottish Parliament and the Welsh Assembly has produced legislation and policy with different emphasis. All three nations have developed Carers' Strategies and committed additional funding to support the development of carers' services, however. Charges affecting social care services and users vary in the three nations, with Scotland

providing free personal care for people over 65, and Wales free prescriptions, neither of which is available in England⁴³.

Despite new legal requirements and a policy steer to support carers in combining work and care, in most authorities progress had been slow. Restrictions on Adults' Services budgets and the eligibility criteria in place meant the authorities in the study were often supporting only carers at the heavy end of caring, many of whom were considered to be a long way from the labour market. While it tended to be assumed that these carers could not or did not want to work, in most cases carers were not being asked about their preferences or needs for support in accessing a paid job. Some local authorities felt their key partners had no incentives to take up a working carers agenda; most had only limited resources to develop provision with local employers. While they often worked closely with local voluntary sector agencies, many of these organisations had only limited experience of supporting working carers. While all authorities had made significant efforts to involve, engage and consult with carers in their commissioning and strategic planning processes, only a few had made many effective contacts with working carers through these arrangements.

Reaching carers in work, beyond those in local authority employment, had mostly been addressed through special projects and short-term initiatives; very few authorities had begun the process of mainstreaming their support for working carers across the full range of local agencies in health, social care, employment, regeneration and education. Viewed in terms of the numbers of carers living in each locality, the number of Carers Assessments conducted among carers of working age was very small. Few, if any, authorities had asked carers of working age about their desire to work, or about the services they needed to combine work and care.

CES Report 5 explores the impact of the two ACE partnerships between 2002 and 2007, identifying the aims and highlighting the activities and innovations of the delivery, policy, transnational and research partnerships which were formed to achieve the different objectives of the partnership.

3. Carers and employment: developing an infrastructure of support

The need for change in support for carers

Our investigation in the CES study, and the analysis we have undertaken, leads us to conclude that much more needs to be done to develop an appropriate infrastructure of support to assist carers in carrying out their role. Carers of working age, who represent 75% of all carers in Great Britain, especially those who want to carry on in their paid jobs or who wish to re-enter paid employment after a period of caring, are poorly served by current arrangements. In most cases they want to provide the care they give – but they believe they should have the right to do this without being penalised for it. They also feel they are entitled to support which respects their contribution. This support needs to come not only from those who provide the services they and those they care for need, but also from employers and the whole of society, not least because taxpayers would pay a very different price if carers were to withdraw their support. According to our own recent estimates, carers' unpaid contribution to the social care system is worth at least £87 billion per annum⁴⁴, a sum surely large enough to give pause for thought to government and politicians, who carry responsibility for the management of the economy and the distribution of public funds, and to every individual and corporate taxpayer.

With this in mind, and on the basis of the full and detailed evidence we have presented, we call, in

this part of the report, for a radical overhaul of the entire infrastructure of support for carers, and for explicit recognition that the social care system needs to focus much more specifically on the situation of carers of working age. It is certainly timely to do so. Refocusing the infrastructure which supports social care will require commitment, engagement and action right across the whole social fabric, which is why we call not just for service improvements, but for a new social contract – a development which we explain and discuss in more detail in the final section of this report.

Local authorities and their departments responsible for supporting vulnerable people – both adults and children – are a major and fundamental element of the infrastructure of local support which carers and those they care for require, but they are far from the only relevant players, and without the contribution of others (employers, health providers, other local agencies, family and community networks), and unless the state, at national level, puts in place the right frameworks and support, they will never be in a position adequately to meet carers' needs or the needs of those they care for.

Almost all the key elements of the infrastructure needed already exist, but the relationships between them need development, their focus needs to shift, and their interdependence needs to be acknowledged and supported. They include our

health and social services, our welfare and social security arrangements, and the institutions and agencies within our education, training and access to work system, as well as the provision made for transport, planning, housing, sport, culture and leisure. Much of this infrastructure was put in place during the 20th century, as Britain's welfare state was constructed. It still bears the hallmark of Beveridge, whose vision for it was predicated on expectations of 'full employment'⁴⁵, a national health service and the 'traditional' family, centred on marriage and a gendered division of labour. The social and economic developments which have transformed Britain since that time, including the 21st century challenges in demography and labour markets outlined above, are the factors which lie behind this need for change.

In the second half of the 20th century, Britain's welfare state evolved into a system designed to support those who were sick, frail or disabled, offering them a limited 'menu' of benefits and services to 'patients', to 'welfare clients', and to families and older people considered to be 'in distress' or 'need of support'. A gendered division of labour within the family, with men carrying responsibility for 'breadwinning' and women for 'home life' (the daily support of children, husbands and other relatives) was assumed, and though never a reality for all, this sexual division of labour laid the care of sick, frail and disabled family members firmly at the door of women, in their roles as wives, mothers and daughters.

In the 1960s, 70s and 80s, the core social values, assumptions and arrangements underpinning the welfare state were subjected to substantial re-evaluation, and new principles emerged, were widely debated and passed into law. They included a commitment to both sex and race equality, and a new focus on disability, as wider social changes gave rise to a more differentiated and diverse society. Women's right to education and employment, together with the economic pressures of the period, put them under particular strain, as they took greater responsibility for their families' economic support in the context of rising living standards, the new consumerism, and a greater focus on individualism and choice. Their 'dual burden' and their 'work-life balance' were widely discussed in Britain, while at the European level,

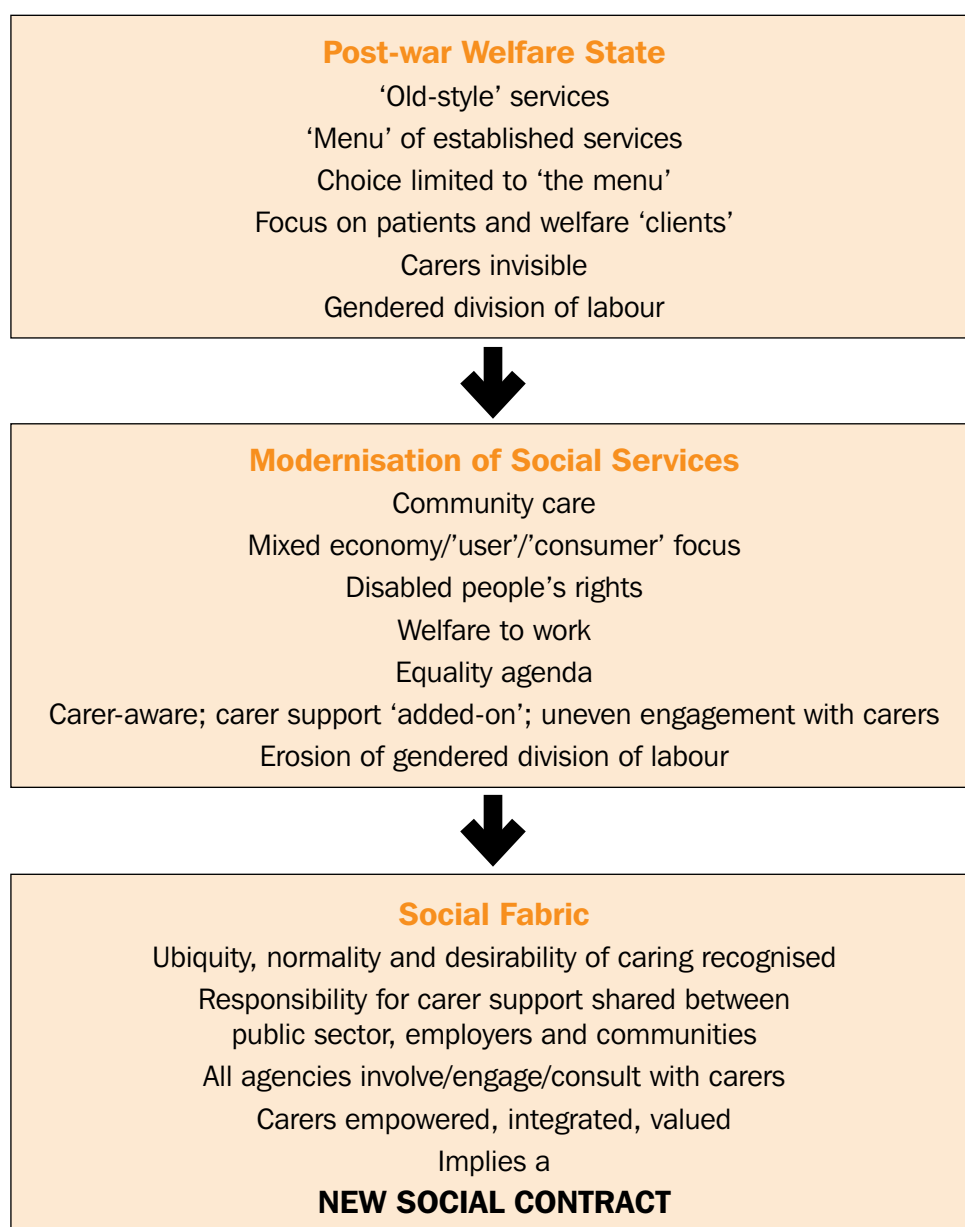
policy attention was given to the 'reconciliation of work and family life' and how best to achieve it.

Out of these developments, and framed in Britain by a shift to the political right and the election of a new Conservative administration in 1979, emerged the agenda for reorganising and 'modernising' social services, exemplified in the *NHS and Community Care Act 1990*. This was a crucial step in the move towards a mixed economy of care. It was also important for the emphasis it gave to 'the community' – primarily families and carers – and its conceptualisation of patients and clients as 'consumers' and 'users'. In the period which followed, managers and practitioners in social services became increasingly aware of 'carers', partly because service provision remained heavily reliant upon them, but also because carers were becoming far more visible, primarily through the work of carers' organisations, but also as a consequence of academic attention to their situation⁴⁶.

For the past decade, the New Labour government, which took office in 1997, has focused much of its attention on a 'welfare to work' agenda, predicated on the belief that 'full employment' is an achievable goal⁴⁷, and that all who are able to work in the paid economy should do so. By embracing the modernisation agenda for health and social services in this 'welfare to work' context, the new administration put considerable emphasis on its National Childcare Strategy, while also making commitments to carers through the less well-resourced National Strategy for Carers. This change, and Labour's wider agenda for modernising and reforming health and social care⁴⁸, has encouraged local authorities – and to a lesser extent health authorities – to become more 'carer aware'. As we showed in CES Report 4, however, the carer support they have developed has mostly been 'added on', with uneven engagement with carers, and with only those carers most visible to social care and health agencies, and under the most obvious strain, receiving breaks, 'respite' and 'sitting' services, and having their own needs assessed. (Figure 6.17 presents a diagram outlining key features of past developments and the changes needed.)

