

**Department for Work and Pensions**

**Research Report No 290**

# **Carers' aspirations and decisions around work and retirement**

**Hilary Arksey, Peter Kemp, Caroline Glendinning, Inna Kotchetkova and Rosemary Tozer**

A report of research carried out by the University of York on behalf of the Department for Work and Pensions

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# Summary

## Background

There are an estimated 5.6 million people in Britain looking after a relative or friend in need of support because of age or frailty, physical or learning disability or illness. The Government aims to support carers in their caring role, and enable them to continue care-giving for as long as that is their wish. Many carers will be working when the need to care arises, and most wish to carry on working. The Department for Work and Pensions (DWP) commissioned research designed to help ascertain what can be done to assist carers to remain in work, or to return to work during or after an episode of caring.

## Research methods

The first stage of the study was a national literature review to identify existing evidence on carers' employment and retirement issues. This was followed by qualitative research in four research sites selected to reflect different labour market conditions. In-depth interviews were conducted with 80 carers with substantial caring responsibilities to explore their hopes and decision-making in respect of working and retirement. Subsequently, a series of separate focus groups were held with front-line professionals from Jobcentre Plus, social services departments and carers organisations who worked with carers to provide advice or support. The fieldwork took place between autumn 2004 and spring 2005.

## Summary of relevant literature

The literature review indicated that most carers wish to remain in work and many are very reluctant to quit. Many employed carers find it difficult to care at the same time; it appears to become more difficult once people provide over 20 hours of care per week. It is co-resident, rather than extra-resident, carers who face the biggest obstacles. Interrupted or short working careers, or moving from full-time to part-time work, have implications for earnings and subsequent pension entitlements, especially if the caring episode lasts for many years.

The evidence suggests that most carers appear to have little access to potential carer-friendly workplace policies and practices, and even where they do exist carers can feel unable to take advantage of them. Most employers, in particular those in the private sector, give little consideration to carer-friendly work practices.

A range of factors influence carers' decisions about whether to remain in work or change their employment status. These relate to whether they can afford to give up work, if they enjoy their job, stress levels at work, being out of work, and access to support. Being able to retire early with a full occupational pension or favourable retirement deal can be a significant incentive to leave work in order to undertake caring duties, especially for men.

## Qualitative research with carers and professionals

### **Carers' decisions around employment and care-giving**

Carers' thinking and decisions about work, retirement and caring took into account a wide range of factors, primarily: finances; their own physical and mental health; personal factors, for instance commitment to careers; work-related issues; availability of formal and informal support; issues related to the person looked after; distances and travelling times. The relative importance of these various factors varied according to whether or not carers were working, and how many hours per week they worked. Generally, no single factor dominated, and decisions tended to be the result of combinations of factors, which could even be contradictory. However, carers' perceptions of their own health and well-being were very important considerations in decisions about whether to work and if so, how many hours per week to work. Uncertainties and unknown factors, for example, relating to changes in health status of both the carer and the care recipient or changes at important transition times such as moving from children's services to adult services, made decision-making even more complicated for carers.

### **Retirement and pension planning**

Carers found planning for retirement difficult, partly because it was influenced by many unknown factors related to the caring situation. However, there was evidence that some carers did not plan ahead because of reasons specific to care-giving. These included a lack of time because of caring responsibilities, not knowing whether adult disabled children would be living independently or still at home with parents, and the possibility of having to pay for residential or nursing home care. For many carers, it was more important to attend to current financial affairs and commitments rather than make financial provisions for a future retirement that for many people could be a considerable number of years away. Carers who were still buying their own homes emphasised the need to pay off mortgages as they did not want to risk losing their homes.

Many carers had limited knowledge about pensions generally, and the impact of care-giving on pensions in particular. Likewise, front-line professionals from all three occupational groups felt they had information gaps relating to pensions and tended to refer carers on to specialist agencies rather than provide carers with misleading or incomplete information themselves.

## **Support from statutory agencies**

### *Jobcentre Plus*

Only a few carers had taken part in a Work Focused Interview (WFI) with a Jobcentre Plus personal adviser. The interviews did not tend to influence carers' decisions about obtaining paid work as long as their current (caring) situation prevailed. However, carers appreciated the advice, information and better-off-in-work calculations provided by advisers. A key weakness identified by carers related to advisers' perceived lack of knowledge about caring in general, and the impact of caring on carers' ability to work in particular.

Personal advisers conducted fewer WFIs with carers compared with other customer groups, which hampered their ability to acquire detailed knowledge of the main challenges and issues for carers wanting to work and care. Advisers believed that many carers had already made the decision not to work before they participated in a WFI. Consequently, they concentrated on raising carers' awareness about how Jobcentre Plus could help them once their caring situation changed. Personal advisers identified a range of organisational constraints (e.g. carers not being a priority group as in the same way as Incapacity Benefit (IB) claimants or disabled people were; the inflexibility of electronic diaries) that restricted the effectiveness of the support they could offer to carers.

### *Social services departments*

Many carers (or care recipients) were unwilling to accept assistance from social services. Whilst some carers who did receive help were full of praise, others were critical. There was no evidence of a direct link between the number of hours that carers worked and the levels of support they received. Generally, social services support was not essential to the ability of carers to undertake paid work partly because it did not easily accommodate work hours or patterns – for instance, day centre hours did not always cover the full working day. Services that carers said would make it easier for them to work and care included longer day centre hours, childcare and after school clubs for disabled children and practical help with domestic responsibilities.

## **Financial support for carers**

Carer's Allowance (CA) is the main welfare benefit for carers. Both carers and professionals regarded the value of the benefit as too small. Carers commonly agreed that the earnings threshold was low and, therefore, restrictive. There was evidence that the benefit might not act as an incentive to work, and that it could act

as a barrier to working more hours. CA was not flexible enough for some carers, for example, paid work could jeopardise receipt of the benefit because of the rules regarding spreading earnings over a reasonable time period. The ceiling on earnings meant that carers who were working were unable to offer employers flexibility by occasionally working additional hours.

### **Workplace policies and practices**

Employed carers benefited from both formal and informal workplace policies and practices. For many, these were essential to their ability to combine work and care. Flexible start and finish times, together with the ability to take time off in emergencies or for planned hospital or doctor's appointments, were particularly important. So, too, were sympathetic line managers and colleagues.

Professionals believed that employment opportunities did exist for carers who wanted to combine work and care, but such jobs were typically low paid, unskilled and possibly part-time and/or seasonal. They suggested that a combination of legislation and awareness raising had the potential to encourage employers to change workplace practices to better accommodate the needs of working carers.

### **Carers centres**

Carers centres provide information, advice and support to assist carers in obtaining the services they need. Not all carers wanted assistance from carers centres, but those who were in touch commented favourably on the help they received. Centres indirectly helped employed carers to sustain paid work by helping to reduce their levels of stress. They achieved this by offering listening services, counselling, advocacy, referrals to social services departments and access to short breaks. Employed carers, especially those working full-time, could find it difficult to access help from carers centres because the latter's office hours and their working hours were often the same.

### **Inter-agency collaboration**

Inter-agency collaboration between Jobcentre Plus, social services departments and carers organisations was limited. This was, in part, a reflection of important information gaps about what organisations existed to support carers and what services they offered. Jobcentre Plus staff were the most isolated professional group; personal advisers' knowledge of the support provided by carers centres and social services was very limited.

# Part 1

## Introduction



# 1 Introduction

## 1.1 Background to the study

The 2001 Census estimates that there are 5.6 million adults in Britain looking after a relative or friend in need of support because of age or frailty, physical or learning disability or illness. In recent years, there has been increasing recognition of the contribution and needs of informal carers. The risk of caring responsibilities increases with age, and the peak age for becoming a carer is between 45 and 64 years. Two-thirds of carers below state pension age are in paid employment, or are self-employed, which means that around 2.7 million people combine work and care-giving (DH, 1999). Paid work is important to carers for financial, social and personal reasons (both in the short- and longer-term). If carers have to significantly reduce the number of hours they work, or give up work altogether, this can lead to severe financial and emotional hardships (DH, 1999).

Policy on carers cuts across Government departments. Although this research was commissioned by the Department for Work and Pensions (DWP), the findings are also relevant to the Department of Health and the Department of Trade and Industry. Policy on social services support to carers is the responsibility of the Department of Health and policies on flexible working are the responsibility of the Department for Trade and Industry.

Government policy aims to support carers in their caring role, and enable them to continue care-giving for as long as that is their wish. Policy measures targeted directly at carers include the Carers (Recognition and Services) Act 1995, the 1999 national strategy for carers (DH, 1999) and the Carers and Disabled Children Act 2000. The latest piece of legislation, the Carers (Equal Opportunities) Act 2004 which came into force in April 2005, aims to give carers more choice and opportunity to lead a fulfilling life. In particular, it places a duty on local authorities to consider whether or not a carer wishes to take part in paid work, education, training or leisure activities when they are carrying out a carer's assessment.

In addition to the above measures, carers also stand to gain from successive European Directives on maternity and paternity leave, flexible working and the organisation of working time that have been put in place and translated into policy and legislation in the UK. Relevant legislation includes the Working Time Regulations 1998, Employment Relations Act 1999, Part-Time Workers (Prevention of Less Favourable Treatment) Regulations 2000, Maternity and Parental Leave, etc Regulations 1999 and the Employment Act 2002. Two measures are of particular interest for the present study. Time off for dependents, under the Employment Relations Act 1999, entitles employees to take a reasonable amount of (unpaid) time off from work to deal with emergencies or unexpected situations involving a dependent and to make any necessary long-term arrangements. More recently, the flexible working regulations, included in the Employment Act 2002, give parents of children under six, or 18 if the child is disabled, the right to request flexible working such as changing hours or working from home after six months in service. At the time of writing, the Government is considering the introduction of further family-friendly working measures. One proposal is to extend the right to request flexible working to cover carers of adult relatives and/or parents of older children (DTI, 2005).

Carer's Allowance (CA) (previously known as Invalid Care Allowance (ICA)) is the main state benefit for carers who have no more than minimal earnings and who care for 35 hours or more per week.<sup>1</sup> Carers who qualify for CA also receive national insurance credits, which help protect basic State Pension. Carers not in work can claim income-related benefits and premiums as a safety net. Working carers may also be eligible for in-work financial benefits, for instance Working Tax Credit (WTC) and Child Tax Credit (CTC), but these are not offered on preferential terms to carers of disabled adults, in other words carers receive tax credits in the same way as the general population, rather than in the same way as people with children and disabled people.

The Government's Welfare to Work Programme aims to support people (re)entering the labour market. Different groups of people are covered by various New Deal programmes which require them to attend a Jobcentre Plus office for a Work Focused Interview (WFI) to discuss work prospects with a personal adviser. Whilst there is no specific 'New Deal for Carers', carers who apply for CA were required to participate in a WFI as a condition of their claim. However, these interviews could be deferred to a later date or waived indefinitely in certain circumstances. A policy change during the course of the study was announced in 2005, namely that mandatory WFI for carers receiving only CA will be discontinued from 31 October 2005. New customers claiming CA will be told about voluntary WFIs in the new claims telephone interview and claim packs. Carers receiving other benefits will still have a mandatory WFI.

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<sup>1</sup> In addition, care recipients must receive Attendance Allowance (AA) or Disability Living Allowance (DLA) at the middle or highest rate for personal care; this ensures the carer is looking after someone with genuine care needs.

## 1.2 Study aims

To help ascertain what can be done to assist carers to remain in work, or to return to work during or after an episode of caring, the DWP commissioned the Social Policy Research Unit (SPRU) at the University of York to undertake research on the aspirations and decisions of carers about caring, work and pensions. Within this overall aim, the specific objectives of the research were to:

- identify and review previous research on the relationships between carers and the labour market, including the decisions that carers make about caring, paid work and retirement;
- understand the decisions that carers make about care, work, retirement and pensions and the factors that influence those decisions;
- explore the work and retirement aspirations of carers;
- consider the effectiveness of the support available to carers in enabling them to remain in or return to work.

Although the research was commissioned by the DWP, issues such as employment policies, welfare benefits, pensions, health and social care services as they affect carers are cross-cutting and of wider concern and interest. From this perspective, the findings are relevant to a large number of Government departments and local agencies.

## 1.3 Research design

The overall research design for the study involved three elements:

- A literature review to identify existing evidence on carers' employment and retirement issues.
- In-depth interviews with carers with substantial caring responsibilities to explore their hopes and decision-making in respect of working and retirement.
- A series of focus groups with front-line professionals from Jobcentre Plus, social services departments and carers' organisations who work with carers to provide advice or support.

The present report draws together the findings from all three elements of the work.

## 1.4 Organisation of the report

A vast amount of data was collected during the course of the study, which, because of time and space constraints, cannot be comprehensively documented here. For the purposes of the present report, we have been guided by the specific topic areas that the research was commissioned to address, together with the information needs of the DWP.

The 14 chapters of the report are organised into five parts. Part 1 comprises the first chapter which introduces the report, and is followed by the literature review findings in Part 2.

Parts 3 and 4 document the findings from the qualitative research. The first chapter in Part 3 (Chapter 3) sets the scene by giving a short overview of the aims and research methods for the empirical work. The following chapters focus on: carers' experiences of care-giving and working (Chapter 4); carers' decision-making around employment and care-giving (Chapter 5); professionals' views on carers and work (Chapter 6); and retirement and pension planning (Chapter 7).

Part 4 of the report presents findings that focus on Government policies with a bearing on employment issues relating to carers, as well as assistance that is available from different agencies. There are specific chapters on: support from Jobcentre Plus (Chapter 8); support from social services departments (Chapter 9); financial support for carers (Chapter 10); workplace policies and practices (Chapter 11) and support from other agencies (Chapter 12).

Parts 5 and 6 contain just one chapter each: Chapters 13 and 14 respectively. The penultimate chapter (Chapter 13) looks at the decisions and aspirations of different groups of carers. Chapter 14, which concludes the report, draws together the key themes emerging from the study and addresses the main research questions. Fuller details of the research methods are presented in the appendices.

Quotes in italics are extracts from study participants' verbatim comments during the interviews with carers or the focus groups with professionals. Identifiers are provided for each individual quote. The term 'carers worker' is used to refer to paid workers or volunteers from carers centres and other voluntary organisations working with carers.

## Part 2

### Literature review



## 2 Review of existing evidence

### 2.1 Introduction

This chapter reviews the existing evidence on carers in relation to employment and retirement. It begins by explaining how the review was conducted. The second section summarises the evidence on the incidence and nature of caring and the characteristics of carers. This provides essential contextual material within which to locate the evidence on carers, employment and retirement. The third part of the chapter describes the existing evidence on employment among people providing unpaid care. Section 2.4 summarises the evidence on the impact of caring on paid employment. Section 2.5 looks at the factors affecting decisions about combining work and unpaid care, while Section 2.6 reviews the workplace policies and practices that would help carers to combine care-giving and employment. Section 2.7 looks at the income consequences of caring, including the impact on earning and pensions. The final section summarises the key points from the review.

### 2.2 Methods

For the purpose of the literature review, 'carers' were defined as people who provide unpaid care for sick, disabled or frail elderly people. The recipients of their care include chronically sick or disabled children, spouses, elderly parents, other relatives, friends or neighbours. Childcare and foster caring were excluded from the remit of the review and the study more generally. The study focused on adult carers below state pension age.

The aim of this part of the study was to conduct a narrative review of the existing evidence base. It was not, therefore, intended to be a 'systematic review' in the sense that the term has begun to be used in the health and social sciences (Torgerson, 2003). However, the review aimed to be transparent and systematic in its methods. The review covered both qualitative and quantitative studies. More details of the methods can be found in Appendix A.

## 2.3 The incidence and nature of caring

According to the most recent Census, 5.6 million adults in Britain were providing unpaid care to a sick, disabled or elderly person in 2001. This was the first time that the Census has included a question about unpaid care-giving; the previous best estimate was based on the General Household Survey (GHS) for 2000, which indicated that there were 6.8 million adult carers in Britain (Maher and Green, 2002). This substantial difference between the two sources may reflect the different wording of the question about care-giving in the Census compared with the GHS. Also, the Census data are based on (almost) the entire population, whereas the GHS is a sample survey which is subject to response bias. In addition, while the Census is now, in effect, a self-completion questionnaire, the GHS uses face-to-face interviewing by trained and experienced interviewers who are in a position to explain the meaning of questions or who they refer to. Because of the latter, more people in the GHS may recognise themselves as carers than is true of the Census. Consequently, the GHS data may include many more people providing relatively small amounts of care than does the Census (Hirst, 2005), which may have relatively little impact on their lives. Although the Census provides the more reliable data on the **incidence** of care-giving, the GHS provides more details about the **composition** of the carer population. Hence, unless specified to the contrary, the data presented in this chapter are from the GHS 2000 (see Maher and Green, 2002) and refer to Great Britain. Wherever possible, the data refer to people providing more than 20 hours care per week.

According to the GHS, 16 per cent of adults (people aged over 16) in Britain were caring for a sick, disabled or elderly person in 2000. In total, 21 per cent of households contained at least one person doing unpaid care. These figures represented an estimated 6.8 million adult carers living in five million households (Maher and Green, 2002).

According to the GHS, about one-third of carers in 2000 were living with the person for whom they were providing care ('co-resident carers'), while the remaining two-thirds were caring for someone in another household ('extra-resident carers'). Co-resident carers included people caring for their spouse or partner and those with a chronically sick or disabled child. Extra-resident carers were mainly helping elderly relatives or friends (Maher and Green, 2002).

In general, co-resident care-giving is more intensive and tends to involve more demanding tasks than extra-resident care. For example, co-resident carers are much more likely than extra-resident carers to provide personal care, such as washing and help with using the toilet, and physical tasks such as help with mobility. Extra-resident carers tended to be doing things like keeping company, taking out, or looking after the cared-for person, as well as help with paperwork and other practical matters; though these are tasks that co-resident carers were doing as well (Maher and Green, 2002).

Women are more likely than men to provide unpaid care for sick, disabled or elderly people. Thus, the GHS 2000 found that 18 per cent of women and 14 per cent of men were carers. In total, women accounted for 58 per cent and men for 42 per cent of carers. Men were as likely as women to be co-resident carers, but women were more likely than men to be extra-resident carers. Where someone had more than one carer, women were more likely than men to be the main carer (Maher and Green, 2002).

The fact that men constitute as many as four out of ten informal carers has sometimes been neglected in academic and policy debates. The relative invisibility of men may be because 'caring' is often seen as being particularly associated with women; and this is especially true when childcare and informal caring are considered together, not least because women **are** the predominant providers of childcare. Moreover, much of the early research on carers was qualitative and based on purposive rather than representative samples. Perhaps because informal caring was assumed to be a largely female activity, researchers tended to select samples of female carers. This research was often focused on extra-resident caring – particularly adult daughters caring for their non-resident, elderly parents – which is much more associated with women than with men. It was only when the first national level data on carers became available via the GHS that the extent of caring by men became apparent. Arber and Gilbert (1989) subsequently wrote an article entitled 'Men: the forgotten carers', but this publication is itself often overlooked.