Since the mid 1990s, incremental legal changes affecting carers⁴⁹, often stemming not from

Figure 6.17 Transitions in the development of the social care system



government policy but from Private Members’ Bills and lobbying by carers themselves, have begun to shift greater attention, and slightly more resources, towards carers and their role. Other developments – the struggle to introduce Direct Payments⁵⁰; the piloting of Individual Budgets for care⁵¹; the first steps towards ‘self-directed care’ and a personalisation agenda which embraces new technology⁵², together with greater visibility and accountability in social care through the reports, investigations and other activities of the new accreditation, regulatory, inspection and quality assurance agencies, have moved carers much higher up the policy and practitioner agenda. Thus a policy focus on carers, which of course forms

only part of the wider public policy agenda relating to Britain’s socio-economic wellbeing, is now an important feature of the public policy landscape (outlined in Figure 6.18).

All of the public policy concerns identified in Figure 6.18 are relevant to carers and to social care policy; and all the key stakeholders identified have a role to play in creating a better system of support for carers. These policy areas, and the developments in our welfare and social support systems described above, form the background to the Prime Minister’s Review of the National Carers Strategy, which commenced its work through four Task Forces (also shown in Figure 6.18) in 2007.

Figure 6.18 The carers' policy agenda and its context in 2007

<i>Public Policy Agendas</i>	<i>Key Stakeholders</i>	<i>Carers Strategy Task Forces</i>
Welfare Reform and Making Work Pay	Local Authorities⁵³ Independent sector providers NHS providers Employers Trade Unions Families, Friends and Neighbours Employment, Careers and Job Search agencies Skills and Training Agencies and IAGs⁵⁴ Voluntary and Community Organisations	Income • Benefits • Barriers to work • Income throughout the life-course
Population Ageing and Pensions		Health and social care • Improving recognition • Maximising independence, opportunities and choice • Carers' health and the NHS
Funding of Long-Term Care		
Skills, Education and Economic Competitiveness		
Regeneration and Urban Renewal		Employment • Flexible working • Access to services • Barriers/incentives to work
Social Inclusion and Equalities		
Labour Supply and Migration within UK and Europe		Equalities • Discrimination • Promoting equality • Barriers to education, work, learning and leisure
Family Policy		
Active Citizenship and Local Democracy		

The evidence we have assembled through the CES study, and government's success in engaging a wide range of government departments⁵⁵ (as well as most relevant agencies within the statutory and voluntary sector and some prominent employer and trade union interests) in current debates about carers, underscores the fact that the time is now ripe for the 'step-change' needed to fully recognise carers' contribution. Their contribution is pivotal not only for the social care system, which depends heavily on their input, but also for the effective functioning of organisations, businesses and local communities. Some commentators, noting that carers are often 'undervalued, unrecognised and unseen', have referred to carers as 'the glue which holds society together'⁵⁶. We concur; but prefer to speak of them as an essential part of the 'social fabric': integral to it, with care woven into all our lives, and forming the supporting threads which bind the different parts of our society together and give it much of its strength.

If we recognise this, and choose to adopt a 'social fabric' approach (as illustrated in Figure 6.17), we will be choosing, as a society, an approach which:

- *Recognises the ubiquity, normality and desirability of caring.*
- *Requires all organisations, agencies and service providers to involve and consult with carers.*
- *Shares responsibility for carer support across all public services, the employment system and the voluntary and community sector.*
- *Empowers, values and integrates carers, protecting them from social exclusion, isolation and poverty.*

In essence, this 'social fabric' approach involves recognising that caring is central to all human relationships, and that the infrastructure of support for carers necessarily includes: family, friends and neighbours; health services; the social care system;

paid employment; and other local services, including the voluntary and community sector. We emphasise that adopting a 'social fabric' approach will also mean agreeing a new social contract for care. Britain's welfare state, as conceptualised in the 20th century, was built, from the outset, on an implicit contract between individual citizens and the state, with both having rights and responsibilities. The new 'social contract for care' which we now call for must move beyond this, to ensure that all agencies of the state recognise and respond to the ubiquity, normality and desirability of caring, engaging also – and very explicitly – with employers and the voluntary sector as well as with those needing care and their carers. Below we summarise the most important aspects of the elements of the infrastructure needed to support carers and to sustain caring, before turning, in the final section of the report, to more detailed discussion of the new social contract for care which we believe our evidence base and analysis now calls for.

Caring, relationships and everyday life

As we emphasise in the other CES Reports, and as evidenced in the 2001 Census and in carers' responses in the CES study, caring is necessary for and central to human relationships, and a desirable feature of family and personal life. We have shown that caring happens to people in all social situations, affects employees across the industrial and occupational spectrum, and (although concentrated among people over 40 and retaining some of its gendered features), is today a common experience for both women and men. Most people do not resent the caring they give, but many experience difficulty in combining work and care, and stress, poor health, social isolation, as well as financial and family strain are too often their reward for the contribution they make. Commitments to equality, and the expectations of governments and employers that those in whose education, training and skills they have invested will take part in the paid economy, mean it is no longer possible – even if it were acceptable – to assume that only some people will have, and will wish to act upon, an obligation to care⁵⁷. Care is not confined to the family, although most unpaid care is delivered to family members, and the social recognition now given to the many different family and household types in

contemporary Britain makes it especially important that we recognise care as a feature not only of conventional family lives, but also of a much wider range of interpersonal relationships. These include not only the civil partnerships (between gay and lesbian couples) recently brought within the arena of legally recognised unions, but also the relationships between neighbours, friends and members of other networks, including faith groups, which can be pivotal to the everyday delivery of assistance 'with a personal touch' in so many different caring situations.

When care is needed, it is almost always needed every day (and often every night too), throughout the period of the cared for person's illness, or, in the case of those who are frail through advanced old age or for those who have a permanent disability or deteriorating condition, throughout the rest of their life. Within the limits of the possible, it should be our aim that those cared for and those who care for them are able to lead normal lives and take part in the full range of activities which are normal for them as citizens and their communities. This means that every organisation and agency which touches their lives must develop an awareness of carers and of the contribution carers make to society, and must operate in ways which include them; for it is these organisations and agencies which form the infrastructure of support on which carers and those they care for need to rely. In Figure 6.19, we summarise the different elements of the support carers need, and draw attention to the conditions which must be met if carers are to access that support.

The way the contribution made by the agencies identified in Figure 6.19 as forming the main elements of the infrastructure of support for carers fits with other support for carers is shown in the following section of this report (in Figure 6.22), which addresses the question of what a new social contract for care needs to involve.

An infrastructure of support

There are four main types of local level support which carers need to be able to rely on in the public sphere (shown in Figure 6.19). The diagram shows two areas where support is already being given to some carers: local providers of social care services and local health services. Both of these, and many

Figure 6.19 The Infrastructure of Support for Carers

Local Providers of Social Care TO ACCESS THESE SERVICES CARERS NEED • Adequately resourced, responsive local social care infrastructure • Access to information, advocacy, advice and assessment • Capacity to articulate needs and negotiate with providers • Separate assessment of need and eligibility Services to users • Information and advocacy • Home care • Day care • Breaks • Residential care • Specialist health care • Befriending/companion services • Out of school care • Home adaptation service Services to carers • Carer's breaks • Sitting services • Training for carers • Flexible temporary/emergency support Supporting arrangements • Brokerage and guidance • Direct Payments • Individual Budgets • Access to ad hoc funding	Local Health Services TO ACCESS THESE SERVICES CARERS NEED • Adequately resourced, responsive local health care infrastructure • Professionals aware of carers' needs • Professionals to work as equal partners • Rapid response/referral Services to users • GP services • Health Visiting/domiciliary health • Hospital admissions, discharge, treatment and planning • Community health services • Home nursing and palliative care • Patient Advisory and Liaison Services • Telecare and tele-health support Services to carers • Information about support services • PALS Carers' Groups • Carer's Plan at time of hospital discharge or diagnosis • Carers' health and wellbeing services
Workplace Support for Carers TO ACCESS WORKPLACE SUPPORT CARERS NEED • Local jobs with decent pay which fit with caring • Knowledge of their employment rights • Supportive organisational policies • 'Carer aware' managers and colleagues Employment rights and entitlements • Right to request flexible working • Time off for emergencies Flexible working arrangements • Hours, place of work, contract types Information and advice • Employment rights, policies Support networks • Within and outside the workplace Acknowledgement, respect and consideration Carer-aware managers and colleagues willing/ able to give their time, care and skill	Other Local Infrastructure TO ACCESS LOCAL SERVICES CARERS NEED • High quality local infrastructure for everyday life • 'Carer aware' local service providers • Effective access to all other support • Vibrant community and voluntary sector Carer-aware public, private and voluntary services • Employment advisory services • Carers' information/support services • Education providers • Vocational training/guidance • Leisure services • Transport services • Housing/home adaptation services • Voluntary/community organisations • Emergency services • Economic development/regeneration agencies

of the more specific services identified within them, recognise and support carers already – although the CES survey and other evidence indicates that at present only a minority of carers of working age feel the support they are getting is adequate. Workplace support for carers, a third area, now has some statutory underpinning, as we have shown, and as other research confirms, some organisations, in a number of different employment sectors, now have quite well developed policies and support arrangements in place for their employees, enabling those who are carers to manage both care and paid work. The contribution of other local infrastructure to carers' wellbeing and support (the fourth element in the jigsaw of integrated support which is required) remains extremely small, with most delivery of carers' support patchy and unstable (usually because it is funded through pilot projects and short-term one-off investments). Thus although some voluntary agencies have delivered ground-breaking and innovative projects supporting carers who want to work in some localities, this has not become mainstream activity for the voluntary sector at local level, and in most localities, many public agencies – which have the primary responsibility for putting a viable local infrastructure of support in place for local citizens – have only quite recently begun to address carers' needs, if they have noticed them at all.

An important point we wish to emphasise, however, is that although much of the infrastructure needed is not yet 'carer-focused', and offers carers very little by way of support, particularly in combining work and care, virtually all elements of this infrastructure already exist and are already funded. This is crucial because it means that shifting the public policy agenda towards mainstreaming support for carers, and meeting carers' needs, can be achieved without a massive injection of additional resources. Making the adjustments necessary will not be cost-free, but it should not be prohibitively expensive, and requires raised awareness and a shift of emphasis, priorities and focus, rather than extensive reorganisation and massively altered management structures. New technology, telecare, creative thinking and the efficiency gains which these will bring, will be important elements in the refocusing of resources and in the shifts of emphasis needed.

4. Conclusion: time for new social contract?

In this final part of the report we draw attention to the main challenges all stakeholders must address if Britain is to move to a situation in which carers are appropriately supported. Here we explain our understanding of the new social contract for care which needs to be agreed, highlighting the respective roles and responsibilities of individuals and families, local communities, employers and the state. We also present a full set of policy recommendations designed to create the right environment for the step-change in support for carers which the evidence in the CES study calls for. Our emphasis is on the shared commitment all must make to achieve the goal of a society in which caring is valued, respected and facilitated, without carers having to pay unfair penalties for the contribution they make.

Challenges in supporting carers

The evidence brought together through the CES study enables us to identify the main challenges in supporting carers which face those with responsibility for local infrastructure and for the social care system. As we will see below – in our discussion of the social contract for care – in our view this involves not just government, local authorities, and the NHS, but also employers, communities, families and individuals. In an ageing society now capable both of enabling many people to live well into their 80s and beyond, and of supporting many younger sick and disabled people to lead longer lives, the health and

social care system is increasingly reliant on unpaid carers, and will need input and commitment from us all if it is to operate successfully, providing good quality support to carers and those they care for with fairness, independence, choice, dignity and respect as its hallmarks.

Below, we briefly outline the major challenges as we see them, having researched and studied the situation of carers of working age in great detail. Our list does not extend to other groups of carers, because those have not been our focus. This means that issues of crucial importance for the health and social care system, such as the perspectives of older and disabled people, and the situation and needs of both young and older carers, are not included here. While these are matters of great importance too, they are not issues on which we can comment using the evidence about carers of working age which it has been our task to assemble.

Carers' health

As we have seen, there is a clear statistical relationship between the duration and intensity of caring and poor health. This means that one of the most important challenges in supporting carers is to find ways of maintaining carers in good health. While there can be no doubt that many carers wish to provide the care they give, with some believing that being a carer is life-enhancing and intrinsically rewarding, many find that the physical, emotional

and other demands of the caring role place them under significant pressure. Many carers experience stress, fatigue and exhaustion, and health and social care professionals and others need to recognise this, and to respond to carers accordingly. Here a key challenge must be to ensure that carers' dealings with health, social care and other agencies as part of their caring role do not contribute to their stress and frustration, and to find ways of providing those who want such support with breaks from care, both on a frequent, regular basis during a normal week, and periodically, so that holidays, recuperation, rest and a change of scene are possible for carers, as for anyone else. Some carers, especially those providing personal care, also need access to specialist training and equipment so that they can care safely without risk to themselves (e.g. in lifting and moving the person they care for or in supporting their mobility). Carers also need 'peace of mind', scope to attend to their own health needs, and opportunities to plan for unexpected or emergency situations in caring, such as periods when they need to be absent from home to deal with other urgent matters for which they may have little time to plan (e.g. attending a funeral, their own hospital, dental or doctors' appointments, responding to a friend or family member who has an accident or personal crisis, or necessary absences from home for business or other reasons at short notice).

Carers' economic and financial security

As we have already indicated, it cannot be acceptable that a carer's reward for providing unpaid care should be months or years of financial worries, low income or poverty (whether while caring or later in life). Nor is it a defensible situation for carers to face restrictions on their normal social participation because, after meeting the additional costs of caring and of ill health or disability within the family, there is not enough left to cover the costs of those activities.

Carers' exposure to poverty in later life is a particular concern, partially addressed in the *Pensions Act 2007*, but its provisions do not address all of the financial problems carers face. Reduced income both while of working age and after reaching state pension age is also associated with working reduced hours to accommodate caring (since so many part-time jobs are in the lowest paid sectors of the

economy) and with the very low level of carers' benefits, which many of the carers in our study found both unacceptable and insulting.

Protecting carers' right to work, and supporting them in accessing education and training, are key elements in the challenge of supporting carers' economic and financial security. This means supporting carers when caring 'happens', so that hasty and irreversible decisions about jobs and careers are not irrevocably made, ensuring that employers, trade unions, managers and work colleagues appreciate the pressures carers can be under and offer support in making suitably flexible arrangements to enable paid work to continue where possible. It also means providing much more support for carers who have had a spell, however long or short, outside of the labour market because of their caring role. Returning to employment after a period of a few months during which care has been given to a terminally ill relative or friend can be as difficult a step for some as returning to paid work after many years of caring, and there are crucial roles here for those agencies charged with supporting return to work, access to employment and training, and providing careers, guidance and advisory services.

Carers' social inclusion, citizenship and equal rights

Perhaps the most important challenge relates to the claim carers now make to freedom from social isolation, discrimination and exclusion. Here the challenge is to secure equal treatment for carers, to accord them citizenship on the same terms as other members of society, and to engage with them in ways which are respectful of their roles, expertise and personal choices about caring, and protect them from being set apart from the mainstream of society because of the unpaid caring work they do. New ways need to be found, using new technology and modern communications systems, of ensuring that carers can take part, like others, in leisure, educational, employment and cultural activities. There are challenges here not just for public bodies and statutory agencies, but also for the voluntary, private and independent sector.

A crucial factor in meeting these challenges will be the development of local services and support

Figure 6.20 Background to the new Social Contract for Care

- Giving and receiving care, within interdependent relationships, are essential components of the human condition: to varying degrees, and at different stages of life, dependency, illness, disability, frailty, and dying are experienced by all and require the support of others.
- Modern healthcare, medicine, assistive technologies and communications systems have created a changed context for the delivery of care in the 21st century.
- Longer lives, higher rates of survival in the context of illness, accident or disability, and more sophisticated consumer attitudes and behaviour impose increasing demands on the social care system.
- The state cannot cover all the (rising) costs of care, nor do individuals, families or communities wish to surrender to the state all responsibility for the delivery and provision of care.
- For families, individuals and communities, quality of life and economic security depends on the achievement of full potential through the educational and employment systems, and on the social and economic participation of all who are able to make a contribution.
- In an increasingly competitive global economic system, the British economy and British employers need to draw on all available labour: carers need support to combine work and care, and protection from the financial, health and other penalties currently incurred by carers.
- Contemporary Britain lacks clarity about the respective roles, rights and entitlements of individuals, families, communities, employers and the state in relation to the delivery of care in this changed context, and needs to take account of commitments to equality and diversity.
- This situation calls for a new and explicit social contract between all relevant parties, which acknowledges their interdependencies, sets out their different responsibilities, and clarifies their rights and entitlements in relation to each other.

arrangements which are ‘fit for purpose’, designed and delivered to meet the needs of each citizen who, whether through obligation or desire, and whether for the short or the longer term, takes on the care and support of a partner, relative or friend. All stakeholders need to play their part if we are to achieve the shared goal (set out in column 2 of Figure 6.21) of a society composed of: active citizens who care for one another; inclusive and integrated local communities; adaptable and competitive organisations and businesses; and an enabling, just and protective state which empowers communities, businesses and the economy to flourish. For this to happen, all stakeholders need to invest jointly in stimulating a vibrant care system and market which offers quality and choice to carers and users alike.

Meeting the challenges we have set out above will require determination, clear focus, and concerted effort, with all playing their part. While for each individual carer and person in need of care, the issues they face in making choices and securing support are deeply personal, these are nonetheless public issues of societal importance, which involve us all, as emphasised throughout this report.

This is why a new social contract for care is needed; for it is much more than a definition of the respective responsibilities of individuals and the state in relation to paying for care (particularly long-term care) which is required, important though that is. In recent years, quite rightly, detailed attention has been given to the financing of care, particularly the care of older people (primarily through the Wanless Review and the debate it has engendered);

however our perspective in this report goes beyond the question of who will pay for care. We argue that – for the benefit of all individuals and groups in society, and taking account of demographic and labour market realities – future policy must enable all to make the full social and economic contribution of which they are capable. This means reshaping existing policy, placing a stronger emphasis on individually tailored support, and making appropriate and imaginative use of technological and other innovations – but, crucially, it also means making it possible for carers to contribute their support without penalty. In this, as we have seen, there are roles for others – social and health care providers, employers and trade unions, the full range of local providers of services, local communities, friends, neighbours and families, as well as for the state, with its responsibility for setting out agendas, policy frameworks and legislative and fiscal regimes.

A new social contract for care?

What do we mean by a new ‘social contract’ for care? In making any contract, the parties to it come together to reach mutual understandings and an agreement that they have reciprocal rights and obligations. These rights and obligations form the terms of their contract, and by agreeing to it, all parties signal both their intention and their obligation to honour it.

In using the term ‘social contract’ here, we indicate that the new social contract for care which we are advocating requires a broad base of ‘signatories’ – and that this will involve negotiations, commitments, obligations and rights across the entire social spectrum. A new social contract for care must be more than simply a contract between government and the governed (or, put another way, more than just a contract between the citizen and the state). In a mature, democratic and now mostly affluent society, the new social contract needs to connect and integrate many different elements of society. It needs to acknowledge that each of the elements makes a contribution (as part of its participation in the agreed social contract); but that each also gains safeguards, protections and rights as part of the contract⁵⁸. As a result, the new social contract for care empowers and protects the different parties

to the contract, thereby adding to the strength and security of the whole. The contributions made by each of the different parties are not, and do not need to be, the same – nor are the gains for each identical – but through the social contract the common good is enhanced; and, crucially, no party to the social contract is expected to make its contribution without some benefit.

The essential background to the new social contract for care is shown in Figure 6.20. This summary of the key aspects of the status quo is strongly underscored by the evidence base we have assembled, and (we believe) represents facts, beliefs and views about which there is widespread consensus in contemporary Britain. In Figure 6.21 we identify (in the left hand column) all the ‘parties’ to the new social contract: individuals of working age and their families and friends; neighbourhoods, communities and voluntary organisations; businesses and employing organisations; the state in all its forms. We also summarise (in the right-hand column of Figure 6.21) the obligations of the state and its agencies (the public sector) to each of the other parties where there is a need for care – noting also (bottom right-hand column) the state’s role in supporting those institutions of civil society which have key roles to play in relation to care. Figure 6.21 also indicates the ‘desirable characteristics’ of each of the parties, which most citizens, political parties and social commentators would probably agree it should be our collective goal to achieve, and notes the contributions each makes (both on an ongoing basis, and in situations where a specific need for care arises) to the social care system.

In Figure 6.22 we show how all the dimensions of the new social contract for care need to be configured. With support from family and friends at its centre (for almost everyone their ‘first port of call’) and set within the context of an infrastructure of support (as discussed in Section 3 of this report) centred on the four foci of carers’ support at local level (providers of social care; health services; employer support; other local infrastructure). This figure also emphasises both that these elements of the infrastructure need to interlock and interact, and that the new social contract for care also depends on two other essential features.