Eight out of ten carers were below state pension age in 2000; among those spending at least 20 hours per week caring, seven out of ten were below state pension age. Using data from the British Household Panel Survey (BHPS) for 1991 to 1998, Hirst (2002) found that the average age of becoming a carer was the same for men and women at 49 years for extra-resident carers and 51 years for co-resident carers. However, the risk of becoming a carer increases with age, peaking in the 45 to 64 year age group, after which it falls somewhat. About a quarter (24 per cent) of people in Britain aged between 45 and 64 years were carers in 2000. This included 19 per cent of men and 27 per cent of women in that age group (Maher and Green, 2002).

The population of carers is not static. Indeed, there is considerable turnover among the carer population. Using BHPS data for 1991 to 1998, Hirst (2002) found that about four out of ten extra-resident carers had begun care-giving in the previous year and a similar proportion ceased care-giving in the following year. Turnover was lower among co-resident carers but still very high: each year about three out of ten co-resident carers started, and a similar proportion ceased, care-giving. Among substantial carers (20 hours or more per week), the turnover rate was about four out of ten (44 per cent start and 41 per cent cease each year).

Because of this very high turnover among carers, the number of people who experience care-giving is much larger than the cross-sectional risk of them doing so at any point in time. Indeed, Hirst (2002) estimated that over half the adult population is likely to be heavily involved in providing informal care at some point in

their lives. This estimate is higher than that calculated by Henz (2004) using the retrospective information in the Family and Working Lives Survey (FWLS). She estimated that the lifetime probability of providing informal care before the age of 65 was 42 per cent for women and 24 per cent for men. Several factors may account for the discrepancy between these estimates. In the first place, the FWLS appears to underestimate the incidence of care-giving, possibly because it has a more restrictive definition of caring than the BHPS and GHS. Secondly, the FWLS had a relatively low response rate (54 per cent). Third, the FWLS is a retrospective survey and, hence, more prone to recall errors than a panel survey like the BHPS. What is clear, however, is that providing informal care for relatives or friends is a relatively common life-course experience in Britain (Henz, 2004).

Not surprisingly, the length of caring spells varies between different carers. For some people, care-giving lasts for a relatively short period while for others it can go on for many years. The 2000 GHS found that one in five (21 per cent) of carers had been providing care to someone for at least ten years and nearly half (45 per cent) for at least five years (Maher and Green, 2002). These data refer only to the duration of caring for the **main** person cared for and only for the period up to the date of the survey. Using the FWLS, Henz (2004) was able to calculate the length of caring spells for all people cared for (not just the main person) and take into account the fact that caring can continue beyond the interview date. On this basis, she calculated that three out of ten carers provided care for at least ten years, a figure that is 50 per cent higher than that found by the GHS.

The length of care-giving spells varies according to the characteristics of the person cared for. Caring spells are particularly long for people looking after a chronically sick or disabled child over the age of 16. Thus, the 2000 GHS found that over half (56 per cent) of care-givers of children aged 16 or more had spent at least ten years caring for them. This was about double the proportion of carers who had spent ten or more years caring for a spouse (27 per cent) and about three times the proportion that had spent that amount of time caring for a parent or parent-in-law (16 per cent). About one in five people caring for a child under 16 (22 per cent) had spent at least ten years doing so (Maher and Green, 2002). Using the FWLS, Henz (2004) calculated that the median duration of caring for partners was four years; for mothers it was nearly four and a half years, but for fathers it was about two years. It is not clear whether the median duration is much shorter for fathers than for mothers because they have a shorter life expectancy or is due to some other reason.

The amount of hours per week that people devote to caring also varies considerably between carers. According to the 2000 GHS, one in 20 adults in Great Britain was spending more than 20 hours per week caring for a sick, disabled or elderly person in 2000 (Maher and Green, 2002). This is a substantial amount of time to be devoting to care-giving each week. Co-resident carers were much more likely than extra-resident carers to be devoting more than 20 hours per week to care-giving. Indeed, nine out of ten extra-resident carers were providing less than 20 hours. By contrast, three out of ten co-resident carers were spending between 20 and 49

hours per week caring; and a similar proportion were devoting up to fifty or more hours per week to caring for someone (Table 2.1). Thus, although most carers are extra-resident, most 'substantial carers' – that is, people spending 20 or more hours per week caring – are co-resident.

**Table 2.1 Number of hours spent caring per week**

Number of hours caring per week	Co-resident	Extra-resident	All carers
	carers %	carers %	
Under 20	37	89	72
20 to 49	32	9	16
50 or more	31	1	11
<b>Total</b>	100	100	100

Source: Maher and Green (2002) Table 4.3.

Table 2.2 shows some key characteristics of the people spending at least 20 hours per week caring for a sick, disabled or frail person. Among the main points to note from the table is that six out of ten substantial carers were women, which is about the same as the proportion among carers as a whole. In addition, seven out of ten substantial carers were below stage pension age, three-quarters were co-resident carers, and nine out of ten were the main carer of the cared-for person. The table also shows the relationship between the carers and the cared-for person. In 18 per cent of cases, carers were looking after a disabled or chronically sick child (of any age). In 45 per cent of cases they were caring for their spouse or partner. Meanwhile, 41 per cent were caring for a parent or parent-in-law and 18 per cent were caring for other relatives, friends or neighbours. Thus, spousal care and elder care are the most common types of care-giving among substantial carers.

According to the 2000 GHS, about half of carers spending more than 20 hours per week care-giving reported that they were unable to leave the cared-for person for more than a few hours (Maher and Green, 2002). This obviously has implications for their ability to maintain paid employment.

Half of people caring for more than 20 hours per week said that they themselves had a long-standing illness and a third said it limited their activities. In fact, the majority of people caring for at least 20 hours per week said that their health was affected by their caring. Co-resident carers were more likely than extra-resident carers to say that their caring responsibilities had a negative affect on their health. However, support services – such as visits from health authorities or social services departments – were more likely to be received by people who were not living with their carer (Maher and Green, 2002). Parker (1993a: 158) argues that spouse carers *'are far more likely to be in need of support from service providers yet least likely to receive them'*.

**Table 2.2 Characteristics of carers spending at least 20 hours per week caring**

	%
<b>Sex</b>	
Male	39
Female	61
<b>Age</b>	
16 to 44	32
45 to 64	40
65 and over	28
<b>Locus of care</b>	
Carer's household	75
Other private household	25
<b>Whether main carer</b>	
Main carer	88
Secondary carer	12
<b>Person cared for</b>	
Spouse	45
Child (of any age)	18
Parent or parent-in-law	41
Other relative or friend	18

Note: Figures may sum to more than 100 because some carers were caring for more than one person.

Source: Maher and Green (2002) Table 4.6.

Recent analysis of 2001 Census data for England and Wales shows that the proportion of the population aged 16 and over providing unpaid care of at least 20 hours per week varied considerably from one area to another. It ranged from 2.0 per cent at one extreme to 7.7 per cent at the other, with an average of 3.9 per cent. It was also found that local authority areas with high proportions of carers had high proportions of the population with limiting long-term illness, high proportions of carers in poor health and high levels of socio-economic deprivation (Young *et al.*, 2005). Analysis of the Office for National Statistics Longitudinal Study (ONS LS) one per cent sample of the population of England and Wales for 2001 found that caring was associated with poor health even when controlling for socio-economic status (Young *et al.*, 2005).

Regression analysis of the ONS LS one per cent sample data for 2001 also found that, after controlling for age, sex and socio-economic variables, there were significant differences in the incidence of caring among different ethnic groups. Adults from Bangladeshi and Pakistani ethnic groups were the most likely to be providing unpaid care of 20 hours or more per week, followed by Indian and then white ethnic groups. People from black ethnic groups were no more or less likely than people from white ethnic groups to be providing care (Young *et al.*, 2005).

## 2.4 Caring and employment

A longstanding concern in the literature on carers has been about how informal care and paid employment compete for time and whether (and if so, how) it is possible to combine the two activities (Arksey, 2002; Laczko and Noden, 1992, 1993; Parker, 1990; Phillips, 1995, 1998). Questions have also been raised about the future **supply** of informal carers in the light of the increasing female participation in the labour market, the rising divorce rate, smaller family size, and increased geographical mobility (Evandrou and Winter, 1993; Parker, 1993a; Phillips *et al.*, 2002). Meanwhile, population ageing means that the **demand** for caring is likely to increase.

According to the 2000 GHS, 13 per cent of adults aged between 16 and 64 in **full-time** paid employment were caring for a sick, disabled or elderly person. A higher percentage of women than men in full-time employment were carers (15 per cent compared with 12 per cent respectively). The percentage of people working **part-time** who were carers was 17 per cent, with, again, the incidence being higher for female than for male part-time workers. The incidence of caring was highest of all among the economically inactive, one in five (21 per cent) of whom were spending time caring for someone (Table 2.3). Thus, the economically inactive are disproportionately likely to be carers. However, what is less clear is the extent to which people become economically inactive because they are carers or become carers because they are economically inactive (Arber and Ginn, 1995).

**Table 2.3 Percentage of adults who were carers by economic activity**

<b>Economic activity status</b>	<b>Men</b>	<b>Women</b>	<b>All adults</b>
Working full-time	12	15	13
Working part-time	14	18	17
Unemployed	15	16	15
Economically inactive	17	23	21
All aged 16 to 64	13	18	16

Source: Maher and Green (2002) Table 2.4.

Table 2.4 shows the economic activity status of people aged 16 to 74 in England and Wales in 2001, as revealed by the Census. The data confirm that caring affects participation in the labour market among those whose care-giving extends beyond 20 hours per week (McLaughlin, 1991). The Census data indicate that only about half of carers who were spending between 20 and 49 hours caring per week were in employment in 2001, compared with about six out of ten non-carers. Among those caring for 50 or more hours per week, only three out of ten were in paid employment. Compared with non-carers and those caring for less than 20 hours, carers spending between 20 and 49 hours per week were less likely to be in work and more likely to be looking after the family or home. Those caring for 50 or more hours per week were more likely than those caring for less than that amount or not caring at all to be retired, looking after the home or family, or permanently sick or disabled (Table 2.4).

**Table 2.4 Economic activity by provision of care among people aged 16 to 74\***

	Does not	Provides care		
	provide care	1-19 hours	20-49 hours	50+ hours
	%	%	%	%
<b>Economically active</b>				
Employee or self-employed	62	65	48	29
Unemployed	3	3	4	2
Full-time student	3	1	1	<1
<b>Economically inactive</b>				
Retired	13	16	17	26
Looking after home/family	6	7	18	27
Permanently sick or disabled	5	4	8	11
Other	8	4	5	4
<b>Total<sup>o</sup></b>	100	100	100	100

\* In households.

<sup>o</sup> Totals may not sum to exactly 100 due to rounding.

Source: 2001 Census of England and Wales Table S026.

Thus, the proportion of carers in work falls as hours of work increase across these groups. Difficulty in combining paid work and informal care seems to particularly affect those undertaking substantial hours of caring per week. Among people aged 16 to 74, only half of those providing between 20 and 49 hours per week were employed or self-employed in 2001; as were only three out of ten people providing 50 or more hours per week of care.

There are important gender differences in the extent to which carers are in full-time or part-time work (Arber and Ginn, 1995; Parker, 1990, 1993a, b; Parker and Lawton, 1994). Table 2.5 shows the proportion of carers spending more than 20 hours per week caring who are working full-time or part-time, as revealed by the 2000 GHS. A higher proportion of men than women with substantial caring responsibilities were working (54 per cent compared with 42 per cent).

What is particularly striking from the table, though, is that men were very much more likely than women to be in full-time employment and much less likely to be in part-time employment (Table 2.5). In fact, 87 per cent of male substantial carers in employment in 2000 were working full-time hours compared with only 38 per cent of women. Conversely, 62 per cent of women in work were working part-time but only 13 per cent of men. The fact that women are much more likely than men to work part-time means that they are less able to build up an entitlement to private, if not state, pension schemes, something that is explored later in the chapter.

Analysis of the 1985 and 1990/91 GHS by Arber and Ginn (1995) found that co-resident carers were less likely to be in paid employment than either extra-resident carers or non-carers. However, whereas in the case of co-resident men, it is only their full-time employment rate that is affected, co-resident caring reduces women's participation in both full-time and part-time employment. Meanwhile, extra-resident caring appeared to have no effect on men's employment. Among women, extra-resident caring was associated with a lower rate of full-time employment and a higher rate of part-time employment than non-carers.

**Table 2.5 Percentage of adults spending at least 20 hours per week caring who were working full- or part-time, by gender\***

	Men %	Women %	All adult carers %
Working full-time	47	16	26
Working part-time	7	26	19
All working	54	42	46

\* Adults aged 16 to 64 living in private households.

Source: Maher and Green (2002) Table 4.7.

Multivariate analysis of the same GHS data confirmed that caring was associated with a significant reduction in the probability of employment. The odds of **co-resident** carers being in paid employment were significantly lower than those of non-carers, especially for women. For male co-resident carers, only caring for a spouse or partner had a depressive effect on employment, but for female co-resident carers the effect applied irrespective of the kin relationship. **Extra-resident** caring had no effect on the odds of male carers being in employment, but among women it reduced the odds of being in full-time employment and increased the odds of being in part-time employment relative to non-carers (Arber and Ginn, 1995).

Evandrou (1995) found broadly similar results in her analysis of the 1990/91 GHS. Arber and Ginn (1995: 468) argue that the higher level of part-time work '*probably reflects both selection of such women into the carer role, and the adverse effects of caring on participation in full-time work*'. In other words, the relatively high incidence of part-time working among women can be both a cause and an effect of providing care.

Analysis of the Family Fund database<sup>2</sup> found that parents of severely disabled children are considerably less likely to be working than other parents (Lawton, 1998). Among recent applicants to the Family Fund, 60 per cent of fathers were in paid employment compared with 88 per cent in the general population. The employment rate among fathers with two or more disabled children (51 per cent) was lower than among those with only one disabled child (63 per cent). The employment rate of mothers with disabled children was especially low. Only 15 per cent of mothers with severely disabled children were in paid work compared with 60 per cent of mothers in the general population (Lawton, 1998). Baldwin (1985) and Beresford (1995) also found that the employment rate of mothers of disabled children was very low compared with mothers of non-disabled children. However, the Family Fund database exhibits some bias towards lower income, more disadvantaged families (Lawton, 1998), which may account for some (but probably not all) of the difference in employment rates.

Hirst (1992) found that, after controlling for age, family size and their partners' economic activity status, the mothers of **severely** disabled young adults were less than half as likely to be in work as mothers in the general population.<sup>3</sup> However, mothers with a less than severely disabled young person were just as likely to be in paid work as mothers generally. This indicates that the severity of the care-recipient's impairment is an important factor in determining whether carers are in paid employment.

## 2.5 The impact of care-giving on paid work

Over the last decade there has been a growing literature on the impact of care-giving on paid employment. Care-giving can potentially impact upon work in several main ways (Arber and Ginn, 1995; Evandrou and Winter, 1993). These include giving up work entirely, switching from full-time to part-time work/reducing working hours, and adjusting work commitments around caring responsibilities. In addition, undertaking substantial caring responsibilities can potentially affect work performance (negatively or positively) including productivity.

### 2.5.1 Giving up paid work

The evidence from a variety of qualitative studies is that some carers have to give up paid work because of their caring responsibilities (Lewis and Meredith, 1988) and this is confirmed by evidence from sample surveys. Analysis of the GHS by Arber and Ginn (1995: 449) indicated that giving up work entirely *'is most likely where there*

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<sup>2</sup> The Family Fund is a charity funded by the Government that provides grants to families with severely disabled children.

<sup>3</sup> Information on disability was collected about six activities (mobility, continence, etc) and combined into a four category scale ranging from no problem, through mild and moderate to severe problem.

*are very heavy demands on time, where the care-recipient cannot be left alone for long, or where the care-recipient is expected to need substantial care over a long period'.*

However, the evidence suggests that only a minority of non-employed carers gave up work because of their caring duties. Instead, most working carers manage to combine the two tasks (Glendinning, 1992; Joshi, 1995; Parker, 1990). Thus, secondary analysis of the Retirement Survey – a survey of people in Great Britain aged 55 to 69 in 1988 – found that the large majority of carers reported no effect of caring on their employment situation (Hancock and Jarvis, 1994). Analysis of the same survey by Askham *et al.* (1992) found that, among those currently undertaking caring responsibilities, co-resident carers were more likely than extra-resident carers to have ever left a paid job to undertake caring responsibilities.

In addition to differences between co-resident and extra-resident carers, some studies have identified gender differences in the extent to which people give up paid employment. For example, analysis of the 1988 Retirement Survey found that, among current carers, women were much more likely than men to report having **ever** given up paid work in order to look after a sick, disabled or elderly relative. Thus, 18 per cent of female co-resident carers compared with only ten per cent of male co-resident carers, had ever given up work because of their caring duties. Likewise, ten per cent of female extra-resident carers compared with only two per cent of male extra-resident carers, reported having left a job for this reason (Askham *et al.*, 1992). Meanwhile, analysis of the Labour Force Survey found that, in 1986, 15 per cent of women aged between 50 and 59 years who had left employment in the **previous three years** said they had done so in order to care for a family member. The number of men who had done the same was negligible (Laczko and Phillipson, 1991).

The 1994/95 FWLS asked carers about the effects of caring on their work arrangements. Analysis of this data by Henz (2004) found that, for the majority of first-time carers, taking on caring responsibilities did not cause any changes in their participation in the labour market. In total, 36 per cent of respondents continued to work as before, 34 per cent stayed outside the labour market, and the remaining 30 per cent reported changes in their work arrangements. The most common change was stopping work altogether, which was reported by 15 per cent of all first time carers or half of those carers who said their work arrangements changed (Table 2.6).

The study by Henz (2004) found that the largest significant gender difference in the impact of starting caring on employment was that women were about twice as likely as men to stop work altogether. In addition, men were more likely than women to report that they continued working with no impact on their employment situation, while women are more likely than men to say that they continued not working (Table 2.6).

**Table 2.6 Effects of starting caring on employment situation<sup>1</sup>**

Effect	Male carers	Female carers	All carers
	%	%	%
Stop work	9.0	17.0	14.7 **
Fewer hours	10.5	10.7	10.7
Different type of work	1.8	2.3	2.1
Earn less money	6.0	5.0	5.3
Only certain times during the day	3.3	5.1	4.6
Miss out promotion	2.1	3.4	3.1
No effect – working	46.4	31.9	36.0 **
No effect – not working	30.4	35.8	34.3 *

<sup>1</sup> Data refers to first lifetime caring episode.

Significant gender differences: \*\*  $p < 0.01$ ; \*  $p < 0.1$ .

Source: Henz (2004) Table 2, p863.