First, we emphasise that the ethical context in which the infrastructure of support for social care is developed needs to be clear: recognising and including carers must be stated as key, non-negotiable principles to which all within the infrastructure are committed; while respect for carers' contribution, and ensuring all carers are treated with dignity, must be key values framing all social care activity. Thus 'dignity and respect' and 'recognition and inclusion' form key elements of the diagram as part of the framework of values, beliefs and ethics which all parties to the social contract for care need to acknowledge and accept, and within which they need to operate.

Second, there must be a set of legal, regulatory and fiscal frameworks which support carers. These need to identify carers as a specific category whose rights need to be protected through equalities legislation, while also providing a framework of satisfactory economic and financial arrangements which secure carers' access to paid work and confirm their entitlements to adequate benefits, allowances, tax and pension credits, taking particular note of many carers' desire to work as well as to care, and the need for the tax and benefits system to work effectively for those who choose to do so. These legal and fiscal frameworks, which frame all the other dimensions of the new social contract for care, need to be regularly reviewed to ensure that they remain fit for purpose and appropriate in the context of wider societal issues – at the time of writing the most important societal issues relate to the changing demographic and labour market context set out earlier in this report.

In order to move from the current position in which carers suffer health, financial and other penalties, and experience social exclusion, to the desirable scenario (depicted in Figures 6.21 and 6.22), Britain needs to address a set of specific policy issues which are called for by the evidence presented in this report. In the next section, therefore, we present our detailed recommendations about the policy changes and developments needed, designed to address the key challenges identified above. These relate to carers' health and wellbeing, to carers' economic and financial security, and to carers' social inclusion and equal rights. Our proposals include

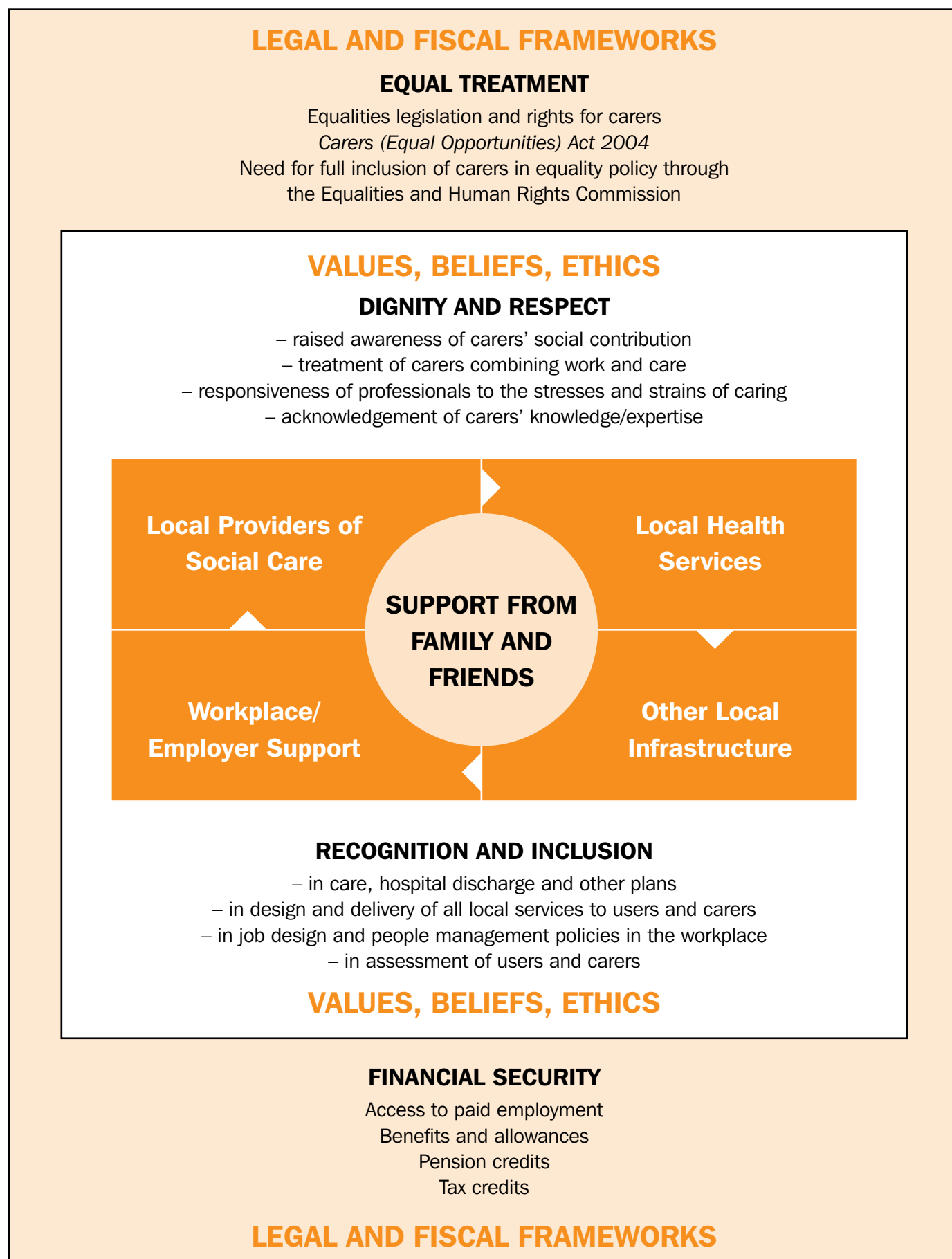
some specific steps and measures which need to be taken to address these challenges, as well as some areas where more research, consultation and investigation is needed. They focus specifically on the measures needed to support carers of working age, and in particular to enable those who wish to combine paid work with unpaid care to do so.

Figure 6.21 New Social Contract for Care: the parties to the contract and their contributions and obligations

Parties to the new social contract	'Desirable character' of each party	Ongoing contributions to the social economy
Individuals of working age and their families and friends	Empowered and protected citizens Participating in paid work and education Able to form committed supportive relationships	Income Tax National Insurance Council Tax Other personal taxation
Neighbourhoods and Communities	Inclusive Integrated Cohesive	Community participation through voluntary, charitable and faith organisations
Organisations and Businesses	Flexible Adaptable Competitive	Corporation tax Business rates Employers' NIC VAT Excise duties Compliance with employment law re carers
The State	Promotes justice, fairness and equality; creates environment enabling business and the economy to flourish	Legislates for and resources social protection and welfare rights care entitlements and standards

Contribution/obligations when there is a need for care	Obligations of the state and its agencies to the other partners in the social contract when there is a need for care
• In GB, 4.27m carers of working age provide unpaid care to family/friends worth at least £58.2bn p.a.⁵⁹ • Individuals and families ‘negotiate’ their obligations as need arises (shaped by ‘generalised’ reciprocity and the quality/history of their relationships). • Family members often the first port of call, and main source of emotional/moral support. • Families and friends often crucial in enabling users to access services.	• Clear information. • Speedy response. • Flexible, sensitive services. • Clarity about costs. • Fair access. • Quality assurance. • Respite and relief. • Respect and recognition. • Training and support. • Prevention/alleviation of hardship.
• Neighbourly support and contact is part of the context for delivering social care. • Neighbours can alert key agencies as needed; are vital in emergency situations. • Neighbours may contribute directly to care. • Voluntary and neighbourly assistance. • Role of faith, community and charitable agencies in sustaining carers; informal and formal roles.	• Provide local infrastructure to support care as core component of everyday life. • Ensure adequate support for carers in all localities. • Recognise geographical/ socio-economic variations in caring. • Provide support sensitive to diversity and needs of particular communities.
• Consideration/ support for working carers. • Flexible working arrangements for carers. • Allow carers to take time off when necessary. • Provide information on combining work and care. • Equal opportunities at work for carers. • Assist carers in retaining jobs and careers.	• Help employers inform working carers of their rights and available support. • Design/deliver services around many carers’ desire to work. • Support carers return to work with carer-focused job, careers and training advice, support and services. • Raise awareness of carers’ and their needs, rights and situation.
• Fiscal regime which supports carers as well as sick and disabled people. • Rights for carers and those who are disabled or ill. • Protection from discrimination on the grounds of disability or care responsibility, and redress for carers when rights are infringed or discrimination occurs.	Support civil society organisations to operate in support of carers and those they care for: charities, trade unions, NGOs, voluntary and community organisations.

Figure 6.22 Dimensions of the new Social Contract for Care



1. Recommendations about carers' health <i>There is a strong link between caring and poor health. The greatest risk of poor health is associated with intensive caring and caring over long periods. To reduce carers' stress, fatigue and ill health and to promote their wellbeing, WE NEED SERVICES FIT FOR PURPOSE. We recommend that the following measures be adopted:</i>	Key Actors*
More responsive services The difficulty of finding out about, locating, and accessing services, and the stress and frustration carers can experience in communicating with professionals in health and social care agencies, contributes to the strain of the caring role. This needs to be addressed through: • Health and social care services fit for purpose. • Revised standards of service, including target response times. • Greater clarity about core values and key principles. • Redress when carers are let down. • Engaging with carers as equal partners in the delivery of health and social care. • A national helpline offering carers information and advice on services and how to access them. Employers also need responsive services; they need to be able to signpost carers to information/services as part of their responsibility for wellbeing and health and safety in the workplace and in their own business interests. Trade unions have a key role to play in supporting this agenda, raising employees' awareness and promoting good practice.	LA SSRs CSCI / HC DH NHS DCSF DBERR RDAs Treasury
Investment in Carers Breaks This should be increased, targeting those who care, over a sustained period, for 20+ hours p.w. Breaks can be crucial in preventing the breakdown of caring relationships and sustaining carers, and should be flexible to meet carers' needs. At least two types of break are needed: • Regular, frequent (e.g. weekly or fortnightly) breaks designed to enable carers to participate as active citizens in everyday community and social life. • Periodic recuperation breaks (e.g. annually or several times a year), to allow rest, recuperation and a change of scene where this would benefit the carer.	DH Treasury LA SSRs DCSF NHS
Improved GP/community health support for carers The best GP services and effective community health provision are highly valued by carers. GP practices should be required to: • Promote carer health and wellbeing services, with regular opportunities for health checks and risk assessment. • Work in partnership with local voluntary and independent sector agencies to design and deliver this enhanced support. • Develop 'rapid response' services to support carers who feel under pressure or have concerns about how caring is affecting their health. • Signpost carers to alternative specialist provision to assist the person they care for.	NHS GPs DH LA SSRs DCSF
Information, training and brokerage services for carers Designed and delivered with the direct involvement of experienced carers, new services offering carers information, training and brokerage, accessible in a wide range of formats and at the time and stage when carers require them, need to be developed. These should support carers in: • Combining work and care. • Identifying and responding to their own needs. • Caring in specific situations, especially those where need is greatest – caring for those with mental health needs, for sick/disabled children, on a long-term basis. • Caring in different family, cultural and geographical settings. • Dealing with key stages and transitions in their journey through caring. • Accessing education (with appropriate funding streams in support).	DH DIUS GSCC DCSF SkfCare LSC

2. Recommendations about carers' economic and financial security <i>The extra costs of caring, and (for those unable to combine work and care), the low level of carers' benefits, are sources of the financial penalty carers pay. But the major risk to financial security for carers of working age is being unable to participate in paid work or having to change their job or career plans. To deal with these risks, WE NEED SERVICES FIT FOR PURPOSE. We recommend that the following measures be adopted:</i>	Key Actors
Set up an advice, guidance and advocacy service on caring and employment, drawing on expertise in the voluntary/independent sector, and the experience of employers committed to supporting carers, to respond to the changing needs of labour force participants across the life course, targeting people: • At risk of giving up their jobs or careers because of caring responsibilities. • Wishing to return to work after caring (with specialist post-bereavement guidance). • Wanting to engage with paid work while continuing in a caring role. The service could be located within Jobcentre Plus and/or linked to a national helpline; it must be accessible via self-referral or via employers. It involves brokerage/advisory support, and should help prevent carers dropping out of employment. Mechanisms could include Carers Employment Advisers in Jobcentres, or Employment Advisers in Carers Centres.	• JC+ • DWP • DBERR • Employers • TUs
Take action to widen the range of jobs available to those working part-time or flexibly, to ensure they are not forced into low paid work or jobs without career prospects. This requires action to promote part-time, job-share and flexible working in senior jobs, including in management and supervisory roles, with the key aim of making job design work for carers in the full range of jobs and occupations. It should be linked to employer obligations under the Right to Request legislation and Health and Safety Guidelines.	• DBERR • DWP • Employers • HR • TUs • Emp. Orgs
Undertake a full review of the integration of the tax, benefits and pensions system as it affects carers. The system needs to offer a coherent way of promoting caring, removing disincentives in the current system, recognising caring as a positive social contribution and encouraging carers to consider combining work and care. New arrangements should ensure carers are better off in work, in line with measures for parents using tax credits.	• Treasury • DWP • PA • IR
Invest in improving access to education, skills and training for carers, focusing on: • Young/early career carers to ensure they can access further and higher education to an equivalent level with non-carers. • Retraining, upskilling and updating opportunities for those who have had to withdraw from work or whose working life has been affected by caring. • 'Change of career' advice and guidance for carers who may wish to use their skills and experiences as carers to change job or career direction. • Policy guidance, backed up by EHRC enforcement actions, to ensure carers remaining in work can access training opportunities in the workplace equally with other employees. • Abolition of the 21 hours study rule.	• Connexions • LSCs • CES • RDAs • IAGs • EHRC
Set up a specialist SME advisory service to assist small businesses in: • Signposting carers who work in SMEs to guidance and support. • Identifying options for flexible working, and reviewing their business impact for SMEs. This should be pump-primed with government support and developed in consultation with relevant agencies, to create a self-funding membership/contributions-based service SMEs can join to access the expert, professional support larger organisations can offer in-house.	• RDAs • Ch. of C. • LSCs • Emp.bodies • BLs
Develop new support packages and services for those whose caring changes or ends. These should use e-learning and new technology for accessibility and impact, should support carers in making their own decisions about how and when to return to work, and be developed with voluntary sector, employer, TU and specialist support.	• Vol. orgs. • TUs

3. Recommendations about carers' social inclusion and equal rights <i>Carers are not identified as a group entitled to protection from discrimination and entitled to equal rights in most legislation and policy-making, although there is strong evidence of their risk of unfair treatment, discrimination, exclusion and social isolation. To address this, we recommend that the following measures be adopted:</i>	Key Actors
Identify and include carers as a specific group in all equalities legislation , and introduce a public sector duty to promote equality for carers: • Ensuring equitable access to and provision of goods and services. • Giving employers clarity about anti-discrimination measures, and guidance on how to work effectively with carers.	Eq Off EHRC
Maintain a strong statistical evidence base about carers , including using the question on carers asked in the 2001 Census in future censuses, so that data on carers is available at local levels, and sub-groups of carers at risk of socio-economic deprivation (and in particular need of support and services) can be identified.	ONS Treasury Census UG
Enable carers to participate in their communities in local democratic structures and as active citizens , on an equal basis with others, and ensure they can contribute to the full range of community, voluntary and leisure activities.	DCLG
Extend the right to request flexible working to all employees , so that carers currently outside the definition used in the <i>Work and Families Act 2006</i> are included, to reduce the risk of stigmatising carers, and to make it easier for employers to operate the legislation.	DBERR
'Carer-proof' all strategic developments and planning processes in local infrastructure , including the design and delivery of services (e.g. in the areas of housing, transport, leisure, education, skills). • Use Local Area Agreements and Local Strategic Partnerships to address issues of social inclusion for carers • Require RDAs and other regional agencies to embed and monitor the inclusion of carers in employment, skills, business and health and wellbeing strategies.	DCLG LAs
Tailor welfare to work policy to meet carers' needs , in the advice given and in the health and social care support provided, to enable them to engage in training, learning and work.	DWP JC+
Promote combining work and care to all employers and trade unions , in a campaign highlighting the 'business case' for flexible working and supporting carers, but also identifying issues of fairness and equity.	DBERR DIUS Emp. Orgs TUs

* See Appendix 2 for a list of the acronyms used in the Recommendations

Caring and employment is an arena where there is, in the 21st century, an alignment of needs – between individuals (with their human need and responsibility to give care to others); families and personal partnerships (with their implicit and essential interdependencies); organisations (with their need for loyal, motivated staff able to contribute to organisational goals); and the wider economy and society (which needs both a growing workforce and many more unpaid carers).

The CES study has provided a substantial evidence base against which future options for our social care system, and for delivering care to the growing numbers of sick, disabled and very aged members of our societies and communities, need to be considered. We have noted that we continually, and increasingly, rely on unpaid carers of working age – yet the majority of this group are also needed in the workplace. They require employment based support, reliable care services for those they care for, breaks and support services, and (in spells of reduced employment commitment or periods outside work) adequate income support and pensions protection.

Most people who need care wish to be cared for at home. Carers wish to give some of the support they require, but effective, widely available and easily accessible home care services are also needed. As the paid home care sector faces considerable pressures in recruiting and retaining staff, which may become even more acute, it will not be practically possible to shift all unpaid care into the paid sector, even if it were desirable to do so.

This implies that a combination of these arrangements is needed by most service users and their carers – calling for integration, flexibility and genuine partnerships built on trust, respect and good communication. We have set out our view that Britain urgently needs to debate the respective roles, rights and responsibilities of all parties, as the basis for a new social contract for care. This new contract must face up to social and economic realities, but needs to be centred on an awareness, recognition and celebration of the ethic and practice of care which underscores our humanity. Caring, as we have seen, is ubiquitous and, in the future, at some point in their lives, will probably ‘happen’ to almost

everyone. The new social contract we require must therefore build on the following realities:

- Vulnerable, sick and disabled people need carers.
- The economy needs carers. Already a key segment of the paid workforce, many carers are experienced employees organisations cannot afford to lose.
- Replacing all unpaid care with formal care services would be impossibly costly and highly undesirable from the human point of view.
- Our social care system has long relied on carers’ contribution. Carers are crucial partners in delivering social care, providing continuity and personal commitment within the context of established family and personal relationships.
- Carers need independence, income and life choices like everyone else and, above all, should not be penalised for the contribution they make.

Over the life course we all need to give and receive care, and care must therefore be the focus of a new ‘social contract’ between individuals, families, communities, organisations and the state.

Appendix 1 Research Methods

The Carers Employment and Services Project 2006-7: Research Methods

Aims and purpose of the study

The main aim of the CES study was to explore issues relating to carers and employment in Scotland, England and Wales, paying attention to the circumstances, views and experiences of carers of working age. A key objective was to design the study so that, as well as making full use of official statistics about carers at national and local level, it could also examine features of carers' situations which could not be examined using this type of data, such as carers' use of local services in combining work and care, the extent to which the availability of local services affects carers' ability to manage caring alongside a paid job, how access to services affects their decisions and perceptions of their options relating to work and care, and detailed aspects of each carer's personal situation, such as their relationship to the person they care for and the diagnosis/condition of that person.

The focus of the research questions developed for the study (in consultation with the research sponsor, Carers UK) reflected the fact that an earlier study, examining organisational responses to working carers including managerial approaches to supporting carers in the workplace, had recently been completed. The CES study was designed to complement that earlier work, and also to build on the evidence of a longitudinal, but much smaller, study of carers of disabled children, whose situation with regard to combining work and care had also recently been studied and reported. The initial research questions identified were as follows:

- Which carers, in what circumstances, access alternative services to enable them to remain in or enter employment or training?
- How do these carers access, choose and pay for the services they use?
- What kinds of alternative services do they use, why do they choose such services, and how do they pay for them?
- What are the relative roles of the carer, the person cared for, and that person's other carers in taking decisions about how and by whom care should be provided?
- What do carers perceive to be the weaknesses of the care available to them? What additional services would they value and use?
- What do providers of care services consider to be the strengths and weaknesses of the infrastructure of support for carers in their locality and at the national level?

Research Design

The research design selected to achieve the aims of the project included the following main elements:

- **Survey of carers of working age** (target 1,320 completed questionnaires).
- **Follow-up qualitative interviews** (with 10-15% of the achieved sample).
- **Key informant interviews** with personnel responsible for policy delivery / service development relating to carers and services (in 10 localities).
- **Statistical work** to further examine the characteristics of carers and to explore evidence of services provided and the population served in the selected localities.
- **Mapping of local services** (in the selected localities).

Survey of carers of working age

For the questionnaire survey of carers it was decided to:

- Include in the achieved sample both carers who were and who were not already in touch with service providers.
- Map the characteristics of carers in a way which would make comparison with data on carers from the 2001 Census possible.
- Target carers whose situation had often not been included in other research:
 - *Carers in paid work, including male carers – targeting carers in employment in the private, public and voluntary sector.*
 - *Carers in ethnic minority groups.*
 - *Carers supporting people living in both urban and rural contexts.*
 - *Carers across the spectrum of poverty – affluence.*
 - *Gay and lesbian carers.*

A purposive sampling strategy was used to cover the fullest possible range of carers. Through a separate distribution strategy, a sample of GLBT carers was also sought (see below). The original target for achieved responses to the survey was 1,320 completed questionnaires; detailed targets and survey results are shown in Table A.2. The strategy used to collect the target sample and gain access to carers of working age in the target categories, was, in each locality:

- Identification of major employers and request for their assistance in distributing the questionnaire to their employees who were carers.
- Asking the local authority to forward copies of the questionnaire to a sample of carers who had been through the Carers Assessment process.
- Approaching local carers' organisations and asking them to distribute and publicise the questionnaire.
- Approaching local voluntary and community groups, particularly those working with ethnic minority communities, and asking them to distribute and publicise the questionnaire.
- Using posters to advertise the survey (with a supply of questionnaires available) in GP surgeries, pharmacies, hospital waiting rooms and other health-focused venues.
- Distributing the questionnaire opportunistically through local events focused on carers' issues.
- Creating opportunities for carers to access the survey on-line via websites and publications of relevant national/local organisations.