Multivariate analysis of the FWLS data by Henz (2004) found that, among women, routine and semi-routine workers were more likely than other employment groups to say they stopped working altogether when they first started caring. Ceasing to work when caring began was also more likely among women working full-time than among women working part-time. Among men, those working in routine and semi-routine jobs were more likely than those in other occupational groups to say that taking on caring duties had no effect on their employment situation. When family and employment circumstances are controlled for, older women were more likely than younger women to leave work altogether (Henz, 2004).

The BHPS also provides insights into the extent to which carers below state pension age have to leave paid employment because of their care-giving responsibilities. For example, cross-sectional analysis of the 1991 BHPS found that, among carers who agreed that family responsibilities had an effect on their employment situation in the **last year**, nine per cent of female and one per cent of male co-resident carers had been required to leave paid employment. Among extra-resident carers, three per cent of females and one per cent of males also said they had given up paid work (Corti *et al.*, 1994). Meanwhile, longitudinal analysis of the BHPS for 1991 to 1996 found that, among people not in employment, 57 per cent of carers compared with 28 per cent of non-carers, said that family commitments prevented them looking for work (Hutton, 2000).

Longitudinal analysis of the BHPS for 1991 to 1996 found that, among those below state pension age, people who take on substantial caring duties were less likely than others to be in paid employment **before** care-giving commenced (Hutton, 2000). This is presumably because people not in work have more time available (or fewer time constraints) to take on substantial caring responsibilities than those who are in paid employment. In addition, it was found that most people did not change their employment status when a caring episode began: after one year of care-giving,

83 per cent were in the same employment status as before. More than half were in paid work before the caring episode began and remained there a year later (Hirst and Hutton, 2000; Hutton, 2000).

There is some evidence that, while the great majority of carers initially remain in work, over time they are more likely to withdraw from the labour market. Thus, analysis of the BHPS for 1991 to 1996 found that, among carers undertaking substantial caring duties of 20 or more hours per week, the proportion in employment fell significantly after the third year of caring (Hutton, 2000; Hirst and Hutton, 2000). In contrast, multivariate analysis of the BHPS for 1991 to 2002 found no evidence that the length of caring spell significantly affected the likelihood of labour market participation (Heitmueller and Inglis, 2004).

### **2.5.2 Moving from full-time to part-time work**

Substantial caring duties are more compatible with part-time than with full-time employment (Joshi, 1995). In this respect it is worth noting that analysis of the BHPS for 1991 to 2002 found that, among people in full-time employment, 47 per cent of carers compared with 39 per cent of non-carers, said they wished to reduce the number of hours they worked (Heitmueller and Inglis, 2004). The same study also found that carers were more likely than non-carers to move from full-time to part-time employment. Longitudinal analysis of the BHPS 1991 to 1996 by Hutton (2000) found that the major adjustment to taking on substantial caring responsibilities is in leaving work or switching from full-time to part-time employment rather than simply reducing the number of hours worked.

It has been argued that men with substantial caring responsibilities are more likely to give up work altogether because they find it more difficult than women to find part-time employment (Parker, 1993a, b; Parker and Lawton, 1994). Certainly, analysis of the BHPS for 1991 to 1996 found that female carers were much more likely than male carers to move from full-time to part-time employment Hutton (2000).

The evidence suggests that the impact of caring on employment is partly dependent upon the household context within which decisions are made. Thus, a qualitative study by Glendinning (1990) found that married women carers were only able to combine caring with the lower earnings associated with part-time work by being dependent on the earnings of a spouse in full-time work. Again, analysis of the Family Resources Survey (FRS) 1995/96 by Madden and Walker (1999) found that higher male earnings were associated with an increase in female care-giving. In other words, women living with better paid men were more likely to be carers than those living with less well paid men.

An alternative to moving from being a full-time to a part-time employee is to reduce hours of work. This could involve giving up overtime working, cutting down hours while remaining largely full-time, or becoming even more part-time. Analysis of data from the FWLS indicates that there is little or no difference in the proportion of men and women reporting that the onset of their first caring episode that led to them

reducing their hours of work (Evandrou and Glaser, 2003; Henz, 2004). However, econometric analysis of the FRS 1995/96 by Madden and Walker (1999) found that, after controlling for other factors, caring had a significant negative effect on women's hours of work, but not on men's. This may be because it is mainly people working **part**-time (rather than full-time) that reduce their hours of work (Henz, 2004) and relatively few men work part-time. At any rate, it seems that part-time jobs may be more flexible (Henz, 2004) in the sense that it may be easier to negotiate reduced hours of work when a job is part-time rather than full-time.

### 2.5.3 Accommodating paid work and care

As well as leaving work or switching from full-time to part-time employment, people can seek to cope with the need to combine work and care by adjusting the content or nature of their work or the conduct of their employment duties. This has been referred to as 'work accommodation' (Stone and Short, 1990, cited in Arber and Ginn, 1995). This broad term can potentially cover a wide range of strategies for combining paid work with substantial caring duties. These responses include:

- changing to a less demanding job;
- moving close to the place of work;
- not applying for better jobs;
- becoming self-employed;
- working different hours;
- using lunchtimes<sup>4</sup>;
- taking time off work;
- using holiday entitlement;
- taking sick leave.

A number of studies have investigated work accommodation by carers. For example, research by the Caring Costs Alliance (1996) found that caring had affected people's ability to work and earn money. This included working different hours, changing jobs, taking casual work only, doing home-based work and becoming self-employed. Some carers were unable to go for promotions and their opportunities to apply for new jobs were limited by their caring responsibilities.

Similarly, analysis of the FWLS 1994/95 (Evandrou and Glaser, 2003) found that two per cent of 'mid-life' carers (women aged 45-59 and men aged 45-64) took up a different type of work as a result of their first or current caring episode, two per cent said they could only work at certain times of the day, and three per cent reported

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<sup>4</sup> Either to keep in touch with the cared-for person or to work and, thereby finish, earlier in the day.

that they had missed out on career opportunities. A survey of Invalid Care Allowance (ICA)<sup>5</sup> recipients and unsuccessful claimants by McLaughlin (1991) found that half of past recipients and/or unsuccessful claimants, and two-thirds of current recipients, said that caring had affected the type of job they could do (in terms of skill level and responsibility). The fact that the figures from the latter study are relatively high probably reflects the fact that recipients of ICA (and its successor, CA) have to devote 35 or more hours per week to caring in order to qualify for the benefit. Hence, their employment is more likely to be affected by caring duties than is the case with people caring for fewer hours per week.

Analysis of the BHPS 1991 found that, among adult carers agreeing that family responsibilities had an effect on their employment situation in the past year, six per cent of female co-resident carers and four per cent of male co-resident carers reported being prevented (i.e. inhibited) from changing jobs, as did three per cent of male extra-resident carers and eight per cent of female extra-resident carers. About one per cent of male and female co-resident carers, two per cent of male extra-resident carers and three per cent of female extra-resident carers reported having to change their job as a result of their family responsibilities (Corti *et al.*, 1994).

A study by Seddon *et al.* (2004) examined carers' strategies for coping with the practical and organisational demands of caring. The main coping strategies reported by carers were to develop flexible routines to enable them to cope with unplanned demands or crises, planning ahead, negotiating help from formal services or informal support networks such as family and friends, and making changes to their employment.

A number of studies have reported that carers often need to use their own holiday entitlement or even go on sick leave in order to cope with caring demands (Laczko and Noden, 1993; Phillips *et al.*, 2002). A study of carers aged 50 and who were over working for two local authorities in England found that, when time off was needed for caring duties, it was more likely to be taken as holiday than as unpaid leave or sickness absence (Mooney *et al.*, 2002).

#### **2.5.4 Coping with emergencies**

Although care-giving is often unremitting, the demands of caring can fluctuate over time, depending upon the nature of the cared-for person's medical condition or needs. In addition, carers may experience unexpected demands or crises, which may result from a change in the situation of the cared-for person or a breakdown in support arrangements for the carer. Dealing with such crises can be particularly problematic for carers in paid employment as they can be difficult to accommodate within the normal working day. For example, the major problem to emerge from qualitative research with carers of older and disabled people was how to respond to unpredictable events (Yeandle *et al.*, 2002).

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<sup>5</sup> ICA is now called Carer's Allowance (CA).

Mooney *et al.* (2002) found that being able to take time off to cope with an emergency was more important to carers than flexible work arrangements. As well as the practical and organisational consequences of crises, working carers may find themselves confronting feelings of guilt, not only about the implications for their attendance or performance at work, but also about the security and well-being of the cared-for person (Seddon *et al.*, 2004).

Coping with a crisis is one of the major areas of concern facing carers of people with a severe mental illness. The mental health of people with mental health problems can fluctuate over time, which places particularly difficult demands on working carers. Although it was not based on a representative sample, the great majority of respondents in a survey of carers of people with a severe mental illness by the National Schizophrenia Fellowship reported that they had experienced a crisis (Hogman and Pearson, 1995).

### **2.5.5 Work performance**

The need to care for a sick, disabled or elderly person can place considerable demands on working carers, causing them psychological stress including feelings of guilt and anxiety (Seddon *et al.*, 2004). Analysis of the BHPS 1991 to 2000 found that carers exhibit higher levels of distress than non-carers and this is particularly true for female carers (Hirst, 2004). The adverse effects on carers include *'lethargy, tiredness and lack of concentration; worry about caring responsibilities at work; and stress brought on by trying to manage the often incompatible roles of employee and carer, each with its own pattern of conflicting demands and expectations'* (Arksey, 2002: 152).

Research has shown that carers worry about the consequences of caring for their work performance, which many of them feel has suffered. Difficulties at work include arriving late and leaving early (Phillips, 1994). Other problems reported by carers include absenteeism, reduced productivity, difficulty in maintaining concentration at work, and interruptions at work due, for example, to phone calls from or about the cared-for person (Seddon *et al.*, 2004). Additional problems at work noted in a review by Phillips (1995) included lack of energy at work, making mistakes due to tiredness, taking long lunch breaks (or having to use the lunch break to catch up on work), re-arranging work schedules, declining to go on training courses. All of these problems have hidden costs for employers (Arksey, 2002; Phillips, 1995).

### **2.5.6 The benefits of working**

Although combining paid work and unpaid caring can cause stress and even ill-health for people with substantial caring responsibilities, it can also provide positive benefits in addition to the income it brings (Arksey, 2002; Kagan *et al.*, 1998; Parker, 1990; Phillips, 1994; Shearn and Todd, 2000). Indeed, many carers report that they enjoy work (Mooney *et al.*, 2002). For example, Yeandle *et al.* (2002) found that, quite apart from the income it brought, the experience of being in work was much

valued by many carers. A qualitative study by Glendinning (1990) found that the carers in full-time employment acknowledged the psychological and social benefits of paid work, not only for themselves, but also for their family. Working can enable carers to avoid social isolation or exclusion (Becker, 2000). A study of carers aged 50 and over by Mooney *et al.* (2002) found that many carers not only enjoyed their work but were very committed to it. It was especially important to women who had returned to the labour market after a break and had begun a new career.

McLaughlin's (1991) study of ICA recipients and unsuccessful applicants found that employed carers strongly felt that work outside the home was valuable. This is because it provided a break from caring or from the cared-for person, facilitated social contact, was a purposeful activity outside of caring, provided an identity separate from that of carer, and financial gain. Similarly, a study of the workforce of a district health authority in the south-east of England found that carers felt work provided a necessary relief from the demands of caring and was important both for self-esteem and for social contact (Rands, 1997). Moreover, going to work can provide a 'legitimate' reason for spending time away from the cared-for person (Seddon *et al.*, 2004) and reduce feelings of guilt about being out of the home.

Various studies have found that employment can provide what amounts to a respite function by providing a break from the demands of caring (Seddon *et al.*, 2004; Shearn and Todd, 2000). Indeed, it appears that being in work can reduce the amount of stress that carers feel. Analysis of the BHPS 1991 to 2000 found that, compared with not working, being in paid employment significantly reduced the odds of reporting high distress levels in both men and women, independently of other factors. It does not appear to make any difference whether carers work full-time or part-time: having a job is associated with measurable psychological health benefits (Hirst, 2003).

## 2.6 Factors affecting decisions about work

The process of becoming a carer may be sudden or gradual (Baldwin, 1995). Either way, the literature indicates that many carers feel they had little choice in becoming a carer. For example, Mooney *et al.* (2002: 26) found that '*Usually carers did not make a decision to care. A decision implies a choice and carers rarely felt they had one*'. Again, Lankshear *et al.* (2000: 6) reported that '*For many carers 'choosing to care' is not an apt description of the situation in which they find themselves. Parents of a disabled child might not see that there is a choice involved. If they do not care for the child who will?*' Lewis *et al.* (1999) found that parents of disabled children felt that not working was not a matter of choice, but the outcome of shortcomings in support services and the lack of affordable and suitable childcare for their children.

Co-resident carers are much less likely to have had any choice in taking on the role of carer than people who are looking after someone who lives elsewhere (Arber and Ginn, 1995). In the absence of formal support services, an alternative to taking on caring responsibilities is to purchase substitute care (Glendinning, 1992). For many

people, however, the cost of substitute care is prohibitively expensive, even if that is an option they would prefer to take. People may take on the role of unpaid carer for a variety of reasons including from a sense of duty, obligation, love or reciprocity (Mooney *et al.*, 2002; Twigg and Atkin, 1994).

Qualitative research has indicated that some people take on the role of carer because of the expectation of others and this is particularly true for women and single people (Lewis and Meridith, 1988). There are strong ideological or cultural pressures on mothers of disabled children to prioritise caring over employment. Mothers said that the assumption that they should be at home and not working is both implicitly and explicitly impressed upon them by service providers (Lewis *et al.*, 1999).

Qualitative research has also found that the attitude of the cared-for person can also be important in the decision of whether to remain in or give up a job. For example, some older people do not approve of their daughter or daughter-in-law working and expected them to be available to care for them (Mooney *et al.*, 2002). Meanwhile, some older people want to be cared for by their family and not by formal services (Twigg, 1998).

Mooney *et al.* (2002) found that a range of factors influenced the decision about whether to remain in work or change their employment status. One factor was financial, namely whether or not they could afford to give up their job. A second was whether or not people enjoyed their job; those who did were much more reluctant to give up work and wanted to hold onto their job if they possibly could. A related factor was stress at work, perhaps caused by intensification of the labour process or other pressures, which made some carers willing to move from full-time to part-time work or give up altogether in order to protect their health. For some people, losing their job or being out of work meant they were available to take on a caring role that prevented them from finding work. Finally, whether or not carers or the care recipient had access to support was also a factor in the decision to stay in, or give up, work.

## 2.7 Workplace policies and practices

Mooney *et al.* (2002) found that most people did not want to leave work altogether; instead they wanted to achieve a reasonable balance between caring and paid employment. The role of the employer can be important in whether carers are able to maintain a viable balance between the two activities.<sup>6</sup>

However, research suggests that most employers have given little or no consideration to the difficulties carers face in trying to combine substantial caring with paid

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<sup>6</sup> The Audit Commission has recently published an extensive review of the literature on carer-friendly employment practices, focusing especially on the public sector (Pickard, 2004).

employment. Public sector organisations and larger employers are more likely to have carer-friendly policies than private sector and smaller employers (Berry-Lound, 1990). In this respect it is important to note that analysis of the BHPS for 1991 to 2002 found that carers in paid work were more likely to work for public sector organisations than private sector ones (Heitmueller and Inglis, 2004).

Although some employers have begun to consider work-life balance issues, they tend to perceive these in terms of childcare rather than informal care (Berry-Lound, 1990; Gilhooly and Redpath, 1997; Hogarth *et al.*, 2001; Phillips, 1995, 1999; Ramcharan and Whittell, 2003). As a result, carers are, at best, only indirect beneficiaries of such policies (Arksey, 2003). Some studies on carers and employment examine together both childcare and informal care for sick, disabled or elderly people, usually with a focus on female carers (e.g., McKie *et al.*, 2001). Yet a number of authors have pointed out that the needs of carers of older people are, to a significant extent different from those of people with childcare responsibilities (Glendinning, 1992) and often different from carers of disabled people below state pension age.

In the first place, people undertaking eldercare are generally older than those bringing up children and, therefore, at a different stage in their employment career and life-cycle. Secondly, many carers of older people do not live in the same household as the care recipient. Thirdly, eldercare is more unpredictable – both in terms of times of the day and duration – than childcare (Laczko and Noden, 1993). Thus, one study of working carers found that *'If the major task for people with childcare responsibilities is to make arrangements that fit a structured timetable determined elsewhere, the major problem for carers of older people and disabled people...is to be able to respond to unpredictable events'* (Yeandle *et al.*, 2002). Fourthly, the condition of chronically sick or disabled care recipients can fluctuate or deteriorate over time, and consequently so too can the demands of caring for them in a way that is not true of ordinary childcare. However, the demands of caring for chronically sick or disabled children are not entirely the same as those involved in eldercare (Kagan *et al.*, 1998).

The research on carers and employment has identified a range of workplace practices that could be described as 'carer-friendly', that is, would help carers to combine care-giving with paid work. These include:

- access to a telephone in private;
- flexible working hours;
- the option of reducing working hours;
- the availability of unpaid leave;
- the ability to work at home (some of the time);
- emergency care;
- the availability of career breaks;
- supportive work colleagues.

A number of studies have found that having access to a telephone, especially one they can use in private, is highly valued by carers who are in paid employment (Laczko and Noden, 1993; Arksey, 2002). They want access to a phone in order, for example, to make care arrangements, speak to the care recipient or contact social services. The increasing use of mobile phones may have reduced the need for access to a phone, but not the need to be able to speak in private.

Flexible working hours include: flexitime, which allows people to vary their start and finish times (within limits), provided they work their contracted hours; a compressed working week, which can enable people to work their contractual hours over a shorter period; and 'banked hours' that enable people to work longer hours in order to save up, or 'bank', hours in order to work reduced hours later on when the need arises. Flexible working is important because it can help carers to fit their hours of work around their caring responsibilities (Phillips, 1995). Being allowed to work at home at least part of the time can also help working carers to combine their job and caring responsibilities (Phillips, 1999). The Work-Life Balance Study found that flexitime, job-shares and part-time working were the most common forms of flexible working available to working carers in 2000. Meanwhile, very few workers believed their employer would allow them to work annualised hours and hardly any were doing so (Hogarth *et al.*, 2001).

Research has found that inflexible working hours are a major barrier to managing work and caring (Kagan *et al.*, 1998, 1999). A staff survey by Wiltshire County Council (2003) found that a substantial minority of carers wanted more flexible working patterns. Most of them said it would be the most important help to enable them to continue working. Another study found that working carers felt that the very fact that flexible working arrangements existed within their organisation (even if they did not in practice make use of them) was itself supportive (Mooney *et al.*, 2002).