Table A.1 CES Survey of carers: organisations contacted in the study

Employers approached to distribute CES questionnaire to employees	England	Wales	Scotland	ALL
Private sector employers	15	2	6	23
<i>participated</i>	6	1	0	7
Public sector employers	13	7	8	28
<i>participated</i>	13	5	8	26
Vol/Com sector organisations	29	11	15	55
<i>participated</i>	23	11	15	49
All organisations	57	19	29	106
<i>participated</i>	42	17	23	82

This strategy met with variable response: some employers were very helpful and actively supported distribution of the questionnaire; others passed it on through organisational websites or publicised it in internal newsletters; some refused to become involved. Some local authorities found it easier to distribute the questionnaire to carers in touch with services than others; some carers' organisations were very supportive of the distribution strategy, although a few were not willing to take part; success in reaching carers through other local voluntary organisations was also variable. Much effort was put into distribution via health-focused venues and agencies in the pilot stage of the research (carried out in Sheffield); ultimately this proved too resource-intensive and in some localities it was not possible to pursue this strategy. Efforts to engage the GLBT community, including national level publicity, yielded poor returns. Achieved responses are shown in Table A.2.

Table A.2 Target/achieved responses: survey and face-to-face interviews

Source: CES study, University of Leeds, 2007.

Locality	Completed survey questionnaires		Face-to face carer interviews	
	Target	Achieved	Target	Achieved
England x 6 localities	720	677	90	79
Hertfordshire	120	110	15	15
Leeds	120	102	15	13
Sandwell	120	102	15	10
Sheffield	120	52	15	14
Southwark	120	59	15	17
West Sussex	120	252	15	10
Scotland x 2 localities	240	323	30	27
East Ayrshire	120	80	15	14
Falkirk	120	69	15	13
Highland	0	174	0	0
Wales x 2 localities	240	203	30	28
Anglesey	120	52	15	14
Swansea/Gower Peninsula	120	151	15	14
GLBT sample⁶⁰	120	5	15	3
'Out of area' responses	0	706	0	0
Total	1,320	1,909	150	134

At an early stage it was decided that it was necessary to have both a postal and an electronic version of the questionnaire. Employers tended to use the electronic version and this was also used by most 'out of area' carers (indeed this was one of the reasons, apart from the general aim of increasing responses, for our decision to distribute the questionnaire to carers in Great Britain who were willing to participate in the study but lived outside of the target localities).

The survey questionnaire (copies can be obtained from the research team at the University of Leeds on request) covered the following topics: carers' personal/demographic characteristics; the characteristics of the person(s) they cared for; details of their care responsibilities and any services they were accessing; their employment and financial situation; their perceptions and attitudes to caring and employment, employer support and a range of issues to do with combining work and care. The survey was distributed over a period of approximately 14 months, between spring 2006 and early 2007.

The responses to the paper-based survey were typed into SPSS (Statistical Package for the Social Sciences), with checks undertaken to ensure this was performed accurately. Responses to the online survey were downloaded into Excel and reformatted to mirror the paper-based responses, before being integrated into SPSS to produce a master file of all responses. This was 'cleaned' to ensure all responses were valid and simple frequencies were calculated to check for any inconsistencies; these were corrected as necessary. This file then formed the basis for all subsequent analysis of this part of the study, with the main results presented in the CES Report Series, and particularly in CES Reports 1-3.

Selection of localities

Because the study aims included 'mapping' the services available to carers and identifying successful innovation and service development as well as weaknesses in service provision and planning, a number of specific localities needed to be selected for the study. It was decided that there should be ten localities, six in England and two each in Wales and Scotland, and that these should be localities in which a single authority had statutory responsibility for the delivery of social services. The rationale for the selection of the 10 localities is set out below.

Two localities in England were chosen because their local authority social services departments (recently re-organised into Adults' and Children's Services) had joined the ACE2 partnership, and were implementing interesting policy innovations. Hertfordshire County Council held 'Beacon' status for its work with carers, while West Sussex County Council was one of a small number of authorities in England piloting Individual Budgets for Care. West Sussex also had plans to develop innovative work on Direct Payments which was relevant to carers. Both these authorities also met our other criteria as they were places where we could hope to engage carers in our target groups, as shown above. In Wales (in consultation with Carers Wales), we chose to include Anglesey (in north Wales, where we could expect to locate rural carers) and Swansea (in south Wales, where urban carers and carers from some ethnic minority groups might be recruited). In Scotland, we chose Falkirk and East Ayrshire, in part because Carers Scotland (which assisted us in planning the research in Scotland) advised that these were areas where both urban and rural carers could be located and where the progress of the research could be expedited, since there were existing contacts with both social services and local employers. The four remaining localities were in England, and were: Sheffield (chosen in part for its geographical location as our pilot); Leeds (where the research was based); Sandwell (in the West Midlands) and Southwark (a London borough), where in both cases we had previous research contacts, there were large ethnic minority populations, and we knew there was an interest in carers' issues within the local authority. The English localities provided a good spread of geographical locations, included urban and rural settings, and offered scope both for including carers living in deprived and affluent circumstances (and in between), and for recruiting carers from a range of different ethnic groups.

Follow-up qualitative interviews

Our aim was to follow up approximately 10-15% of the achieved sample of carers, using a targeted approach to ensure this part of the research collected data relevant to the main themes of the study. The survey questionnaire invited respondents to indicate if they were willing to take part in this phase of the research and to provide contact details enabling them to be followed up in appropriate cases. 89% of respondents gave permission for this.

Using the data provided in the completed questionnaires to identify carers with suitable characteristics, individual respondents were identified in each of the ten selected localities and approached to arrange a face-to-face interview. Our aim was to select carers across different age groups, of both sexes, in different employment statuses and of different ethnicity. We also targeted respondents to ensure the caring relationships and the conditions/diagnoses of those cared for, as revealed in the questionnaire data, were broadly reflected in the sample selected for the follow-up interviews. (Table A.3.)

Initial follow-up contact with carers was made by telephone (occasionally by email). Most were pleased to be contacted and agreed to participate. The interview location was selected by the participant; most chose to be interviewed in their own homes, but a few interviews took place in the respondent's place of work, or in alternative venues such as cafes, a car, pubs and libraries.

Researchers followed an agreed protocol for the interviews, paying attention to identifying themselves correctly, to their own personal safety, and to putting interviewees at ease and clarifying their rights to confidentiality, to conclude the interview at any time they wished, and to ask questions about the research. The interviews were conducted using an agreed aide-mémoire, which had been piloted and tested; training sessions were run within the research team to ensure all researchers had a shared understanding of the important topics and issues which needed to be the focus of the interview. Permission to tape record the interview was always requested and almost always given. At the end of the interview, respondents were thanked and provided with details of how to contact the University about the research if they wished. In appropriate cases, interviewees were also given contact details of local/national organisations which support carers, to follow up if they chose. Interviews lasted between 40 minutes and two hours, according to the complexity of the caring situation and how much the interviewee had to say about it.

Table A.3 Carers interviewed face-to-face by locality, sex, ethnicity and employment status

Source: CES study, University of Leeds, 2007.

	Hertfordshire	Leeds	Sandwell	Sheffield	Southwark	West Sussex	Anglesey	Swansea	East Ayrshire	Falkirk	ALL
Sex											
Women	9	9	7	10	13	7	11	8	10	8	92
Men	6	4	3	4	4	3	3	6	4	5	42
Ethnic group											
White British	13	9	3	12	8	10	14	13	14	13	109
Any other ethnic group/nationality	2	4	7	2	9	0	0	1	0	0	25
Employment status											
Full-time employed	3	8	0	6	9	5	6	6	6	2	51
Part-time employed	8	2	1	4	3	3	6	6	5	4	42
Economically inactive/unemployed	4	3	9	4	5	2	2	2	3	7	41
ALL interviewees	15	13	10	14	17	10	14	14	14	13	134

The main topics covered in the aide mémoire were:

- Carers' roles, relationships and decision making
- Types of alternative services carers use, why they choose such services, and how they pay for them
- How the caring role fits with work
- What carers perceive to be the weaknesses of the care available to them
- Additional services carers value and use

Participants were encouraged to talk freely about their situation; researchers asked key questions from the interview schedule and otherwise intervened only to keep the focus on the central issues of the project. Other people, including the cared for person, were occasionally present, and in these cases they also sometimes contributed comments and opinions. Where interviews were conducted in the participant's workplace they tended to be more formal and business-like, usually taking place in the participant's office or a meeting room, and often under stricter time constraints. Some interviewees chose a workplace location because they felt that being at home could cause distress or inconvenience to the cared-for person.

After the interview, researchers wrote up field notes and transcribed the tape-recorded material, using a specially designed template which focused on key issues relating to the project. This template had been developed in the team training sessions during the assessment of the pilot interviews. The completed templates were later subjected to thematic analysis, and a number of team sessions were organised to discuss emerging findings, consider ethical issues and any other concerns, and to ensure all members of the research team had an opportunity to contribute their insights into the meaning both of specific examples of data and to its wider significance.

Key informant interviews

As part of the service mapping exercise, 'key informants' were approached for a one hour face-to-face interview in each of the selected localities. They included the local authority Carers Lead, other senior officers with a remit to address issues affecting carers and, where possible, local staff in the health and voluntary sectors who were involved in the planning of carers' services. The interview schedule for these interviews was structured to capture their perception of strategic developments in carers' services (since the National Strategies for Carers had been launched), and was developed through piloting with expert participants. These interviews covered the processes used for Carers Assessment and carer engagement, local partnership structures, and the commissioning procedures underpinning service delivery. Interviewees were also asked to reflect on what was working well for employed carers, and to highlight any challenges which remained to be tackled. Up to four key informants were selected in each of the ten localities. These interviews, usually lasting between an hour and hour and a half, also provided an opportunity to collect up-to-date versions of key documents, such as the local Carers Strategy, details of Carers Grant budgets and expenditure, and other relevant documents.

Prior to carrying out the interview, an extensive website search was undertaken to identify records relating to social care delivery in the locality (e.g. committee papers), Adult Social Care Services inspection and performance reports, details of local projects or services available to carers, etc. These were systematically reviewed with relevant data recorded using a 'service mapping' template which aimed to identify past approaches, strategies and structures relating to services affecting carers, as well as any recent developments.

Statistical work

Extensive work was undertaken to further examine the characteristics of carers in the localities identified and across Great Britain. For this the best source, and the one most often used, was the 2001 Census, which had asked a question about carers in 2001 for the first time. Standard tables from the 2001 Censuses were downloaded via NOMIS and the General Register Office for Scotland websites. These provided data on carers by age, sex and health at local authority and national level. Data tables were also commissioned from the General Register Office for Scotland and the Office for National Statistics to provide data on the amount of unpaid care provided, by economic activity, for carers aged 16 to state pension age (64 for men and 59 for women), and also for carers by ethnicity.

In addition to census statistics, 2001 Census microdata were obtained from the Cathie Marsh Centre for Census and Survey Research (University of Manchester). These are census data files with a separate record for each individual from which any identifying data have been removed. These files cover the full range of census variables; however, the dataset with the most detailed variables, the Sample of Anonymised Records (SAR),

only has a regional geographic indicator and although the Small Area Microdata (SAM) set has a local authority indicator the data provided is much less detailed. These data files are similar to the sort of data obtained from a sample survey, but the sample size is much larger than most surveys, thus permitting analysis of small groups and sub-national areas. The SAR is a 3% and the SAM a 5% sample of the 2001 Census responses, representing 1.84 million and 2.96 million records respectively. Although the SAR has been available for some time, the SAM was only released in late 2005/early 2006.

Statistics on local services were also collected. Statistics on English local authority social service home care provision and assessment, provision of services and direct payments for carers were obtained from the NHS Information Service [www.ic.nhs.uk]. Data on service provision by Welsh local authorities was obtained from the Local Government Data Unit (Wales) [www.lgdu-wales.gov.uk], and for Scottish local authorities from the Scottish Executive (www.scottishexecutive.gov.uk).

Research team

The project was directed by Professor Sue Yeandle who led on overall research design, quality assurance, analysis, interpretation and writing up, also conducting some of the key informant interviews. Dr Cinnamon Bennett managed the fieldwork, led on the documentary analysis and contributed to the key informant interviews, data analysis and report writing. Dr Lisa Buckner led on statistical aspects of the research, conducted analysis of the Census and of the survey results, and was responsible for presentation of statistical data in the research reports. The other members of the research team were Dr Gary Fry, Leah Harris, Amanda Rodney and Christopher Price. These staff conducted the face-to-face interviews, supported the distribution of the survey questionnaire, were responsible for first-level analysis of the interview data collected in the interviews with carers, and (in the cases of Gary Fry and Christopher Price) selected and wrote up some of the qualitative material used in the CES reports. All members of the team contributed to the identification of key themes and issues, and worked collaboratively, sharing insights from their various professional disciplines and careers which included: sociology, social policy, social psychology, statistics, health studies, community and development studies and work in government research. The team was supported by the administrative staff within the *Centre for International Research on Care Labour and Equalities* throughout the project, and thanks them for their assistance.

Appendix 2 Acronyms used in the Recommendations

BL	Business Links
Census UG	Census User Group
Ch of C	Chambers of Commerce
CES	Commission for Employment and Skills (replacing Sector Skills Development Agency & National Employment Panel from April 2008)
CSCI	Commission for Social Care Inspection (from 2009 Care and Quality Commission)
DBERR	Department for Business, Enterprise and Regulatory Reform
DCLG	Department for Communities and Local Government
DCSF.....	Department for Children, Schools and Families
DH	Department of Health
DIUS	Department for Innovation, Universities & Skills
DWP.....	Department for Work and Pensions
EHRC	Equality and Human Rights Commission
Eq Off.....	Government Equalities Office
GPs	General Practitioners
GSCC	General Social Care Council
HC	Healthcare Commission (from 2009 part of the Care and Quality Commission)
HR	Human Resources professionals
IAGs	Information, Advice and Guidance
JC+	Jobcentre Plus
LA SSRs	Local Authorities with social services responsibilities
LSC	Learning and Skills Councils
ONS	Office for National Statistics
NHS	National Health Service
RDAs.....	Regional Development Agencies
SkfCare	Skills for Care
TUs	Trade unions
Vol. Orgs.	Voluntary organisations

Notes

- ¹ As one of us wrote over a decade ago, 'Adequate social policies cannot be developed if policy-makers fail to recognise the consequences of individuals' attachments to their families, or that one set of changes in a family's organisation of work and care inevitably affects all other aspects of that work and care. Implementing social policy must come to involve supporting individuals in making arrangements which are consonant with their family relationships, circumstances and histories.' [Yeandle, S (1996) 'Work and Care in the Life Course: understanding the context for family arrangements', *Journal of Social Policy* Vol. 25 No. 4, 507-527.]
- ² Finch, J (1989) *Family Obligations and Social Change* Cambridge: Polity Press; Finch, J and Mason, J (1993) *Negotiating Family Responsibilities* London: Routledge.
- ³ In sociology, there has been extensive debate about the relationship between 'individualisation', described as a situation in which 'each person's biography is removed from given determinations and placed in his or her own hands, open and dependent on decisions' (Beck, U (1992) *Risk Society* London: Sage p135) and 'modernity'. In popular/political debate, it is often assumed that changes in family life and mores, in religious affiliation and belief, and in opportunities for geographical/social mobility have engendered a more 'selfish' age, in which each 'looks to him/herself', rejecting filial or familial responsibilities and duties. Together with the evidence of other studies (e.g. the work of Finch, op. cit., and recent research on the prevalence of caring in the context of international migration (Baldassar, L, Baldock, C V and Wilding, R (2007) *Families Caring Across Borders: migration, ageing and transnational caregiving* Basingstoke: Palgrave Macmillan), our evidence in the CES study about the ubiquity of unpaid caring suggests the assumption of a general trend towards selfishness and narrow, self-interested behaviour is misplaced.
- ⁴ See Ungerson, C and Yeandle, S (eds.) (2006) *Cash for Care in Developed Welfare States* Basingstoke: Palgrave Macmillan for a discussion of the blurring of the boundaries between paid and unpaid care in some new 'cash for care' systems, including the Direct Payments scheme in England.
- ⁵ The 10 localities selected were all areas where a single local authority had responsibility for the provision of social care services: Hertfordshire; West Sussex; Southwark, Leeds, Sheffield, Sandwell, Falkirk, East Ayrshire, Anglesey and Swansea.
- ⁶ Buckner, L and Yeandle, S (2007) *Care and Caring in EU Member States* London: Eurocarers.
- ⁷ LSC (2005) *Skills in England 2004* Vol. 2 Research Report p 60; M George (2001) *It could be you: a report on the chances of becoming a carer* London: Carers UK.
- ⁸ Bajekal, M (2005) 'Healthy life expectancy by area deprivation: magnitude and trends in England, 1994 -1999' *Health Statistics Quarterly* London: Office for National Statistics, cited in Yeandle, S 'Carers, employers and the state: clarifying the social contract', paper presented to *Caregivers: essential partners in care* Conference (FICCDAT), Toronto, Canada, June 16-19 2007.
- ⁹ In 2006, 12% of people lived alone in Great Britain, compared with only 6% in 1971. Latest figures (for 2005) showed that 60% of women aged 75 and older, and almost 30% of men in this age group, lived alone [ONS (2007) *Social Trends* 37].
- ¹⁰ Carone, G. (2005) "Long-term labour force projections for the 25 EU Member States: a set of data for assessing the economic impact of ageing", *European Economy* No. 235, EC: DG Economic & Financial Affairs; European Commission (2006) *The Demographic Future of Europe: from challenge to opportunity* Luxembourg: Office for Official Publications of the European Communities.
- ¹¹ Dickerson, A, Homenidou, K and Wilson R (2006) *Working Futures: Sectoral Report*, Warwick: Institute for Employment Research, University of Warwick.

- ¹² Buckner, L and Yeandle, S (2006) *Who Cares Wins: Statistical Appendix* London: Carers UK, page 3.
- ¹³ See also additional evidence in Buckner, L and Yeandle, S (2006) op. cit. page 11.
- ¹⁴ See Buckner, L and Yeandle, S (2006) op.cit.
- ¹⁵ CSCI (2006) *The State of Social Care in England 2005-6* London: Commission for Social Care Inspection.
- ¹⁶ Turner, A (2005) *A New Pension Settlement for the Twenty-First Century: The Second Report of the Pensions Commission*, London: Pensions Commission, The Stationery Office; Leitch, S (2006) *Prosperity for all in the global economy – Final Report of the Leitch Review of Skills* London: TSO (The Stationery Office) on behalf of HM Treasury; Freud, D (2007) *Reducing dependency, increasing opportunity: options for the future of welfare to work* London: Department for Work and Pensions.
- ¹⁷ McClimont, B. and Grove, K. (2004) *Who Cares Now? An Updated Profile of the Independent Sector Home Care Workforce in England* London: UKHCA (United Kingdom Home Care Association) and Skills for Care; Yeandle, S, Shipton, L and Buckner, L (2006) *Local Challenges in Meeting Demand for Domiciliary Care: Synthesis Report* Sheffield: Centre for Social Inclusion, Sheffield Hallam University.
- ¹⁸ All figures in this paragraph are from the 2001 Census.
- ¹⁹ Yeandle, S, Bennett, C, Buckner, L, Shipton, L, and Suokas, A (2006) *Who Cares Wins: the social and business benefits of supporting working carers* London: Carers UK.
- ²⁰ Carers UK (formerly Carers National Association) has played a key role in lobbying for legislative/policy change, securing considerable all-party support. With other carers' organisations, such as Contact a Family, which has also engaged in lobbying and campaigning activities, and the Princess Royal Trust for Carers and Crossroads (Caring for Carers), it has worked with local agencies and representatives of older, sick and disabled people and their carers, to raise the profile of carers and deliver appropriate information and services.
- ²¹ See Cook, T (2007) *The History of the Carers' Movement* London: Carers UK for a detailed account.
- ²² For details of relevant legislation see CES Report 4 Table 4.2.
- ²³ The officially listed membership of the All Party Parliamentary Group for Carers includes Conservative, Labour, Liberal and Plaid Cymru members, and was established 'To ensure the equality of opportunity for carers in the UK by liaising with carers organisations, lobbying Government and promoting legislation on their behalf; to promote awareness amongst members of both Houses of the needs of carers and former carers; to liaise with members of the devolved administrations within the UK in order to share best practice; and to link with appropriate bodies, including carers organisations, on an international basis.' It has members in both the House of Commons and the House of Lords.
- ²⁴ The CBI is the Confederation of British Industry.
- ²⁵ Carers UK (2007) *Real Change not Short Change: time to deliver for carers* London: Carers UK.
- ²⁶ CSCI (2006) op. cit.
- ²⁷ This is provided for in the *Work and Families Act 2006*. Research into the impact of the right to request flexible working available to working parents of young children (up to age 6) and of disabled children (up to age 18), provided for in the *Employment Act 2002*, is encouraging. Early research showed that only 13% of women and 23% of men who negotiated about flexible working arrangements with their employer had their request refused. (Fitzner, G and Grainger, H (2007) *The Right to Request Flexible Working: a review of the evidence*, DTI Britain at Work Seminar Series, March 2007.
- ²⁸ The slightly different arrangements for Carers Grant in England, Scotland and Wales are explained in CES Report 4.
- ²⁹ CSCI (2005) *The State of Social Care in England 2004-5*; and (2006) *The State of Social Care in England 2005-6* London: Commission for Social Care Inspection.