However, even where carer-friendly employment practices exist, carers may not necessarily take advantage of them. In the first place, several studies have found a low level of awareness among carers of their employer's policies to support carers. Secondly, it has also been found that some workers are reluctant to reveal their carer status to employers or to take advantage of flexible working arrangements, for fear of being thought of as a weak employee (Arksey, 2002; Lewis *et al.*, 2000). Moreover, there can be tensions between the needs of the organisation and those of the working carer, which may make some line managers reluctant to help carers (Arksey, 2002). Hence, the scope to work flexibly is constrained by the practical needs and demands of the employing organisation (Seddon *et al.*, 2004).

Several studies have found that very few workers are in fact able to work in a flexible manner (Evandrou and Glaser, 2003; Hogarth *et al.*, 2001). It is not always easy to take time off in response to the demands of caring while working. For some carers, it is difficult to work flexible hours because of the nature of the job. However, it has been found that whether or not carers could work flexible hours made little difference to whether caring had an impact on their work. What was really wanted was the ability to take time off at short notice (Mooney *et al.*, 2002).

The ability to take time off in an emergency is important for many carers, where they have to cope with an unexpected event or crisis (Arksey, 2002). A study of carers and employers found that temporarily reduced working hours and shift swapping were seen as very useful ways of helping carers to cope with the unpredictable demands of care-giving (Seddon *et al.*, 2004).

The implementation of flexible employment policies and practices requires a degree of trust between managers and employees. However, research has found that some line managers feel such policies '*could be abused*', with some employees making use of flexible working arrangements and leave entitlements for what they referred to as '*illegitimate reasons*' (Yeandle *et al.*, 2002: 14). Thus, the attitudes of managers and fellow workers can be important factors in whether carers are able and willing to take advantage of flexible working arrangements. Many carers believe that working flexible hours can cause ill-feeling among fellow workers (Seddon *et al.*, 2004), but equally, fellow workers can be supportive (Arksey, 2002). One study found that carers particularly valued female managers for being flexible and understanding towards their needs and circumstances (Rands, 1997). While some carers have sympathetic managers, others have ones that are unwilling or unable to respond positively to carers' circumstances (Arksey, 2002; Kagan *et al.*, 1998).

Reduced working hours, unpaid leave and 'carer breaks' are also practices that can help carers to combine work and care-giving. However, one disadvantage of these options is that they lower the carer's earnings. Thus, a study of carers in two local authorities found that unpaid leave was an option made available to workers in both organisations, but many could not afford financially to take it (Mooney *et al.*, 2002).

## 2.8 Financial consequences of caring

As we have seen, many carers devote substantial amounts of their time each week to providing care for a sick, disabled or elderly relative, neighbour or friend, and this can affect their ability to work. This, in turn, can have adverse implications for their incomes, both in the short- and the long-term. Moreover, it is not just their earnings that may be affected, but also their future pensions.

### 2.8.1 Earnings

Switching from full-time to part-time jobs or otherwise reducing the number of hours they work can help working carers to combine the dual demands of substantial caring responsibilities and paid employment. However, these strategies also generally result in a reduction in earnings. The cost is exacerbated if the rate of pay is also reduced (Joshi, 1995). A number of researchers have investigated whether, and if so to what extent, there is a 'wage penalty' to caring. However, most of the studies are now quite dated and further research is, therefore, required.

A study of ICA recipients and unsuccessful applicants found that the employment earnings of the partners of carers were below the national average earnings (McLaughlin, 1991). Secondary analysis of the 1985 GHS found that the gross weekly earnings of carers were well below those of non-carers. Co-resident carers and people undertaking at least 20 hours care per week had lower hourly earnings than non-carers. However, extra-resident carers had average hourly earnings that were similar to those of non-carers (Evandrou and Winter, 1993). Analysis of the 1990/91 GHS confirmed that carers have a lower average hourly wage rate than non-carers. Male co-resident carers and men caring for more than 50 hours per week had a markedly lower hourly wage rate than non-carers. Male extra-resident carers had a broadly similar wage rate to non-carers. The pattern was similar among women, but the variation was smaller (Evandrou, 1995).

Other econometric analysis of the 1990 GHS also found that the negative effect of informal caring on the hourly wage rate was considerably greater for men than for women (Carmichael and Charles, 2003b). Similarly, Parker and Lawton's (1994) analysis of the 1985 GHS also found that the adverse effect of caring on earnings was greater for male than for female carers. In contrast (and for reasons that are unclear), econometric analysis of the 1995/95 FRS found that being a carer had a negative effect on the wages of women but not of men (Madden and Walker, 1999).

Econometric analysis of female respondents to the 1985 GHS found evidence of a threshold of 20 hours per week at which informal care-giving begins to have an adverse effect on women's wage rates. For women providing 20 or more hours per week, caring reduced the hourly wage rate by around ten per cent (Carmichael and Charles, 1998). Subsequent analysis of the 1990 GHS data on women aged 16 to 59, found that the effect of caring on the wage rate was smaller and less significant among those who were caring for less than ten hours per week (Carmichael and Charles, 2003a). However, these threshold effects are based on surveys that collect categorical data on hours of caring and, therefore, may be artificial.

Heitmueller and Inglis (2004) have recently examined the impact of care-giving on carers' earnings from employment using 12 years' data from the BHPS (1991 to 2002). They found that carers have longer periods of absence from the labour market than non-carers, but *'once employed they have longer spells in the labour market, suggesting that carers are less mobile in general'* (Heitmueller and Inglis, 2004: 7). Being a carer was associated with lower hourly wages when other factors were controlled for. Moreover, the longer the length of the caring spell, the bigger the negative impact on earnings. However, the number of hours care provided per week and the type of cared-for person (parent, child, spouse, etc) did not have a statistically significant effect. This suggests that the number of hours caring and type of cared-for person are more important for the decision whether to participate in the labour market, but do not affect wages rates. Nevertheless, it appears that carers may be *'systematically disadvantaged with respect to pay'* (Heitmueller and Inglis, 2004: 18).

As well as this pooled cross-sectional analysis of the BHPS data, Heitmueller and Inglis (2004) also looked longitudinally at the wage differential between carers and non-carers between 1991 and 2002. They found that the overall gap was negligible in first half of the 1990s, but widened in the second half of the decade and peaked at 14 per cent in 1998. By 2002, the gap was 11 per cent. For men in particular, much of the differential in earnings between carers and non-carers cannot be explained by differences in their characteristics. Interestingly, the gender wage differential that applies to all people in work (men tend to have higher hourly wages than women, even after controlling for other characteristics) is reduced among carers. All of this appears to indicate that men are disproportionately affected by caring responsibilities (Heitmueller and Inglis, 2004).

### 2.8.2 Incomes

It is not just earnings that may be lower as a consequence of becoming a substantial carer, it is also incomes (Baldwin, 1995; Carers National Association, 2000).<sup>7</sup> This is because benefit income does not sufficiently compensate for lower earnings (McLaughlin, 1991; Shearn and Todd, 2000). For example, a survey of ICA recipients and unsuccessful applicants found that carers had a lowered income from reduced or no participation in paid employment. The carers in the survey had lower average personal and household incomes compared with the general population (McLaughlin, 1991, 1993).

Analysis of the 1985 GHS found that the **personal** income of female carers was similar to that of their non-carer peers, but for men the difference was significant and substantial. However, when equivalent **household** incomes were compared, the differences were not so great (Parker and Lawton, 1994). Other analysis of the same dataset found that the average net personal income of carers was lower than that of non-carers and this was especially true for men (Evandrou and Winter, 1993). Analysis of the 1990/91 GHS found that, among men who were caring for 20 or more hours per week, the mean net income (including benefit income) of those in paid work was much lower than that of non-carers; for those not working, mean income was even lower. The pattern among women was similar but the variation was smaller. Co-resident carers were also more likely to be in poverty – defined as having an equivalent disposable income less than 50 per cent of the mean – than non-carers (Evandrou, 1995).

Analysis of the 1988 retirement survey of people aged between 55 and 69 found that the family incomes of people who had cared for ten or more years were considerably lower than those who had cared for less than that amount of time. The analysis also found that caring had an effect on post-caring incomes: former carers

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<sup>7</sup> Econometric analysis of BHPS data for 1991 to 1995 by London Economics found no effect of being either a co-resident or extra-resident carer on incomes. However, it was also unusual in finding no effect on employment status either.

aged 55 to 69 had lower incomes than non-carers (Hancock and Jarvis, 1994). The ICA survey found that ex-carers had substantially lower incomes than non-carers (McLaughlin, 1991).

Thus caring can have a negative financial legacy for ex-carers (McLaughlin, 1993). People who give up work to care and have no income in their own right, can find themselves financially dependent on the care recipient. The fact that entitlement to CA is based on the latter's benefit status (receipt of Attendance Allowance (AA) or Disability Living Allowance (DLA) at the middle or highest rate for personal care) can reinforce the carer's feelings of financial dependency on the care recipient. This dependency can be a source of anxiety for many carers and especially relates to concern about how they will get by if the care recipient moves into a residential or nursing home or dies (Glendinning, 1990).

### **2.8.3 Pensions and retirement**

The financial legacy of caring may also include an adverse effect on pensions. As Evandrou and Glaser (2003) have put it, as well as a 'wage penalty' there may also be a 'pension penalty' to caring, especially for women. Giving up work to care for a sick, disabled or elderly person can reduce the number of years during which carers are building up entitlement to state, occupational or private pensions (Ginn and Arber, 2000). However, there has been relatively little research on the extent to which pension income in practice is reduced as a result of time out of the labour market due to care-giving (Evandrou and Glaser, 2003). Little is also known about the knowledge and attitudes that carers have about pensions or about their planning for retirement.

What is clear is that an interrupted or short working career is likely to have more implications for occupational and private personal pensions than for State Pensions. This is because, in certain defined circumstances, Home Responsibilities Protection (HRP) can provide protection of the State Pension entitlements of some carers. Analysis of the FWLS found that HRP and credits do protect mid-life women's entitlement to the basic State Pension, but their entitlement is only around two-thirds that of men. Meanwhile, members of occupational pension schemes who had stopped work to care had accumulated fewer years of contributions than those who had continued working (Evandrou and Glaser, 2003).

Research on carers aged over 50 found that being able to retire early with a full occupational pension or favourable retirement deal was a significant incentive to leave work in order to undertake caring duties. This applied especially to men, since they were more likely than women to have a continuous employment career and, hence, to have built up a sufficient pension entitlement. In contrast, having an insufficient pension entitlement was an incentive for female carers aged over 50 to stay on in work. However, some carers, in any case, wished to continue working beyond state pension age, particularly if they could work part-time (Mooney *et al.*, 2002).

Analysis of the 1988 Retirement Survey of people in Great Britain aged 55 to 69, found that female former carers who were beyond state pension age were more likely to be in paid work than non-carers, but they worked fewer hours. By contrast, male former carers were less likely to be in paid employment than non-carers (Hancock and Jarvis, 1994). This suggests that some female past, substantial carers may be working beyond state pension age in order to make good the gaps in their pension contributions resulting from their previous care-giving duties.

Analysis of the 1988 Retirement Survey also found that co-resident carers were much more likely than extra-resident carers to say that caring responsibilities had affected their decision to retire. Over a quarter of co-resident carers (26 per cent of men and 29 per cent of women) reported that they had retired early because of their caring responsibilities (Askham *et al.*, 1992). Analysis of the FWLS found that both men and women were more likely than younger age groups to give up work if they took on caring responsibilities close to state pension age (Evandrou and Glaser, 2003).

Analysis of the 1995/96 GHS found that carers (including co-resident carers) who were approaching retirement age – defined as aged 50 or older – were no more likely to say they were retired than non-carers. Among the pre-retirement group, receipt of income from occupational and private pensions was similar between co-resident carers, extra-resident carers and non-carers. *'Thus there is little evidence that carers use pension income to allow them to provide care in the years prior to state retirement age'* (Hutton and Williams, 2000: 16-17).

The same research also found that co-resident carers approaching state pension age were much more likely than extra-resident carers and non-carers to be receiving Incapacity Benefits (IB). They were also more likely to be on Income Support (IS), but no more likely to be getting Unemployment Benefit. This suggests that it is benefit income rather than pension income that enables people to be substantial co-resident carers in the period approaching retirement (Hutton and Williams, 2000).

The ICA study found that retired ex-carers had household incomes that were not dissimilar to those of retired people in the general population (McLaughlin, 1991). However, analysis of the 1988 Retirement Survey found that retired people who had cared for more than ten years had a lower average income than people who had cared for a shorter period than that. This was the case for both men and women (Hancock and Jarvis, 1994). This suggests that it is largely when substantial caring responsibilities endure for a considerable number of years that there are long-term, negative income effects.

## 2.9 Summary of key points

- In Britain there are an estimated 5.6 million adults below state pension age caring for a sick, disabled or elderly person. The majority of these carers are in paid employment or self-employment.
- A significant minority of people with substantial caring responsibilities give up work in order to provide informal care while others, mainly women, move from full-time to part-time work. This can, and does, have implications for their earnings and subsequent pension entitlements, especially if the caring episode lasts for many years.
- The evidence indicates that most carers wish to remain in work and many give up their jobs very reluctantly. Quite apart from the monetary advantages, there are important social and health benefits from going to work.
- Many carers who remain in work struggle to combine the two activities. Combining care with paid work appears to become more difficult once people provide over 20 hours of care per week.
- It is important to recognise the different characteristics and circumstances of carers and not treat them as an homogenous group. For instance, co-resident, rather than extra-resident, carers face the biggest obstacles in coping with their caring responsibilities while holding down a paid job.
- Although there is a wide range of potential carer-friendly employment practices, the literature review suggests that most carers appear to have little access to such practices; and in some cases, feel unable to take advantage of them even where they do exist. Most employers, but especially those in the private sector, have yet to give much consideration to carer-friendly work practices.
- It is apparent that the prime focus of the policy debate about the work-life balance has been on childcare rather than on informal caring for chronically sick, disabled or frail people.

## Part 3

Qualitative research on  
carers' patterns of work  
and decisions about work  
and retirement



# 3 Aims and summary of research methods for interviews and focus groups

## 3.1 Introduction

The data collection undertaken for the study was intended to shed light on carers' and professionals' perspectives about the:

- decisions that carers make about care, work, retirement and pensions and the factors that influence those decisions;
- work and retirement aspirations of carers;
- effectiveness of the support available to carers in enabling them to remain in, or return to, work.

Part 3 (Chapters 4-7) documents the findings from the qualitative research relating to carers' patterns of work, and their decisions about work and retirement. Part 4 (Chapters 8-12) presents the findings about employment and financial support for carers. Part 5 (Chapter 13) looks at the issues that emerged as important or distinctive for different groups of carers.

## 3.2 Summary of methods

The research design involved in-depth interviews with carers, both working and non-working, together with focus groups for front-line professionals who worked directly with carers.

### 3.2.1 Research sites

Both elements of the fieldwork were conducted in four different regions of England, areas specifically chosen to represent four different labour market conditions. The four research sites comprised:

- a high labour demand area (Site 1);
- an inner city area (Site 2);
- a rural area (Site 3);
- a declining industrial area (Site 4).

In addition, the four research sites had to meet other criteria:

- have an integrated Jobcentre Plus office;
- have a well-established carers centre run by the voluntary sector;
- not be an existing Department for Work and Pensions (DWP) research area.

The NOMIS website,<sup>8</sup> which is one section of the Office for National Statistics (ONS) website, was used for the selection of potential research sites. NOMIS contains local authority level labour market statistics, including details of unemployment (per cent of Jobseeker's Allowance (JSA) claimants; GB average = 2.5 per cent) and 'job density' (ratio of jobs per adult resident; average = 0.8 jobs). 'Job density' was used as a proxy measure for high labour demand.

Site 1, the high labour demand area, was in the North West of England. The inner city area, Site 2, was in the East Midlands. Site 3, the rural area, was also situated in the North West. The declining industrial area, Site 4, was located in the North.

See Appendix A for more details of the four research sites.

### 3.2.2 Interviews with carers

In order to achieve a sample of 80 people caring for 20 or more hours per week, an extensive screening strategy was implemented to try to obtain diversity in terms of gender, age, ethnicity and relationship to care recipient. Carers were recruited through a variety of sources, including Carer's Allowances (CA) records, Jobcentre Plus records, social services departments, carers centres, local employers and snowballing. The sample comprised both working and non-working carers, some of whom had taken part in Work Focused Interviews (WFI). Many of the carers taking part in the study were in receipt of CA and/or statutory service provision. However, deliberate efforts were made to recruit a sub-sample of 'unsupported' carers, i.e. carers in receipt of neither statutory carers support services nor CA.<sup>9</sup>

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<sup>8</sup> [www.nomisweb.co.uk](http://www.nomisweb.co.uk)

<sup>9</sup> Some of these carers were in receipt of other welfare benefits.

The final sample comprised 80 carers below state pension age, three of whom had recently stopped caring. The 77 current carers looked after a total of 99 care recipients; some 19 carers were responsible for two or more people. The full sample of 80 contained 58 female carers and 22 male carers. Some 37 female carers and ten male carers were under 55 years of age. Fifteen carers were from ethnic minority communities. A total of 43 carers took part in paid work, either part-time or full-time. Of these, 37 were women and six were men. The majority were paid employees, but there was a small number who were self-employed. Eight of the 37 carers in the sample who were not working had taken early retirement. Nineteen carers were extra-resident and did not live with the person(s) they were looking after; a further seven individuals were both co-resident and extra-resident carers. Caring relationships took many forms including: parents looking after dependent and adult children; adult children looking after elderly parents; partners looking after partners; siblings looking after siblings.

In-depth interviews lasting an average of one hour were conducted with carers. The majority of interviews were face-to-face, although for practical reasons 13 were undertaken by telephone. Care recipients were present during 11 interviews; generally this was a co-decision and by choice, but on rare occasions was unavoidable.

Fuller details of the methods for the interviews with carers, together with profiles of the study sample (Tables A.4 and A.5) and care recipients (Figure A.2) are provided in Appendix A.

### **3.2.3 Focus Groups with front-line professionals**

Focus groups for front-line professionals who worked directly with carers were organised via Jobcentre Plus offices, social services departments and carers centres in the four research sites. The occupational backgrounds of participants included personal advisers for a range of benefits, disability employment advisers and social workers for different client groups and/or based in different settings (including hospital sites). Carers workers taking part in the discussions were employed by carers centres and other voluntary organisations, such as the Alzheimer's Society, CVS, Crossroads - Caring for Carers, the Red Cross, and a mental health project. Participants in one focus group also included two volunteer workers. For ease of reading, all focus group participants from voluntary organisations are referred to throughout the report as 'carers worker' and included under the umbrella term of 'professional(s)'.

The number of staff taking part in the focus groups totalled 59; individual groups contained between three and seven participants. Nine of the 12 groups involved five or more individuals. An outline topic guide had been circulated previously so focus group participants were aware of the areas to be covered in the discussions. The focus groups lasted between 60 and 90 minutes.

More details about the methods for the focus groups with professionals, together with further information about occupational backgrounds, can be found in Appendix A.



# 4 Carers' current patterns of care-giving and working

## 4.1 Introduction

This chapter draws on the data from the interviews with the 80 carers taking part in the research. It starts by outlining participants' patterns of caring, and the care-giving activities carried out by different groups of carers. Next comes information about the work patterns of employed carers, and the adjustments they made to accommodate work. The chapter then looks at the reasons why non-working carers had left paid employment, and their aspirations and views on the likelihood of returning to work in the future, before concluding with a summary of key points.

## 4.2 Patterns of care-giving

Common or generic care-giving activities undertaken to a greater or lesser extent by all carers in the study included:

- help with personal care (e.g. dressing, bathing, toileting);
- help with mobility (e.g. walking, getting in and out of bed);
- nursing tasks (e.g. daily blood checking; changing dressings); giving/supervising medicines;
- escorting to appointments (e.g. General Practitioner (GP), hospital, chiropodist, hairdressers);
- supervision and keeping an eye on the person looked after;
- emotional support;
- keeping the care recipient company;
- practical household tasks (e.g. preparing meals, doing shopping, domestic labour);
- help with financial matters or paperwork.

The evidence indicated that particular activities featured more prominently for some groups of carers than for others within the full range of tasks undertaken on behalf of care recipients, as shown below.

#### **4.2.1 Parent carers<sup>10</sup>**

- Behaviour management.
- Social stimulation.
- Choosing clothing appropriate for the weather or the activities of the day.
- Personal hygiene.
- Constant supervision, especially for those children with no real concept of danger.
- Entertainment and occupying time, especially in school holidays.
- Supervising homework for children who struggle to do things independently.
- Handling money for child.

#### **4.2.2 Spouse carers**

- Decision-making.
- Running the household.
- Emotional support.

#### **4.2.3 Carers of older people**

- Providing company and keeping care recipients' spirits up; reassurance; taking out (for social and/or religious purposes); encouraging independence.
- Personal hygiene.
- Ordering and supervising medication.
- Ensuring proper eating.
- Arranging and escorting to appointments.
- Dealing with finances, paperwork, pensions, correspondence and phone calls.

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<sup>10</sup> The age range of the children looked after by parent carers taking part in the study ranged from four to 37.

#### 4.2.4 Carers of people with mental health problems

- Keeping safe; keeping an eye on.
- Dealing with bizarre and/or aggressive behaviour.
- Personal hygiene.
- Taking medication on time.

#### 4.2.5 Extra-resident carers

- Regular telephone checking, e.g. first thing in the morning and last thing at night.
- Laundry, cleaning, gardening, shopping, small repairs.
- Regular overnight stays, e.g. at weekends.

The practicalities and complexities of caring were compounded for those carers who did not live with the person(s) they were looking after, especially if they had to rely on public transport. Travelling distances between carers' and care recipients' homes varied from less than half a mile to over 80 miles. There were two instances of extra-resident carers looking after two relatives each living in different homes.

There was evidence from the interviews that caring could develop into a '24/7' experience. If carers were not actively involved in some sort of practical caring or household task, then they were providing emotional support or a listening ear. Lack of sleep was a common phenomenon and many carers reported feeling worn out and exhausted, adding to the difficulties of combining work and care. For instance, disturbed nights related to continence problems meant that beds might need changing; if the care recipient was wandering, then carers had to help them back to bed.

Unpredictability, and looking after someone who was well in the morning yet by lunch time could be ill, also made working and caring difficult for carers, who knew that at any moment they might get a telephone call requesting them to return home as quickly as possible. Carers of people with mental health problems often found themselves in this sort of a situation. Real crises arose for this group of carers when their relatives disappeared without any prior warning at all, taking no clothes with them and leaving no clues whatsoever as to where they were heading which, in some examples reported by interviewees, could be up to 200-300 miles away from home. Situations like these required immediate attention and usually involved the police, if only to report a missing person (see Chapter 12). At the risk of stating the obvious, carers who were also working had to negotiate instant time off work to deal with this sort of emergency.

Other potential crisis points related to periods of hospitalisation for the person being looked after, which, in principle, is a period when the support needs of carers can be identified. Whilst hospital discharge is known to be a difficult time (Arksey *et al.*, 1997; Henwood, 1998; Holzhausen, 2001), there was little evidence from the

present study of carers being thrown into crisis and having to make radical decisions when the person they were supporting was discharged back into the community (see Chapter 12).

The evidence about carers' levels of support from close family members, other relatives and friends showed that this ranged from a great deal to nothing. The reasons for lack of support varied, but quite often reflected carers' wishes not to place demands on other people who had responsibilities and commitments of their own. Carers of elderly parents tended to feel it was not appropriate that their own children, more than likely teenagers, should get involved in personal care for grandparents. Likewise, some parent carers believed that other relatives or friends would not be able to cope with their child's challenging behaviour, or would not be able to understand the way their child communicated. Employed carers who had previously relied on their teenage children to keep an eye on a disabled sibling between the end of the school day and the end of the working day lost this source of support when the young person left home for university or to live independently.

### 4.3 Employed carers' working patterns and adjustments

Forty-three carers, six male and 37 female, worked on either a full-time or part-time basis.<sup>11</sup> The number of hours female carers worked varied hugely, ranging from just four hours per week to 37 or more. All six male carers were employed for 30 hours or more per week. Although the numbers are small, there was a larger proportion of male carers not working (72 per cent) compared to female carers (36 per cent). Table A.5 gives a breakdown of the economic activity status for all 80 carers in the study sample.

There was great diversity in the jobs carers undertook. Jobs that were 20 hours or more per week were mainly, but not exclusively, professional; they included health care professionals, and teachers in schools, further education and higher education. Some carers were employed in voluntary organisations, paid work which they had been offered having previously done voluntary work for the same organisation.

In contrast, carers working 15 hours or less per week were more likely to be in low paid service or routine office type work. Examples of these jobs included school kitchen work, care assistant in a residential home and clerical worker.

There was large variation in carers' scope for flexibility in their patterns of work. This tended to relate to the type of job rather than whether it was full- or part-time. Some jobs were more or less completely inflexible, for instance a goods delivery worker who could not vary his working hours or drop off just half his load.

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<sup>11</sup> Two of the 37 female working carers were no longer caring because the person they had looked after had died in the previous few months.

Those carers who could work flexi-time tended to organise their work commitments around their care-giving responsibilities. The patterns that emerged from the interviews included:

- accumulating hours in order to have a day off fairly frequently – time off which was often used for hospital appointments, or in other ways related to care-giving;
- starting and finishing work later in the day, to fit in better with caring routines and appointments;
- working from home.

The issue of flexibility is discussed in more detail in Chapter 11, which focuses on workplace policies and practices.

There was wide evidence to demonstrate that whilst carers did not find it easy to combine work and care, it could be achieved by, for example, obtaining work specifically tailored to meet the requirements of the care-giving situation. Some parent carers of disabled children, for instance, had obtained new jobs where they worked during school hours and term time only. Other carers had got jobs with shift patterns where they worked evenings, nights or at weekends – times that fitted in with caring. Some carers had changed jobs whilst already caring; new jobs tended to involve fewer hours and/or more flexible working hours, be less demanding or closer to home.

#### 4.4 Non-working carers' circumstances

Some 37 carers taking part in the study were not working, 16 men and 21 women.<sup>12</sup> Previous jobs ranged from low paid manual work, such as assembly line worker, machinist and cleaner, to highly qualified professional work, like solicitor and engineer. Some of these jobs allowed for flexible working arrangements, whereas others had little or no scope for flexibility.

An important question is what comes first: leaving work and then taking on a caring role, or taking on a caring role and then leaving work? The evidence from this study supported the first pattern or trajectory. Few of the carers had given up work expressly to take on a full-time caring role. In contrast, other carers had left work some five or ten years before they started caring. This might have been due to reasons beyond their control including, for example: poor health; they were

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<sup>12</sup> One male carer had ceased caring because he had separated from his disabled wife two years ago, nor was he working due to an accident at work some years previously which left him disabled.

employed in a declining industry, had been made redundant and could not get another job; their workplace had relocated and they were not in a position to move. As far as parent carers were concerned, many were not working when they began caring, although, again, there were exceptions, for example those mothers who had returned to work after the birth of older children.

The evidence was mixed about the prospects of non-working carers returning to paid work. For quite a significant number, the prospects of them returning to the labour market were poor and, indeed, there were a few who had no intention of doing so. Some interviewees either explicitly or implicitly indicated that they saw caring as their 'job' and they could be described as 'engulfed' (Twigg and Atkin, 1994) by their caring responsibilities. They had no significant alternative occupation or focus in their lives and felt that caring usefully provided them with a purpose and an identity. Carers in this group were concerned about potentially negative effects on the person cared for if they obtained a job. Some believed they would be letting their relative down, and/or they did not trust anyone else to provide the same quality of care as they could. Other perceived barriers against returning to work included: the potentially negative impact on carers' own (poor) health; having to start reclaiming benefits and the financial unknowns if carers took up employment and it did not work out satisfactorily; the care recipient being unwilling to accept care from an outsider; the care recipient's condition deteriorating; wanting to stay at home whilst the children were still at school.

However, there were at least two cases where the personal relationships of carers looking after disabled partners were deteriorating, and both of these carers were keen to return to the labour force. A handful of carers with a past history of paid employment had taken part in vocational training courses, such as IT or handling and lifting, with a view to future employment (see Chapter 12). Others, however, had done training courses more as stimulation for the mind than to stay attached to the labour market.

Overall, the evidence from the interviews with carers suggested that non-working carers' motivations to return to work were not that strong and were conditional. In order to both work and care, the work itself had to be perceived as 'right' in terms of the number of hours, and level of pay (see Chapters 5 and 8). Older carers' perceptions about age discrimination, the limited number of jobs available in areas where traditional industries were declining, and not having transferable skills served to reduce their levels of motivation.

Overall, the evidence from the interviews with carers suggested that non-working carers' motivations to return to work were not that strong and they were conditional. In order to both work and care, the work itself had to be perceived as 'right' in terms of the number of hours, and level of pay (see Chapters 5 and 8).

Closer analysis of the interview material suggested that it is misleading to think that there is a straightforward association between levels of motivation and length of time away from the labour market. There were a few examples of carers at opposite

ends of the age range, i.e. below 35 and also over 50, who were keen to return to the labour force having finished work within the last 12 months. At the same time, however, re-entry into the labour force for the 30 year old male carer was dependent upon improvements in his wife's medical condition. In complete contrast were two male carers in their late 50s who had not worked for some four or five years. Both admitted they were not particularly interested in seeking work, claiming that at their age they faced age discrimination. There were additional reasons that served to reduce their levels of motivation, for example poor health, not being able to obtain part-time work in their particular field and inappropriate and inflexible day centre hours. Some mothers of disabled and non-disabled children who had not worked for many years because of bringing up a family, nonetheless, talked positively about finding work in the future, a point in time that tended to be linked to when children finished school.

Carers were mindful of the realities of their lives and the constraints they faced, for instance childcare difficulties, no recent job experience, having skills and experience in declining industries, and needing to work full-time hours in order to obtain an income that was the equivalent of welfare benefits. These factors combined together to temper carers' motivations to find work. Interestingly, non-working carers were as, if not more, likely to want to return to work for reasons to do with increasing levels of self-esteem, status and emotional well-being as for monetary gain, suggesting that for some people (higher) financial rewards are not the only inducement.

#### 4.5 Summary of key points

- Carers undertook a wide range of caring activities, some of which were generic whilst others were more specific and tended to reflect the age/condition of the care recipient, or the locus of care.
- Caring that was unpredictable could make combining work and care more challenging.
- Levels of help from close family members, relatives and friends varied, and could not be relied upon. Valuable additional support provided by children ended when they left for university or to live away from home.
- Female carers worked a wide range of hours, from four hours per week to 37 and above. No male carers worked less than 30 hours per week.
- There was evidence that full-time jobs tended to be professional, whereas those under 16 hours per week were more likely to be low paid service or office jobs.
- Scope for flexibility in working patterns varied. Whilst carers did not find it easy to combine work and care, many tried very hard to remain in work as long as

possible by, for instance, obtaining work that fitted in with care-giving responsibilities, reducing their hours or changing to a less demanding job.

- Some non-working carers had already left the labour market some years before they started caring. This was frequently, but not exclusively, because of their own poor health.
- Non-working carers' levels of motivation to return to work tended not to be strong and were conditional on the job being 'right' in terms of hours and earnings.
- Some non-working carers regarded caring as their 'job'.

# 5 Carers' decisions around employment and care-giving

## 5.1 Introduction

This chapter of the report is based on the interviews with carers, and explores their thinking and decision-making around paid work and care-giving. The primary aim is to shed light on the factors that carers take into account when making important decisions about combining work and care, or returning to work either whilst still caring or when the caring situation has changed.

As a preliminary to reporting the influences on carers' decision-making, it is worth drawing attention to two important areas of consensus that emerged from the data. To start with, carers' decisions were not clear-cut, straightforward or discrete 'one-off' events. On the contrary, carers were involved in constant on-going decision-making and review of previous decisions, often in response to external constraints and factors beyond their control. On occasions, changing situations could lead to 'non-decisions' as well as decisions. Frequently, decisions were reached in conjunction with the care recipient and/or other family members, rather than by the carer alone.

Crucially, for many carers, making decisions and planning ahead was made more difficult because there were so many unknown factors, such as the:

- carer's own health;
- care recipient's health and/or life span; consultants unable to give a prognosis;
- levels of support needed after critical transition points, such as discharge from hospital or changing from, say, children's services to adult services;
- carer's long-term job security, especially if they worked in declining industries.

Parent carers, in particular, had to try to think ahead and take account of key transitions such as moving from junior school to secondary school; for example, it could be hard to predict how easily their child would settle down. Changing from secondary school to training college was another critical time. In these instances, uncertainties that had the potential to impact on decisions relating to paid work included: how many days per week the young adult would spend at training college (or involved in other activities); hours of attendance; or whether transport was provided. As they reached 16 years of age, there would also be the shift from children's to adult social care and health services. In sum, it could be very difficult for many carers to plan ahead or make decisions, especially if any decision-making came at fraught or unsettling times, or involved systems that carers did not understand or know very much about.

In order to try to tease out any issues related to levels and patterns of work and/or caring that might influence carers' decisions, the interview material was examined in terms of carers' economic activity. This chapter starts by looking first at those carers who worked 30 hours per week and over, secondly at carers working 16 to 29 hours and thirdly at carers working 15 hours or less. Finally, the evidence relating to carers who were not in paid employment is reported. Some of the issues touched on below are looked at in more depth in later chapters of the report.

## 5.2 Factors influencing the decisions of carers working 30 hours or more per week

There were 18 carers (including one former carer) in the study who worked for 30 or more hours per week. The majority were caring for between 20 and 34 hours, in some cases, but not all, with help from social services and/or family and friends. Whilst combining work and care-giving was generally perceived to be stressful and demanding, nonetheless there was a consensus that giving up work was not an option.

The factors that emerged from the interviews as having an influence on previous and on-going decision-making about working and caring are grouped together below. They were wide-ranging and not necessarily held by all carers, or prioritised in the same way across the group as a whole. Likewise, some appear contradictory: for instance, those carers who indicated they were committed to their career, yet at the same time emphasised how the person they were looking after came first.

### 5.2.1 Financial factors

#### *Household incomes and mortgages*

The decisions made by many carers who worked 30 or more hours per week centred around finances, in particular the necessity to earn high salaries. This was especially so in those households where the carer was the main breadwinner, either because they looked after a partner who had had to give up work because of their illness or disability or because they were divorced or separated. Carers who were still buying their own homes emphasised the need to pay off large mortgages as they did not want to risk losing their homes.<sup>13</sup> For a few carers, a further financial pressure related to supporting children through university.

#### *Pensions*

Interviewees, especially female carers (often divorced or separated, but not necessarily), were concerned about their levels of income once they had retired from work, and decision-making tended to reflect the perceived need to continue working in order to secure as valuable a pension as possible. This was particularly the case for those women who had not paid enough national insurance contributions, and so were not eligible for a full basic State Pension.

#### *Welfare benefits*

Generally, welfare benefits did not act as an incentive in any decision-making. Carers talked about the low levels of Carer's Allowance (CA) and other benefits. There was a consensus amongst interviewees that it would not be possible to give up paid work and maintain the standard of living they were used to, given the financial responsibilities identified above.

### 5.2.2 Health and well-being

#### *Health-related issues*

Paradoxically, interviewees tended to regard work an important factor in maintaining emotional well-being and 'sanity', whilst acknowledging that there could be negative impacts on their health at the same time. Some carers had decided to continue in the same job as they suspected that learning a new job, which might involve retraining, could be (too) stressful. In complete contrast, a few others had successfully obtained new jobs with more flexible working hours to try to reduce the demands placed on them.

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<sup>13</sup> The only welfare benefits that provide help towards mortgages are IS and income-based Jobseeker's Allowance which may include an amount for mortgage interest for eligible recipients.

### 5.2.3 Personal factors

#### *Identity*

Carers chose to take part in paid employment as a way to maintain a different identity. They did not want to be perceived as 'just a carer'; instead, they wanted something that gave them some status in their own eyes, as well as the eyes of friends and colleagues. One interviewee employed in the National Health Service (NHS), who for the last 15 years had looked after her husband with mental health problems, had this to say:

*'What's really got me through it is being at work. It's been something that belongs to me. Nobody can take that away from me...it's the only thing that's kept me sane really...the only thing that really I have to look forward to is going to work.'*

(Female carer, employed, 55-64)

#### *Freedom and independence*

Carers wanted to have freedom and independence. Paid employment was seen as the way to achieve a 'life of their own'. As one male carer stated bluntly:

*'No job, no money. No freedom. You need money to buy freedom, to go places. I enjoy travelling. My job comes first. I've got to go out to work, regardless of the caring for my mother.'*

(Male carer, employed, 45-54)

#### *Commitment to career*

There was evidence that some carers in professional jobs were committed to their careers; they were unwilling to lose the investment they had built up over their working life, especially those who also enjoyed work. Furthermore, people looking after elderly relatives tended to be unwilling to make radical changes to their workplace situation, given that the caring situation would inevitably change at some point in the future. Reinforcing the above point about self-identify, there was a sense in which carers in this group thought of themselves more as 'workers' than 'carers'.

### 5.2.4 Work-related issues

#### *Supportive employers*

Carers valued supportive, and understanding, managers and colleagues. Those people who had been in post for many years – and some interviewees had been with the same organisation for well over 20 years – had built up good working relationships and knew where they stood in terms of formal and informal flexibility (see Chapter 11). In any decision-making about changing jobs, carers reported having to weigh up whether contracts of employment, or opportunities for flexible working hours, would make them better or worse off. Other factors that carers took

into account related to perceived age discrimination and not having transferable skills. In fact, hardly anyone working 30 hours and over had changed jobs in the recent past; the majority preferred to continue with existing employers (although not necessarily in the same job).

### *Working hours*

Carers thought carefully about what hours they could work in order to accommodate their caring activities. In practice, this meant carers changed their patterns of working, took advantage of opportunities to work at home, and/or reduced the number of hours they worked. There was evidence to suggest that carers tended to shy away from jobs that involved unsociable hours or long shifts.