- ³⁰ See Arksey, H, Kemp, P, Glendinning, C, Kotchetkova, I and Tozer, R (2005) *Carers' aspirations and decisions around work and retirement* Leeds, Department for Work and Pensions Research Report No. 290 for an overview of relevant official sources of statistics about carers.
- ³¹ See Arksey et al (2005) op. cit. for a review of analyses of data relating to carers from other sources, including the GHS (General Household Survey), FWLS (Family and Working Lives Survey), ONS LS (Office for National Statistics Longitudinal Study) and BHPS (British Household Panel Survey). As these sources are all sample surveys, they lack the complete coverage possible using the Census, and cannot produce data about smaller geographical areas, such as local authority districts.
- ³² Buckner, L and Yeandle, S (2005) *We Care: Do You?* London: Carers UK; and Buckner and Yeandle (2006) op. cit.
- ³³ The 2001 SAR is a 3% sample and the SAM a 5% sample of anonymised 2001 Census records. These are microdata files with a separate record for each individual, similar to the sort of data obtained from a sample survey. However, as the sample size is much larger than most surveys, analysis of small groups and sub-national areas is possible. The SARs/SAM allow flexible, multivariate analysis at the individual level, and cover the full range of Census topics, including: housing; education; health; transport; employment; and ethnicity. The 2001 SARs and 2001 SAM are 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.
- ³⁴ Buckner, L and Yeandle, S (2005) *We Care, Do You?* London: Carers UK
- ³⁵ The government publication *Local Area Agreements: Guidance for Round 3 and Refresh of Rounds 1 and 2* [Office of the Deputy Prime Minister (2006)] states that 'Local Area Agreements will be a key mechanism for joint planning and delivery' of health and social care (p 38).
- ³⁶ Statistical data on carers who provide 1-19 hours of care each week indicate, for most topics, that they are generally in a more favourable position than non-carers or those with more time-consuming caring roles. It is likely that this is related to their different age and family stage profiles, and to the fact that some non-carers are people who would not be able to care for others because of their own health problems, or are outside of the kind of family and household relationships in which caring responsibilities typically arise.
- ³⁷ Buckner, L, Yeandle, S and Botcherby, S (2007) *Ethnic Minority Women and Local Labour Markets* Manchester: Equal Opportunities Commission.
- ³⁸ CES Reports 7 – 13, available from Carers UK, published autumn 2007.
- ³⁹ Carers UK (2007) *Real Change not Short Change: time to deliver for carers* London: Carers UK.
- ⁴⁰ Notable exceptions to this include Arber, S and Gilbert, N (1989) 'Men: the forgotten carers' *Sociology*, Vol. 23, No. 1, 111-118; Johnson, J and Bytheway B (1997) 'Illustrating care: images of care relationships with older people', in Jamieson, A et al (eds), *Critical Approaches to Ageing and Later Life*, Open University Press; Bytheway, B and Johnson J (1998) 'The social construction of carers', in Symonds, A and Kelly, A (eds), *The Social Construction of Care in the Community*, Macmillan.
- ⁴¹ When women aged 60-64 are included, the total is 1,645.
- ⁴² The *Who Cares Wins* report contextualised our investigation in the wider literature on carers and parents in employment and on family-friendly working practices and work-life balance. See also Dex, S (2003) *Families and work in the twenty-first century*, Bristol: The Policy Press and York: Joseph Rowntree Foundation; and Yeandle, S, Phillips, J, Scheibl, F, Wise, S and Wigfield, A (2003) *Line Managers and Family-friendly employment: roles and perspectives* Bristol: Policy Press.
- ⁴³ The financing of social care when it is delivered through services in the social care market (whether publicly funded or otherwise) is a complex question which falls outside the remit of the CES study. This matter

has been extensively debated by academics and policy-makers, with the Wanless Review [Wanless, D, Forder, J, Poole, T, Beesley, L and Moscone, F (2006) *Wanless Social Care Review: Securing Good Care for Older People – taking a long-term view* London: King's Fund] the most influential and important recent contribution. See also Karlsson, M (2007) 'Distributional Effects of Reform in Long-term Care' *Ageing Horizons* No. 6 pp33-41, which reviews recent contributions to this debate.

- ⁴⁴ Buckner, L and Yeandle, S (2007) *Valuing Carers: calculating the value of unpaid care* London: Carers UK.
- ⁴⁵ Beveridge's concept of 'full employment', set out in his 1942 report *Social Insurance and Allied Services* and also in his *Full Employment in a Free Society* (1944), referred to full employment among men.
- ⁴⁶ Social policy and feminist academics focused considerable attention on carers in the 1980s, with important contributions including: Finch, J and Groves, D (eds.) (1983) *A Labour of Love: women, work and caring*; Glendinning, C (1983) *Unshared Care: parents and their disabled children* London: Routledge and Kegan Paul; Wenger, C (1984) *The Supportive Network: coping with old age* London: Allen and Unwin; Wicks, M and Henwood, M (1984) *The Forgotten Army: Family Care and Elderly People* London: Family Policy Studies Centre; Willmott, P (1986) *Social Networks, Informal Care and Public Policy* PSI Research Report 655, London: Policy Studies Institute; Ungerson, C (1987) *Policy is Personal: sex, gender and informal care* London: Tavistock; Dalley, G (1988) *Ideologies of Caring: rethinking communities and collectivism* London: Macmillan; Lewis, J and Meredith, B (1988) *Daughters who Care: daughters caring for their mothers at home* London: Routledge; Qureshi, H and Walker, A (1988) *The Caring Relationship* London: Routledge and Kegan Paul.
- ⁴⁷ By 1997, New Labour's conceptualisation of 'full employment' referred to both the male and female population.
- ⁴⁸ See Jones, R (2007) 'A Journey through the years: Ageing and Social Care' in *Ageing Horizons* No 6 (pp42-51) for a discussion of historical developments in relation to the care of older people. Jones notes that the changes implemented in the 1990s '*repattern(ed) services to support more disabled and older people within their own homes, turn(ed) the focus of local authorities to strategic planning, commissioning and service purchasing rather than the direct management of service provision, and stimulate(d) choice for service users within a mixed economy of services. However, for those requiring public funding for their services their choice was increasingly limited by tight local authority budgets, which led to a heightening in the thresholds of need which had to be met before local authorities would fund a service*' (p 47).
- ⁴⁹ A detailed account of the law affecting carers is available in Clements, L (2007 2nd edition) *Carers and their Rights: the law relating to carers* London: Carers UK. The relevant legislation is also briefly outlined in CES Report No. 4.
- ⁵⁰ See Leece, J and Bornat, J (2006) *Developments in direct payments* Bristol: Policy Press; Jones (2007 op. cit); and Yeandle, S and Stiell, B (2007) 'Issues in the Development of the Direct Payments Scheme for Older People in England' in Ungerson, C and Yeandle, S (eds.) *Cash for Care in Developed Welfare States* Basingstoke: Palgrave Macmillan.
- ⁵¹ Individual budgets, which were being piloted in 13 local authorities in England during the period of the CES study, are the subject of a major evaluation study funded by the Department of Health 2006-8, conducted by a consortium of UK universities and co-ordinated by Mark Wilberforce at the University of York, and due to publish its major findings in 2008.
- ⁵² For example, Kent County Council, in partnership with other agencies, has introduced both telecare equipment and 'Smart Houses' as a way of providing residents of the county with support and reassurance from outside of their homes, using the help of technology.
- ⁵³ Relevant local authority responsibilities include: Adults' and Children's Services, Housing, Planning, Economic Development, Regeneration and Neighbourhood Renewal; Rural Affairs; Emergency Planning.
- ⁵⁴ IAGs are Information, Advice and Guidance organisations.

- ⁵⁵ Government departments involved in the 2007-8 Review of the National Strategy for Carers include: Work and Pensions; Health; Treasury; Children, Schools and Families; Business, Enterprise and Regulatory Reform; Communities and Local Government.
- ⁵⁶ Marian Harkin, MEP, addressing the seminar, *We Care, Do You? Unpaid care and its role in a sustainable future for Europe*, Brussels, 10 October 2007, and Harkin, M (October 2007) *Policy Debate, The Parliament Magazine*, Brussels.
- ⁵⁷ To this we can add that while population ageing and labour market trends inevitably place limits on the ability of family members to provide the increased care which is needed, public policy needs also to take account of the importance of unpaid care being freely given ('voluntary'); some argue it is '*unfair of the wider community to expect or require anything of family members in the way of unpaid care*' (Howse, K (2007) 'Long-term care policy: the difficulties of taking a global view' *Ageing Horizons* Issue No. 6:11). We emphasise that the 'social contract' advocated in this report goes beyond issues of 'whether or not to extend the reach of social solidarity in meeting the costs of purchasing care', as a way of dealing with the 'lottery in the distribution of the cost burden associated with the need for long-term care' (op. cit. p 9).
- ⁵⁸ For debate on the ethics of care, and conceptualisations of care as involving 'rights' to give and receive care, see, *inter alia*, Williams, F (2001) 'In and beyond New Labour: towards a new political ethic of care' in *Critical Social Policy*, 21(4); and Sevenhuijsen, S (1998) *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics* London: Routledge.
- ⁵⁹ Carers of working age in GB save the economy £58.2 billion a year. When all carers across the whole of the UK are taken into account, the total saving to the economy is £87 billion.
- ⁶⁰ We decided to use targeted recruitment of respondents in the GLBT community, via relevant organisations, rather than to ask a question about sexuality in the survey questionnaire. As a result, there may be some unidentified gay and lesbian carers in the rest of our sample. Advertising the research via national and local GLBT organisations yielded only a very small response.

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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