## **5.2.5 Support services**

### *General service provision*

Social services support was important in enabling some (but not all) carers in this group to combine work and care (see Chapter 9). They had made the decision that support such as paid care workers, day care services, short breaks or other forms of statutory help could substitute for their own presence when they were at work. Concerns about the quality or reliability of services, or changes to the caring situation, might prompt carers to ask for a review of the care package.

### *Childcare provision*

Parent carers stressed how their ability to work was partly dependent on the availability of good quality, affordable childcare for disabled children (and also non-disabled children) (see Chapter 13).

## **5.2.6 Factors related to the care recipient**

- **Commitment to care recipient.** Despite wanting to carry on working and further progress in their careers, carers in this group emphasised how keen they were to take on, or continue, care-giving for as long as it was reasonably possible to combine the two roles. Those looking after elderly parents saw it as a way to reciprocate being looked after when they were growing up, and/or for the support they received when they had young families themselves. They were under no illusions about the availability of support and/or that there could be negative impacts financially when making decisions about caring. One interviewee employed in higher education commented:

*'I was certain that I wanted to look after my mum, my husband was supportive of that...he encouraged me...we just took it on the chin and decided, you know, we had to do it. So we just had to fund it ourselves somehow and if the pension suffers, it suffers.'*

(Female former carer, 55-64)

Parent carers were totally committed to looking after their children and ensuring they had a good education and a well-supported transition to independent living if that was feasible.

### 5.2.7 Distance issues

#### *Distances and travelling times*

As indicated in the last chapter, for extra-resident carers (or carers who lived a long way from work) distance and the length of time spent travelling was a real issue. Typical measures to address work and home mobility and distance dilemmas included moving house or transferring from one branch of the organisation to another. Steps taken by those carers who wanted to live closer to the person they looked after could result in additional financial pressures especially if they involved, as they did in one case, taking out a new mortgage to buy a neighbouring flat for elderly parents.

## 5.3 Factors influencing the decisions of carers working 16-29 hours per week

Fourteen carers (including one former carer) who were interviewed for the study worked between 16 and 29 hours per week. They were generally working these part-time hours when their caring began. In comparison with carers working 30 hours and above, carers in this group tended to have heavier care-giving responsibilities. For example, six estimated that they cared for a minimum of 50 hours per week irrespective of any help from outside sources. Carers reported that combining work and care-giving was stressful, and some were seriously considering giving up work at some time in the future to take on a full-time caring role. They saw this as the only feasible solution to reduce the pressure they were under, in part because they believed there was little, if any, scope to make changes in their work situation. Generally, their employers were fully aware of their care-giving responsibilities, and accommodated them to the best of their ability. Some interviewees were in jobs, for example, where the hours just could not be reduced any further and/or they job-shared, so any decrease in hours would have implications in terms of the job-share arrangement.

Some of the factors that emerged from the interview material as impacting on decision-making about working and caring were similar to those reported for carers working 30 or more hours per week, and for the sake of brevity they will not be repeated again. However, the priorities of carers working between 16 and 29 hours each week tended to be somewhat different in relation to financial factors, health and well-being, and personal factors. These are outlined below, under the same main headings as used earlier.

### 5.3.1 Financial factors

#### *Household income and mortgages*

Whilst money was still important, the evidence indicated that it was somewhat less of a driving force for this group of carers, even for those who were the main breadwinners because of divorce. For example, interviewees' comments suggested they were prepared to reduce the standard of living to which they had become accustomed if they felt they would gain in other ways, in terms of their own health, say, or not having to hold down a demanding job. A typical comment was '*I don't need any more money, I'm not money driven as long as I've got enough.*' ([divorced] Female carer, employed, 45-54). And whilst the issue of paying off a mortgage was raised, there were carers in this group who were renting property so did not have the perceived financial pressure of house purchase.

#### *Pensions*

Some carers were fully aware that their pension prospects were poor. Even so, carers indicated that they were prepared, at some point in the future, to make the decision to give up work to care full-time, especially if they felt they could gain in other ways, for example in relation to their own health.

#### *Welfare benefits*

One interviewee made the point that she wanted to work no more than 16 hours and/or earn above a certain amount of money, as she did not want to jeopardise what she referred to as 'family credit' for her daughter.

### 5.3.2 Health and well-being

#### *Health-related issues*

The evidence, as indicated above, demonstrated that carers working between 16 and 19 hours were concerned about their own health. Some interviewees strongly believed that maintaining a good level of health was more important than working, especially if they found their job was stressful. There were examples of carers who had quit work because they felt their health was deteriorating, but had since returned to the labour market, to jobs with fewer hours, that were less demanding and/or that fitted in better with caring responsibilities – in essence, jobs that they felt would be less detrimental to their health and well-being. As one carer said during her interview for the study:

*'I don't regret the decision [to leave work] and actually, if I'm totally honest, I suppose in some ways I feel...happier that I haven't got this great stressful position, taking phone calls all the time and having to go to work. I actually feel I go and do my little job [at the office], come home at night, and I may not have much money in the bank but I feel a lot better for it.'*

(Female carer, employed, 45-54)

### 5.3.3 Personal factors

#### *Commitment to career*

A common theme to emerge from this group of carers was that they did not show an unduly strong commitment to their career or their jobs, which were often described as 'demanding', 'pressurised' and 'stressful'. Irrespective of past working histories, the attitudes, conduct and identity of carers in this group were (now) more in line with those of 'carers' than 'workers'. As just evidenced above, carers prioritised their health above work.

## 5.4 Factors influencing the decisions of carers working below 16 hours per week

Eleven interviewees worked less than 16 hours per week, in jobs such as school dinner lady and clerical worker. Although five of the 11 carers estimated that they spent over 50 hours per week caring, balancing work and care tended not to be perceived as particularly stressful. This might reflect the fact that the number of hours worked was low, four hours per week in one case.

Working patterns for carers employed for less than 16 hours per week varied. Some mothers of disabled children had been in low paid jobs of one sort or another for most of their working lives, taking jobs that fitted in with school or day care centre hours. In contrast, a few female parent carers who had previously worked in managerial or professional jobs were currently in jobs for which they were overqualified and which they found boring. However, they were the only ones they could find to fit in with school hours, transport and/or the earnings threshold for CA (see Chapter 10).

The influences on decision-making that carers highlighted in their interviews were similar to those reported in the previous two sections of the chapter. However, there was less of an emphasis on the impact on carers' own health of holding down stressful jobs whilst caring, and more of an emphasis on the financial restrictions on earnings of welfare benefits. The ability to work was also tied in with finding a job that fitted in with caring responsibilities and other constraints.

### 5.4.1 Financial factors

#### *Household income and mortgages*

Household incomes for carers in this group were relatively low, but there was a consensus that caring and families came first. As a consequence, any paid work had to fit within the constraints of care-giving.

#### *Pensions*

There was little evidence from the interviews to suggest that concerns about retirement incomes and pension provisions influenced carers' decisions about work.

### *Welfare benefits*

Carers in this group commonly flagged up how the CA earnings limit influenced their decisions about paid work (see Chapter 10). This was to ensure that they did not inadvertently earn over the threshold, which could in turn jeopardise not only CA but also other benefits such as Housing Benefit (HB) and Council Tax Benefit (CTB).

## **5.4.2 Personal factors**

### *Freedom and independence*

Carers in this group had heavy caring responsibilities, which for some had already lasted a considerable number of years. Not surprisingly, some interviewees indicated that having contacts and interests outside the home were important, in some cases, more important than the actual wages they were earning. One female carer who worked six hours at the weekend in a residential home explained it like this:

*'It's just having that little bit of freedom for yourself... I know the children are at school during the week...but ...it's just one day a week where I have that little bit of freedom to do something for myself without the children, without my husband and...I think sometimes it's what you need...[the money's] not important, that's not the reason why I got that little job.'*

(Female carer, employed, 25-34)

## **5.4.3 Work-related issues**

### *Finding the 'right' job*

The evidence showed first that finding the right job that fitted in with caring responsibilities was important for carers in this group, and secondly that this was not an easy task. Different carers had different priorities but the following quote is typical of the type of requirements that carers were trying to meet:

*'I'd looked for a long time for a job that I felt ... I could perhaps manage ... I needed something where I didn't have to work nights, I couldn't work nights, it had to be reasonably near, it couldn't really be any more than two days a week and it had to be sort of hours that I could sort of work around, fairly flexible, you know.'*

(Female carer, employed, 45-54)

Carers had to compromise and some were doing jobs they found boring or physically demanding or just not what they wanted to do. An interviewee currently working as a school dinner lady had this to say:

*'It's been soul destroying because I'm an office person. I've learnt a lot and I'm grateful for what I learnt, but it's not my sort of job and I frequently used to stonk around the playground saying to children 'I hate this job, I'm going to leave this job, it's not my kind of a job'.'*

(Female carer, employed, 45-54)

## 5.5 Factors influencing the decisions of non-working carers

Thirty-seven carers, including one former carer, were not taking part in any form of paid work although some were involved in voluntary work. The interviews made clear that decisions to quit work might well have come about as the result of a constellation of factors that just happened to coincide. An example here was a carer who decided to quit work at a time when he was self-employed but his business was failing, his father was terminally ill with cancer and he himself was suffering from severe depression. As noted earlier (see Chapter 4), most non-working carers had low levels of motivation regarding a return to work either whilst still caring or after caring ceased.

To try to unpack levels of care-giving responsibilities and their impact on work-related decisions, we initially scrutinised the relevant data according to number of hours of care-giving per week: 50 hours and over; 35-49 hours; 20-34 hours; and 1-19 hours. In the event, very similar issues influenced non-working carers' decisions irrespective of levels of caring, so what follows does not differentiate between carers in this way.

### 5.5.1 Financial factors

#### *Household incomes*

Issues related to money played an important role in decision-making, although possibly not to the extent that might have been expected. This might have been related to the fact that before quitting work completely some carers had previously worked part-time hours only, so from that point of view were already used to living on a reduced income. There were examples of inheritances being used to provide alternative regular incomes, for example one parent carer who was not thinking of returning to the labour market had used the property/money her mother had left her when she died to invest in property, which she rented out.

#### *Pensions*

Some consideration was given to the impact of leaving work on their future provision for retirement. In the main, however, a pension was not seen as a crucial enough motivating factor to warrant working. Non-working carers saw dealing with day-to-day financial (and other) pressures as more important than thinking about financial provisions that would fund their future retirement. One or two carers commented that they might not live to see their retirement; others indicated that whilst they were worried about how they would manage financially, at the same time they felt impotent to do anything about it.

### *Welfare benefits*

Generally, carers were in receipt of CA. Not all of them were aware of the benefit at the time of leaving work, though, so for some people it did not feature strongly in any decision-making. Those who did know about the benefit, and who decided to leave work in anticipation of claiming it, knew they were taking a risk as there was no guarantee that their application would be successful.

## **5.5.2 Health and well-being**

### *Health-related issues*

There was evidence from the interviews with non-working carers that matters relating to health and well-being influenced decisions about whether or not to work. Many carers experienced poor health themselves and they wanted to try to improve their own physical and mental health status. They emphasised just how difficult it was to combine work and care-giving, and that they did not have enough time. Interviewees drew attention to the intensity of caring, and the emotional stress of worrying about how the care recipient was when they were not there to look after them, especially if the illness and/or care recipient's behaviour was unpredictable. There was a trade-off here, though, as some interviewees acknowledged how the social aspects, outside interests and other benefits attached to going out to work were important to maintaining their own mental well-being. At the same time, however, carers wanted to prevent further deterioration in their physical health and increased levels of stress, which they believed were linked to the difficulties of trying to combine work and care.

## **5.5.3 Work-related issues**

### *Flexibility*

Non-working carers claimed that however supportive employers were, in practice they generally could not provide the high degree of flexibility needed. This perception tended to be held by those carers whose caring was unpredictable and who might suddenly have to rush home at a moment's notice, or carers who had to attend a lot of hospital and other appointments with the person they were looking after. This belief negatively influenced decisions about (re)entering paid work.

### *Reliability*

In a related vein, carers expressed the view that their caring situation was likely to make them unreliable workers, an opinion which reinforced some carers' inclinations not to return to work.

### *Working hours*

The number of hours carers could work affected their decisions about whether or not to try to obtain a job. For instance, some carers said that it was not financially worthwhile for them to work part-time yet their care-giving responsibilities were such that they were unable to work full-time.

### *Retirement/redundancy packages*

Employers wanting to make changes to the workforce had the potential to influence carers' decisions. For example, a small number of carers had taken advantage of good retirement or redundancy packages, which coincidentally were on offer at a time when balancing work and care was becoming increasingly difficult.

#### **5.5.4 Support services**

##### *General service provision*

Charges influenced whether or not carers (or care recipients) accepted care services that were available and offered. If care recipients did not like respite care or day care, which had to be paid for, then some carers decided to stop using the service.

#### **5.5.5 Factors related to the care recipient**

##### *Care recipients' wishes and needs*

A common pattern to emerge was that the wishes and/or needs of care recipients influenced carers' decisions about working and caring. This was especially the case in relation to alternative care from statutory services to cover the carer's absence if they found a job. Some carers emphasised how the person they were looking after was unwilling to accept help – particularly personal care – from people they did not know and/or did not want strangers in the house. At the same time, carers clearly felt a moral responsibility towards the person supported. They talked in terms of caring being the 'right thing to do' and that 'the family comes first'.

#### **5.5.6 Distance issues**

##### *Distances and travelling time*

Distance between work and home was an issue for some carers, and had implications for job mobility. Carers tended to see jobs that involved travelling, or which might take over 30 minutes to get home, as unsuitable and not 'right'.

## **5.6 Summary of key points**

- A complex interplay of factors influenced carers' thinking and decisions about work and caring. Generally, no single factor dominated decisions; instead, they were the result of combinations or clusters of factors (sometimes contradictory) and made in response to external constraints. Decisions (and non-decisions) were constantly under review, and not discrete 'one-off' events.
- Uncertainties and unknown factors made planning and decision-making around work (and retirement) even more complicated.
- Generally, carers working 30 or more hours per week did not want to give up work and their decisions focused on how best to accommodate care-giving whilst working.

- Carers' decisions about work and caring were subject to a wide range of influences, principally: financial factors; their own physical and mental health; personal factors; work-related issues; support services; issues related to the person looked after; distances and travelling. The relative importance of these factors varied according to whether or not carers were working, and how many hours per week they worked.
- Carers working 30 or more hours per week were primarily motivated by financial reasons (including wanting full pensions and/or to maintain current lifestyles). In addition, they tended to be committed to their careers and were keen to maintain a professional identity.
- The decisions of carers working less than 30 hours per week reflected reduced concerns about financial matters (although this did not necessarily mean they were better off), and the importance of maintaining their own health.
- Carers working less than 16 hours per week made decisions about work and care that were influenced by the constraints of care-giving and/or the financial restrictions of CA.
- Many non-working carers experienced poor health themselves. These health problems, together with other factors (such as lack of financial motivation and the perception that employers could not provide the flexibility they needed to work and care) tended to inhibit serious considerations of any return to the labour market either whilst still caring or after caring ceased.
- Carers' perceptions of their own health and well-being were very important factors in decisions about whether or not to work and if so, how many hours per week to work.



# 6 Professionals' views about carers and work

## 6.1 Introduction

This chapter of the report draws on the evidence generated in the 12 focus groups with front-line professionals. As detailed in Appendix A, the 59 professionals worked primarily in Jobcentre Plus offices, social services departments and carers centres. In addition, there were also a small number of carers workers from voluntary organisations involved with carers. The observations and comments that participants made in the focus groups were founded on their professional experience and knowledge of carers. Carers workers from carers centres and other organisations, for example, were involved with carers on a daily basis for a wide range of issues, which could include giving information and advice about paid employment. Social services practitioners undertook carers' assessments, which again offered the opportunity to discuss work-related matters, and/or saw carers at the same time as they assessed service users. Personal advisers from Jobcentre Plus had the lowest levels of contact with carers, conducting around ten or twelve Work Focused Interviews (WFI) with carers per month, following an application for Carer's Allowance (CA) or other welfare benefit. Some professionals, for instance a social services planning and performance manager, had limited direct contact with carers but instead were more involved in matters directly relevant to carers via forums or consultations. At the same time as being involved with carers in a professional capacity, some staff also had personal experience of care-giving – in some cases, for many years – for both disabled children and frail elderly parents.

The first point to make is that professionals from all three occupational backgrounds were aware of the main tasks and activities involved in care-giving, and how these responsibilities could restrict carers' ability to take part in paid work. However, it is reasonable to say that personal advisers from Jobcentre Plus found it somewhat less easy to distinguish the differences in circumstances, needs and constraints of different groups of carers (e.g. parent carers of disabled children, carers of people with mental health problems and so on) than did the other two professional groups.

This chapter starts by documenting front-line professionals' perceptions of carers' attitudes to work and its importance to them, as a preliminary to a discussion about the factors that were seen to impact on carers' decisions. This is followed by a short section giving professionals' views about Department for Work and Pensions (DWP) initiatives designed to encourage carers to take part in paid work. Some of the issues reported are very similar to those documented in the last chapter reporting on carers' decisions around employment and care-giving, albeit this time seen from the perspective of professionals rather than carers. In the interests of continuity, the same headings that were used in Chapter 5 are used in this chapter.

## 6.2 Views on carers' attitudes to work

A commonly held view was that caring situations were all individual, and that each carer's attitude towards work and needs for support was unique. There was some agreement that carers who were already in work would do all they could to continue in the labour market. A typical way to do this was for carers to take jobs that were poorly paid but on the other hand had very flexible hours, for instance café or bar work. Staff in the rural area believed that there were opportunities for carers to create a 'portfolio' of jobs, that together added up to a reasonable number of hours. Other social services practitioners believed that continuing in paid employment was important for those carers in their late 40s and 50s, who were coming up to retirement and had concerns about pensions and how they might manage financially. Rather than being unreliable workers, carers with understanding and sympathetic employers were thought to be a real asset to the workforce, as they tended to want to give a lot back because they were so grateful. A small number of examples were given of carers who were self-employed, a work status which gave them sufficient freedom to combine work and care reasonably satisfactorily.

Professionals felt that work was much less a priority for lone parents with additional care-giving responsibilities, and carers of people with mental health problems or other fluctuating/unpredictable conditions. Likewise, staff felt that work was not seen as important by carers who left school with no qualifications and/or had never worked but had somehow 'slipped' into a caring role which, over time, had become their 'job'. Jobcentre Plus personal advisers in one research area pointed out that they were now seeing the third generation of families in receipt of benefits, the implication being that for these families the 'normal' situation was not working rather than working.

A number of focus group participants claimed that there was a direct relationship between levels of care and attitudes to employment. Their argument was that if the care recipient had low levels of care needs, then the carer was generally more than willing to undertake paid work. As levels of care needs grew, the carer became increasingly concerned about risks and safety issues related to leaving the care recipient at home, especially where social services and other formal support was deemed poor. Gradually, carers reached a point where they started to consider

giving up work. As professionals pointed out, if carers did quit work, they then entered a situation with no known end point, which made decision-making yet more problematic.

Professionals from all backgrounds cited similar reasons to explain why (continuing in) employment was important for carers. Paid work:

- helped carers financially, both now and in the future, and was particularly important for those carers with a mortgage;
- gave carers a 'sanity' break from the caring situation;
- was a social occasion that offered a sense of normality and the opportunity to talk to non-carers about non-caring matters;
- offered intellectual stimulation;
- helped maintain levels of confidence;
- provided carers with an identity in their own right;
- helped carers develop, and sustain, a career path;
- helped to pay for relatives' care either currently or in the future (for instance top-up fees for residential care).

In contrast, there were professionals from all three occupational backgrounds whose experiences had led them to believe that paid work was not a primary concern of carers. They explained this attitude in terms of carers':

- strong family commitment and/or feelings of duty;
- inability to see beyond the caring role;
- desire for the care recipient to be well looked after;
- lack of time due to caring and other family responsibilities.

Some professionals held the view that whilst carers might talk positively about wanting to (return to) work, in reality they perceived too many barriers and it was too complicated especially in relation to benefits and organising service provision. A number of examples were provided by carers workers of unsuccessful attempts by carers to return to work, including a lone mother who was keen to return to the labour market and had twice started a university degree course. Each time she had to finish it because her son was excluded on a permanent basis from different educational placements without any warning whatsoever.

A small number of focus group participants pointed out that some carers who were unwilling to take part in paid work instead took on active voluntary roles. Rather than be seen as unreliable employees and feeling guilty about letting colleagues down, voluntary work gave carers a degree of freedom if difficulties arose relating to the caring situation and they could not get into work one day, or they had to attend hospital or doctor's appointments. It also gave them some status and a feeling of worth.

## 6.3 Perceptions of factors influencing carers' decision-making

Discussions in the focus groups covered professionals' perceptions of the issues that influenced carers' decisions. As will be seen, there is a good deal of similarity between the factors that carers identified (see previous chapter) and the ones that professionals commented on.

### 6.3.1 Financial factors

All groups of professionals thought that many carers were confused by the benefit system. The prospect of losing their benefits was of paramount concern, and central to non-working carers' decision-making. Even with the results of better-off-in-work calculations, some focus group participants stated that they found it very difficult to convince carers that they would not be worse off by starting work. Work had to pay, in other words the financial rewards of employment had to be worthwhile. One professional (now working for social services) who was also a carer, had returned to work a number of years ago. She made the point that at the time she re-entered the labour force she needed a job with a salary of at least £16,000 per annum to match the full package of benefits that she received.

### 6.3.2 Health and well-being

Focus group participants recognised that many carers were in poor health themselves, which could in turn be compounded by disturbed and/or sleepless nights, all of which influenced decisions about whether or not to work.

### 6.3.3 Personal factors

Views were mixed about the influence of age on decisions about working (see Chapter 13). As just noted, some professionals felt that carers who were drawing closer to state pension age were motivated to work to help improve their retirement income. However, a contradictory view was that carers in their 50s were less motivated to work, especially if they had been out of the labour force for a long time. For instance, a social services practitioner made the point that parents in their 50s who had not worked for 20 or 30 years because of caring for a child with learning disabilities tended to have few work-related aspirations.

### 6.3.4 Work-related issues

Professionals identified a wide range of work-related issues that they believed impacted on carers' decisions about combining work and care, or about returning to work when the caring situation changed. These included:

- not having up-to-date skills; carers' belief that they did not possess skills that employers wanted; fear of new technology;
- anxieties about being unreliable workers;

- not knowing how to deal with unexpected emergencies and/or regular hospital or doctor's appointments;
- being constantly telephoned by schools and asked to deal with a child's challenging behavioural problems;
- uncertainties about how much flexibility employers could offer.

On a more positive note, focus group participants believed that the wish to be in a different environment and meet other people prompted decisions to combine work and care.

Jobcentre Plus personal advisers were aware that in order to combine work and care, carers needed to find the right sort of job with particular characteristics: that was for a limited number of hours; that fitted in with caring routines; that was flexible and able to accommodate doctor's or hospital appointments; that was close to home so involved little travelling; of limited pressure (see Chapter 5). Whilst personal advisers believed that they could find this sort of work for carers because the labour market was changing, they also thought that many carers believed that the sort of jobs they could combine with caring did not really exist.

Some personal advisers held the view that there were carers keen to work but felt that they could not commit themselves. Others took the opposite view, arguing that some carers used their care-giving responsibilities as a reason for not working; for them, it was preferable to be in receipt of CA rather than Jobseeker's Allowance (JSA) as then there was no need to report regularly to a Jobcentre Plus office. Already being on a career path was seen as a strong driver for deciding to continue in paid employment, whereas, there was far less impetus to work for those carers who were in low-paid, low-skilled work and who were no better off financially than they were on benefits.

### **6.3.5 Support services**

There was strong evidence from all three groups of professionals that carers' views about the adequacy, quality, flexibility and costs of social services and other formal support impacted on their decisions about working. Professionals singled out care for disabled children during school holidays, and the costs of child care for both disabled and non-disabled children, as barriers to working and caring. Unreliable public transport was also believed to be a problem, especially for those carers who had to be at home by a certain time and who relied on, say, an hourly bus service.

Some professionals expressed the view that carers did not want to risk initiating anything that might consequently have a negative impact on an existing package of care, for example carers might need to request more/different support for the care recipient if they embarked on part-time work. Furthermore, there was the potential for them to be worse off financially, through costs of services, especially if they were buying their own homes and responsible for maintenance and upkeep.

### 6.3.6 Factors related to the care recipient

There was a strong message from the professionals' focus groups that concerns about what would happen to the care recipient in their absence was an important factor in carers' decision-making about work. On the basis of their experience of working with carers, staff from carers' organisations reported that often carers did not feel it was safe to leave the person they looked after alone, but at the same time neither they nor the care recipient was prepared to let a stranger undertake the necessary care activities, particularly if this involved personal care. Many carers had strong family commitments, and saw caring as their duty: they did not perceive that there was any choice to be made about taking on a caring role. These sort of feelings could be compounded if the care recipient put pressure on the carer to undertake care-giving rather than make use of statutory services.

Another perceived influence on carers' decisions about working concerned the stability or predictability of the situation. This was especially pertinent for carers of people with mental health problems or learning disabilities, attention deficit hyperactivity disorder and other types of challenging areas of behaviour, and deteriorating long-term illnesses.

## 6.4 Views on policies to encourage carers to work

Front-line professionals were asked how they felt about the DWP's encouragement of carers back into the labour market. Views were wide ranging, and covered the spectrum of unsupportive, to ambivalent, through to very supportive. Social workers thought that encouraging carers to work was a good idea as long as social services departments had the resources to support those carers who wished to work, otherwise any initiative would lose credibility.

Jobcentre Plus personal advisers put forward similar views, arguing that it was important to look at what was available through social services and also through employers to ensure that advisers had something concrete they could offer carers. At the same time, though, advisers did not believe that carers should be coerced into doing anything they did not want to do as they were already doing a very challenging job for little monetary reward.

Finally, staff from one of the carers' organisations strongly believed that carers should not be put under any moral pressure to combine work and care. They believed that the letters inviting carers to take part in WFIs could have the effect of making carers feel guilty because they were in receipt of benefits yet they saw themselves as doing a public service rather than being poor and did not feel that they received enough recognition.

## 6.5 Summary of key points

- It was clear from the evidence that front-line professionals from social services departments, Jobcentre Plus and carers' organisations were aware of the main constraints and challenges relating to combining work and care.
- Professionals believed that different groups of carers held different views about paid work. They perceived it as more important for some groups, for instance carers wishing to pursue a career path and carers who were already in employment, and less important for other groups, such as carers of people with mental health problems, carers with few, if any, qualifications, carers who had not worked for a long time.
- The benefit system was thought to be confusing for carers, and was seen as an important barrier to combining work and care.
- The issues that professionals identified as having a bearing on carers' decision-making mirrored those identified by carers: financial factors; health and well-being; personal factors; work-related issues; support services; matters relating to the person supported.



# 7 Retirement and pension planning

## 7.1 Introduction

This chapter concentrates on what carers and professionals had to say about retirement and pensions issues for carers. Some of these issues have been touched on earlier when reporting the evidence on influences on carers' decision-making about employment and care-giving (Chapters 5 and 6).

This chapter might appear relatively 'thin' in comparison with others. This is because pensions and retirement incomes did not loom large in carers' thoughts; generally, they were too preoccupied with the task in hand to think very far ahead. However, many carers believed that their financial situation had been negatively affected by care-giving; as a result, some carers did not think that the funds they had available for retirement would be adequate. Invariably, causes for carers' low incomes were those that were documented in the literature review (see Chapter 2), and included: not being in paid work; working in low paid jobs; switching from full-time to part-time work; not applying for promotion in work.

This chapter starts by looking at the factors that influenced carers' (anticipated) retirement, as well as identifying some of the uncertainties that carers had to try to address in their decision-making. This leads into the consideration given to pensions, the impact of caring on pensions-related decisions and reasons why some carers tended not to plan ahead. Professionals' views on issues related to retirement and pensions for carers follow next, before the key points from the chapter are summarised.

## 7.2 Planning and decision-making around age of retirement

The Government is keen to provide older workers with options for flexible retirement (DWP, 2005). To that end, some employers are now introducing flexibility over the date of employees' retirement (or over both the date and working patterns) as a way to further refine work-life and diversity policies and to integrate equality and fairness principles more fully into existing employment policies (Employers Forum on Age, 2002). In principle, carers who wish to combine work and care could benefit from flexible retirement policies.

Carers taking part in the study expected to retire at different ages, for example there were some male carers employed in organisations where the retirement age for men was 60. The following key factors emerged from the interviews with carers as instrumental in their decision-making about when to retire: carers' own health, the condition or health status of the care recipient; current and anticipated financial situation; personal and social reasons.

There was a strong message from the interviews that carers' own health status played a key role in deciding to leave work before reaching state pension age. For example, the study sample contained a number of carers who had already taken early retirement on the grounds of their own ill-health. In addition, there were cases of carers who wished to pre-empt that sort of situation by retiring early whilst still in reasonable health. The following comment was typical:

*'What has been very significant for me is that over the last year or two I have aged like ten years and I feel exhausted and shattered and work is positive and is something that keeps me going but I think, you know, if I can retire at fifty-five I will.'*

(Female carer, employed, 45-54)

Another reason why working carers said they might decide to leave work early was if the condition of the person supported deteriorated and they were needed to provide more care.

In contrast, some carers anticipated that they might have to work beyond state pension age. State pension age is currently 65 for men and 60 for women, but between 2010 and 2020, state pension age will be equalised at 65 for both sexes. This was primarily for financial reasons, and especially applied to female divorced carers who had financial commitments relating to house purchase or supporting children through university. Other reasons given for retiring after normal state pension age were: to reduce the risk of boredom; to get out of the house and meet people; to retain a professional or non-carer identity for as long as possible.

Just as uncertainties made taking decisions about employment issues problematic (see Chapter 5), unknowns also impacted on carers' planning and decision-making for retirement. Uncertainties cited by interviewees included not knowing: what might happen when care recipients were discharged from hospital; what might happen when disabled children finished school or college; whether adult disabled children would ever be able to live independently; the disease trajectory, and speed of deterioration, of the person looked after; at what point in time (i.e. before or after retirement) inheritances would be received. The following quote is typical of other similar responses from carers trying to explain why they had not done any planning towards her retirement:

*'I think you've got that muzziness; you don't know; I don't know; I think you live in this constant state of not being able to plan anything because you don't know...I think you basically live one day at a time... you don't know what's going to happen.'*

(Female carer, employed, 55-64)

Finally, and going back to a point made in Chapter 4 about care-giving being regarded as a job, there was some evidence to suggest that carers thought about retirement more in terms of retiring from caring than retiring from paid work. To give just one example, one carer of an adult child could not anticipate how or when 'retirement' was ever likely to happen, especially as her son's previous attempt at independent living had failed and he had returned home to live with her and her husband.

### 7.3 Planning and decision-making around pensions

The approaches of both working and non-working carers to making financial provisions for their eventual retirement varied from one extreme to the other. At one end of the spectrum were those carers who acknowledged making no plans whatsoever, and at the other end were those who had acted upon financial advice obtained over 20 years ago. The majority of interviewees were somewhere in the middle. As carers got older, they tended to start thinking about savings, investments and pensions but not necessarily to have acted on any advice or information. Having said that, two female carers aged 57 and 58 years, respectively, both talked about doing things when the time came. A relatively large number of both working and non-working carers already owned their homes outright, suggesting that discharging mortgages was more likely to be viewed as a priority.

What reasons did carers give for not planning ahead? Some were general and as relevant to non-carers as carers:

- taking every day as it came: carers' priorities were day-to-day even though at the same time some were anxious about what the future held for them as far as financing their retirement was concerned;
- doing things when the time came and/or the need arose, and not before;

- adopting what could be interpreted as a fatalistic approach and that 'whatever will be will be';
- trusting in the state to provide some sort of pension;
- feeling too young to be thinking about retirement issues;
- having to deal with the perceived complexities surrounding pension arrangements, which were further exacerbated by changes in pension schemes and media debates about increasing state pension age;
- giving priority to discharging existing financial commitments (for instance, mortgages or [large] debts arising from businesses that had gone bankrupt and/or divorce).

One person in her early 40s did plan but even so found she could not think as far ahead as her retirement:

*'I think I have like a ten year ability to think ahead, and I do see myself in ten year's time being in employment and then starting to worry about pension age, but as I am at the moment I couldn't think that far ahead because I don't have a partner...I know that financially you should be thinking about it early but I can't deal with that and deal with [my disabled child]'.*

(Female carer, not employed, 45-54)

The evidence indicated that the following issues, more specific or distinctive to caring, impacted on carers' decision-making:

- **Time, or more specifically lack of time.** Even carers who judged that the funds they had for retirement would be inadequate talked about not having the opportunity or the energy to look into the wide range of pension provisions available these days. Their time was totally absorbed, especially if they were both working and care-giving.
- **Uncertainties related to the future caring situation.** Parent carers of adult disabled children, for example, described how it was difficult to make plans or provisions when they had no clear idea of whether their child would still be living with them, or instead would be settled in sheltered housing or some form of independent living. Even if the care recipient did live separately, carers still needed enough income to help support them financially, take them on holiday and so on, as well as to maintain a reasonable standard of living for themselves.
- **The possibility of future expense.** For instance, some carers were disinclined to take on additional financial commitments related to planning their retirement income because of concerns about possibly having to contribute towards the costs of residential care for elderly parents even though, in theory, carers should not have to.

Overall, the evidence demonstrated that both working and non-working carers had serious concerns about financing their retirement. Carers who experienced poor health themselves, and were not working, were aware they would be affected by changes to welfare benefits, for instance that they would no longer be entitled to Incapacity Benefit (IB) once they started to draw their State Pension.

Turning now to those carers who had made plans for their retirement, financial provisions included: their own, and/or their spouse's, private, occupational or State Pensions; insurance policies; savings; inheritances (either now or in the future); assets such as a house (nearly 30 interviewees across the sample as a whole already owned their house outright); Individual Savings Account (ISAs); Tax Exempt Special Savings Accounts (TESSAs). Property, in particular, was seen as a valuable nest egg for the future; one carer who had taken early retirement indicated that if necessary he and his wife would be able to raise money on it through an equity release scheme. Future inheritances in the form of property, however, could not be assumed as there was at least one example of a carer who had to sell her mother-in-law's house to pay for residential care.

One negative message that emerged from the interviews related to private pensions. Carers were critical of the prospect that they were now likely to yield a very low income, and one that would be far less than they had planned for, as pension funds had devalued considerably. Some carers pointed out that because they were no longer working they were not eligible to continue paying into their occupational pension scheme.

Pensions forecasts from The Pension Service had been requested by a number of carers taking part in the study. One person had asked for his because:

*'It's only right that you need to know what your future is. I mean anybody who's educated and understands these procedures should be asking these questions because there's a lot of faults with pensions.'*

(Male carer, not employed, 55-64)

Overall, the evidence suggested that many carers had low levels of knowledge about State Pensions. Carers did not know, for example, whether they were eligible for a State Pension, how much it was likely to be (or how much it was currently), the impact on pension entitlements of leaving work to care, or the impact of prolonged sick leave on their State Pension. The few carers who were knowledgeable cited the financial sections of the weekend broadsheets, financial advisers and accountants as useful sources of information on pensions. About ten carers had actively sought information and advice on retirement incomes. Sources of advice varied and included independent financial advisers, accountants, banks and insurance companies.

## 7.4 Professionals' views on carers and retirement and pensions

There was a good deal of similarity between professionals' experiences and opinions on carers' attitudes towards retirement and pensions and carers' own views, just documented above. For example, there was strong evidence from all 12 focus groups with professionals that in their experience, carers did not view matters about retirement and pensions as important issues for them. The consensus view was that the majority of carers did not plan ahead for retirement in general, and retirement income in particular. Professionals put forward a number of reasons for carers' apparent lack of interest in their longer-term future:

- Carers were much too involved in managing their immediate or day-to-day concerns to have the time or the energy to make provisions for an event that, in some cases, was far ahead, and/or likely to involve a lot of unknown factors.
- Those carers who had never worked because of full-time caring responsibilities did not perceive issues related to retirement or pensions as pertinent to them. Throughout their caring 'career', the expectation had developed that, on reaching the specified age, they would be entitled to the basic State Pension.
- In a similar vein, many people might continue to care into their 60s or 70s, so for them the idea of 'retirement' was irrelevant – there would be little, if any, change to their practical situation or circumstances.
- Carers were already used to having a low income, so a potentially low retirement income was not an issue for them.
- Those carers currently in receipt of Carer's Allowance (CA) (see Chapter 10) who intended to return to work at some point in the future were thought to be reassured that their national insurance payments would be covered one way or another, which was important to them in the context of retirement.

Common patterns in professionals' approaches to providing carers with information and advice about pension-related matters emerged from the focus group discussions. For instance, staff emphasised that they made carers aware of the importance of CA as a means to protect the basic State Pension because of the national insurance credits that carers received. This was because, in their experience, many non-working carers did not realise that they might not qualify for a full State Pension if they did not claim CA.

Beyond the above, however, it was clear from the focus group discussions that, regardless of their occupational background, professionals did not feel confident talking about pensions; this was seen as far too complicated and confusing a topic area, and they did not want to give misleading or incomplete information. Consequently, professionals preferred to refer the small number of carers who did raise issues about pensions to specialists who could give them expert advice. The main agencies to which professionals indicated they would refer carers were The

Pension Service or alternatively local pension centres/surgeries or Citizen's Advice Bureau. Voluntary organisations such as Age Concern or the Alzheimer's Society were thought to be alternative sources of advice. Professionals also said that they suggested to carers that they requested a pension forecast from The Pension Service.

One area of concern that was raised related to (female) carers aged 60 who received a small amount of money from an occupational pension scheme at the point of retirement. Staff from carers' organisations pointed out that such carers could be over the threshold for benefits. At the same time, the savings credit element of the Pension Credit, which is intended to reward people who have modest savings, is not available to recipients until they are aged 65 years.

## 7.5 Summary of key points

- Carers were likely to consider taking early retirement if their own health was poor, or the care recipient's condition was deteriorating and they needed to provide more care.
- The main reason for working beyond state pension age was financial.
- Retirement planning was difficult, partly because it was influenced by many unknown factors related to the caring situation.
- Reasons specific to care-giving for not planning pension provisions in advance included: lack of time because of caring responsibilities; not knowing whether adult disabled children would be living independently or still at home with their parents; the possibility of having to pay for residential or nursing home care.
- Many carers prioritised managing current financial pressures and commitments rather than planning and making financial provisions for their future retirement.
- Carers had low levels of knowledge about pensions in general and the impact of care-giving on pensions in particular.
- Front-line professionals believed that the majority of carers did not plan ahead for retirement in general, and retirement income in particular.
- Whilst professionals routinely gave carers information about CA, they tended to refer any carers who wanted advice about pensions to specialists because they did not feel confident to offer this themselves.



## Part 4

# Qualitative research on employment and financial support for carers



# 8 Support from Jobcentre Plus

## 8.1 Introduction

This section of the report discusses carers' and professionals' perceptions of the overall service provision offered by Jobcentre Plus offices, with a particular focus on Work Focused Interviews (WFIs).<sup>14</sup> The underlying aim is to explore to what extent Jobcentre Plus activities and WFIs have helped carers into work, and what could be done differently to improve services.

Carers who make a claim for Carer's Allowance (CA) (see Chapter 10) are asked to take part in a WFI to discuss future work prospects as a condition of their claim. However, during the course of writing this report it was announced that the regulations for WFIs are to be changed. As from the end of October 2005, carers will not be invited to WFIs. New customers claiming CA will be told in the new claims telephone interview and in the claims pack, that they can attend a voluntary WFI if they wish. However, people caring for a partner in receipt of Incapacity Benefit (IB) or Income Support (IS) may still be required to attend a WFI for partners in respect of their partner's claim.

As a preliminary to documenting study participants' views about Jobcentre Plus services, it is worth listing the range of services available to Department for Work and Pensions (DWP) customers across the four offices collaborating with the project. These were either provided directly from Jobcentre Plus, or could be accessed through other organisations following referral from a Jobcentre Plus office:

- help with obtaining a job and/or improving employability;
- better-off-in-work calculations;
- benefits check;

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<sup>14</sup> Some comments from carers may pre-date the roll-out of local Jobcentre Plus offices which integrate job centres and social security offices, and do not reflect current practice.

- help with: drawing up CVs; completing application forms; interview skills;
- courses to develop personal skills, for instance confidence building;
- advice on training courses available;
- information about, and referral to, organisations that gave careers advice;
- mentoring.

## 8.2 Views on Jobcentre Plus services

### 8.2.1 Carers' views on Jobcentre Plus services

Just over one-quarter of interviewees recalled visiting a Jobcentre Plus office or job centre in the last four or five years either because they were looking for work and/or training, or wanted advice and information. Only two carers could recollect ever having obtained a job through a job centre, and in both cases, that was more than five years ago and before they started caring.

Carers held mixed views about their experiences. On the one hand, they reported that advisers were generally helpful, considerate and sympathetic. They gave carers useful advice in relation to, say, claiming benefits such as CA or Jobseeker's Allowance (JSA). The better-off-in-work calculations that helped determine whether or not paid work would make them better or worse off financially were seen as particularly useful.

In contrast, a small handful of carers reported finding the Jobcentre Plus environment so intimidating that, having looked at the notice boards, they walked out without speaking to anyone. Others reported being told about inappropriate jobs which did not match their particular skills and experience. One interviewee, recounting a visit to the job centre (admittedly many years ago), explained his caring situation to the manager only to be told to go home *'because I cost the State less being at home than I would if services were put into place so that I could go to work, and I was gob smacked.'* (Male carer, not employed, 35-44).

Perceived weaknesses reported by carers who did discuss work possibilities with personal advisers included the following, some of which are specific to care-giving whilst others are more general:

- Staff unfamiliar with the full range of aspects involved in care-giving, who, therefore, did not understand the impact or consequences for carers in terms of combining work and care. This meant that advisers might not appreciate the need for flexible working hours rather than a rigid 9-5 job, or that carers were not in a position to spend time travelling considerable distances to work.
- Little, if any, help available for carers already in work but looking to change their place of work and/or to retrain in order to fit in better with care-giving.

- Staff who might be willing and helpful, but at the same time were not sufficiently well-informed about qualifications and knowledge areas and were unable to differentiate between different jobs in, say, engineering so would send details of jobs that were unsuitable.
- Little, if any, help available in terms of finding specialised, or part-time, work.
- Feeling patronised by staff with poor interviewing skills who did not see customers as individuals with their own particular skills and areas of expertise, but instead viewed everyone in the same framework regardless of whether their previous experience had been in management or unskilled manual work.
- Being advised to find a suitable job and then go back to the personal adviser who would calculate whether or not it would be financially worthwhile. This could be a lengthy process, during which time the job might have already gone. It was also seen as off-putting for anyone with low levels of motivation and, therefore, easily deterred.
- Making a request for training on the basis that would enhance job prospects, only to be told that it was a case of having a job first and if the employer was prepared to offer training, then that could be supported.

### **8.2.2 Professionals' views on Jobcentre Plus activities**

There was a consensus from all three professional groups that the effectiveness of Jobcentre Plus services for carers was limited. Personal advisers commonly cited a range of organisational constraints that inhibited the support they could offer. These included: carers not being a target group or priority, in the same way as IB claimants or disabled people; the particular benefit claimed by a Jobcentre Plus customer affecting what sort of help that could be offered; 'job entry' targets focusing on jobs of more than eight hours per week, an incentive for advisers that did not encourage them to spend a lot of time looking for jobs for individuals wanting less than this limit; electronic diaries whereby appointments for WFIs were made up to three weeks ahead, so it could be very difficult to suddenly slot in a carer (or other type of customer) who wanted an urgent appointment.

In a related vein, a common theme to emerge from the focus groups with personal advisers related to their lack of time: to regularly telephone carers to see if their situation had changed or they could be of any help; to support working carers who wanted to remain in work; or to offer any post-employment 'mentoring' type support. Likewise, time shortages prevented advisers from networking or building up good relationships with other agencies such as social services or local carers centres (see Chapter 12).

Other barriers to effectiveness raised by both personal advisers and carers workers included not having the right jobs available, in terms of flexibility, hours or location (see Chapter 5). The type of jobs available through Jobcentre Plus offices could also be an obstacle: whilst there might be cleaning jobs available, jobs in management, engineering or the law, say, were not.

Personal advisers also commented on the 'image problem' of Jobcentre Plus, suggesting that some people thought their sole purpose was to deny receipt of benefits. Similarly, social services practitioners and carers workers raised issues about offices not being welcoming or friendly, for instance if security guards were the first point of contact, or if people were told they should have telephoned rather than made a personal visit without an appointment. These sort of experiences were seen as potentially intimidating, especially for people who lacked confidence.

## 8.3 Work Focused Interviews

### 8.3.1 Carers' views on Work Focused Interviews

Eleven or 12 interviewees had attended a WFI whilst caring, connected to a benefit claim for CA, IS or JSA. A further two carers remembered having some sort of an interview at a job centre in the past whilst caring, in one case possibly triggered by being a lone parent.

Some interviewees said that they were not clear about the purpose of the WFI before they attended. Those who did were at a loss to understand why they were being asked to take part in an interview about the possibility of undertaking paid work when they saw themselves as full-time carers. In their view, there was nothing to discuss and they were not afraid to make this clear to the personal adviser as this quote from a female carer illustrates: *'I told them so firmly I wasn't looking for work that they didn't bother, you know, to take it any further.'* (Female carer, not employed, 55-64). This particular carer claimed her WFI lasted about ten minutes, which was consistent with other interviewees' (and personal advisers') estimates. However, she was annoyed because her bus fare had cost her £2 and she could not understand why the matter could not have been dealt with over the telephone.

Carers reported that advisers were sympathetic to their caring situation and helpful. If they indicated they did not feel they were currently in a position to work, then advisers did not try to persuade them to consider returning to the labour force. Indeed, some carers said they were advised not to re-enter the labour market in their present circumstances. Again, advisers explained to carers that they could be worse off if they started paid work, and that before accepting a job they should ask them for better-off-in-work calculations to check out the financial implications.

The extent to which advisers sought out information about any caring responsibilities of people attending WFIs that were not related to the benefit claimed was not clear. For example, one parent carer who was called in for an interview because of the length of time she had been in receipt of IS did not think that she had informed her adviser that she was a carer of a disabled child because in her mind she was a mother and a parent, but not a carer. In contrast, another IS claimant did tell the adviser that he was a carer, information that was noted down but not followed up with any further questions about what his care-giving responsibilities involved.

Generally, carers had few criticisms to make of WFIs beyond that they could not really understand the underlying purpose. They tended not to lead to any changes in carers' decisions about employment and no carers in the study sample got involved in voluntary work, paid work or training courses as a result of taking part in a WFI.

The issue of following-up initial letters about WFIs was raised by two or three interviewees, who said they had received a letter indicating that they could expect to be invited to attend a WFI but at the time of interview for the study, had heard nothing further.

### **8.3.2 Professionals' views on Work Focused Interviews**

Personal advisers reported that they were likely to conduct no more than ten or 12 WFIs with carers in any one month. This was viewed as a disadvantage, because it meant they were less likely to accumulate knowledge and understanding about important issues for carers, and/or develop confidence in conducting interviews with carers.

Advisers from all four research sites confirmed that the interviews could be quite short: ten or 15 minutes at the maximum. It was their experience that many carers had already made the decision not to work (at that point in time) before they attended the interview. Rather than direct the conversation, advisers said they would take their lead from the carer in the same way that social workers did when conducting carers' assessments (see Chapter 9). If they received a negative reaction to issues related to paid work, they would simply make the point that they were there to help in the future when carers were ready for such assistance, check that carers were in receipt of the right benefits and give them information about other relevant organisations such as social services or Age Concern if they had contact details to hand. Whilst they might very occasionally search for jobs, generally speaking, they did not find ones that were appropriate because carers were thought to be very particular about what was right for their particular circumstances (see Chapter 5).

Advisers taking part in the focus groups spontaneously spoke about some of the more challenging WFIs or situations that they had been faced with, including one where the carer's terminally ill wife was also present. There was a consensus that it could be difficult to discuss a change to the caring situation, especially when that was implicitly talking about the care recipient dying or entering nursing or residential home care. It was not unknown for carers to become emotional and upset (in which case, those interviews were likely to take up to 40 minutes), and personal advisers had to be very sensitive in how they handled the interview.

Specific training in WFIs for carers has the potential to help in these sorts of situations as different approaches were thought to be needed for different customer groups. No personal advisers had received training specifically around CA, but some had attended courses aimed at IB claimants which had also covered CA. However, one adviser pointed out that they could be quite directive with, say, recipients of JSA whereas with carers it was thought to be important to let them tell the adviser what

they wanted to do and pick up on topics as and when they arose in the discussion. A common message from advisers was that whilst training and role playing different scenarios was useful, putting the new learning into practice in real situations was not necessarily straightforward. Moreover, if advisers did not do enough WFIs with carers, then they felt they lost the benefits of any training.

There could be occasions when personal advisers might conduct WFIs with former carers (see Chapter 13) once their caring had ceased, however, it would be unlikely that they would delve into the past. Again, they would concentrate on the future, giving serious consideration to retraining for those carers who had not worked for a long time, or whose skills related to declining industries. In these cases, it could be at least six months before a carer was likely to be job-ready because of the retraining in technical skills and confidence building that could be required.

Reflecting their limited knowledge, there was little discussion in the focus groups with social services practitioners and carers workers about WFIs. Carers workers reported carers occasionally telephoning them on receipt of a letter from Jobcentre Plus asking them to attend an interview, often perplexed that there could be any question of them working whilst fulfilling their care-giving responsibilities.

## 8.4 Suggestions to improve Jobcentre Plus services and Work Focused Interviews

### 8.4.1 Carers' suggestions

Carers made various suggestions for improvements to the services offered by Jobcentre Plus based on their own first-hand experiences. As would be expected, recommendations addressed the perceived criticisms outlined above.

- Introduce personal advisers with specialist knowledge of carers' issues.
- Advisers to adopt a more personalised approach; be more accommodating of the needs of carers with a professional background; and offer serious help rather than unsuitable solutions.
- Advisers to spend more time on interviews, as ten to 15 minutes was not seen as long enough for them to get a good grasp of individual caring situations.
- Advisers to be proactive and send carers information about suitable jobs that would be financially worthwhile.
- Rearrange the timing of WFIs, so that they take place before carers leave paid work rather than after.
- Encourage employers to make more part-time jobs available.

### 8.4.2 Professionals' suggestions

Professionals from all three occupational groups made the following suggestions to improve Jobcentre Plus services in general, and WFIs for carers in particular. Overall, it was thought that to be effective, support should be more closely tailored to carers' circumstances and needs.

- Make changes to the benefits system, for example: introduce 'linking rules' for CA recipients who move into paid work so that they can return to benefits on the same terms as their previous claim if the job does not work out; bring in the 16 hour rule, so that carers can work for less than 16 hours per week at the national minimum wage and claim Working Tax Credit (WTC); offer more financial incentives to encourage carers back to work.
- Reconsider the timing of WFIs and see new claimants at least eight weeks after a claim for CA, by which time they will have a better sense of implications of the caring situation on their overall circumstances.
- Target individuals who have been in receipt of CA for some considerable time rather than new claimants; try and build up a rapport with carers, and start to work with them six to 12 months after they start receiving the benefit.
- Introduce specially trained personal advisers at Jobcentre Plus to target and work with carers, including acting as advocate on their behalf with employers (in a similar way that disability employment advisers work with disabled people); further training for personal advisers in carer's issues, CA and conducting WFIs with carers.
- Develop a carers' equivalent of the 'Access to Work' scheme for disabled people, so that funding is available for support for carers to work (for instance, to pay for sitting services for the person supported).
- Provide staff who can talk to new carers and outline all the possibilities in relation to service provision, possibilities/opportunities for paid work, and signpost on to the full range of relevant agencies.
- Offer more of a 'Job Broker' service, i.e. adopt a tailored approach for carers rather than 'one size fits all'; focus on meeting individual needs, rather than concentrating on getting people into jobs or on training courses; provide occupational guidance with a view to longer-term career progression.
- Develop action plans for carers in the same way that this is done for lone parents and disabled people.
- Reintroduce 'career' interviews.
- Give personal advisers more information about claimants (via the contact centres).
- Give personal advisers more information about available services from other agencies, and relevant contact names, so advisers can offer something practical and useful to carers.

- Develop a culture where carers feel they can obtain non-threatening, impartial advice.
- Increase publicity about what assistance is available to help carers return to work.
- Do more outreach work with carers.
- Introduce a 'one stop shop' information point.

## 8.5 Summary of key points

- Some carers reported positive experiences of Jobcentre Plus and personal advisers, and appreciated the advice, information and better-off-in-work calculations.
- A key weakness identified by carers was advisers' perceived lack of knowledge about caring in general, and the impact of caring on carers' ability to work in particular.
- Carers wanting to change jobs, or maintain some connection with the labour market, could feel frustrated if they were unable to get information and advice about available (part-time) jobs or training courses.
- Those carers who had experienced a WFI did not find them particularly useful; they tended to be short and the discussions with a personal adviser were unlikely to influence carers' decisions about obtaining paid work as long as their current (caring) situation lasted.
- The extent to which advisers questioned people attending WFIs about any caring responsibilities is questionable.
- Initial letters from Jobcentre Plus about WFIs were not always followed-up.
- Personal advisers identified a range of organisational and time constraints that restricted the effectiveness of the support they could offer to carers.
- Advisers tended to conduct few WFIs with carers compared to other customer groups.
- Because personal advisers believed that many carers had already made the decision not to work before they participated in a WFI, they concentrated on raising carers' awareness about how Jobcentre Plus could help them in the future when their caring situation changed.

# 9 Support from social services

## 9.1 Introduction

This chapter presents the findings concerning support for carers from social services from the carer interviews and the focus groups with professionals. Social services support is known to be vital if carers are to successfully combine work and care (Kagan *et al.*, 1998; Carers National Association, 1999; Seddon *et al.*, 2004). The Government recognised this in the national strategy for carers (DH, 1999).

The following background information may be useful. Social services authorities are the lead agencies for providing support for carers. Services for the care recipient can be as important as services for carers and there can be instances, respite care services are just one example, where it is not always clear whether the primary aim of the service is to benefit carers or the person supported (Arksey *et al.*, 2004).

The Carers (Recognition and Services) Act 1995 gave carers providing regular and substantial care the right to request an assessment of their own ability to provide care. These rights were further strengthened under the subsequent Carers and Disabled Children Act 2000. Assessments are seen as the gateway to services and information/advice, but research suggests that practice is variable throughout the country (SSI, 1998a) and that often carers are not assessed (or do not realise they are being assessed), receive only limited assistance or experience delays in obtaining support (Arksey *et al.*, 2000).

The practice guide to the Carers and Disabled Children Act emphasises that carers should be helped to stay in work, or return to work, where this is what they want to do, and that practitioners need to consider how they can support carers by providing flexible and reliable packages of care to allow them to continue in work (DH, 2000). To reinforce this emphasis, the practitioner's guide to carers' assessments contains a series of modules to be used during assessment, two of which focus on work, and education and training, respectively (DH, 2001a). Whilst the guidance emphasises supporting carers, there is no statutory duty on social services to meet carers' needs in relation to paid work.

The Carers and Disabled Children Act 2000 also gives local authorities powers to provide services to carers in their own right and to charge carers for them, or alternatively to provide direct payments for the purchase of social care.<sup>15</sup> Eligible parent carers are also entitled to receive direct payments for services for their disabled children. Direct payments can be used by carers to provide services for the care recipient, or to help maintain the carer's own health and well-being. For example, they could be used to replace a washing machine, to purchase a mobile phone, or to provide respite care or childcare for disabled children – provisions that potentially could be very helpful to carers wishing to both work and care.

Charging for services can be an issue for carers, and can result in financial hardship or the service being cancelled or refused (Howard, 2001). Individual councils are responsible for deciding if and what to charge, but they must take into account people's ability to pay. Following new Department of Health guidance (DH, 2001b), carers should only be charged for services provided to them under the Carers and Disabled Children Act 2000. A subsequent survey of local authority charging policies (Thompson and Mathew, 2004) found that 80 per cent had decided not to charge for carers' services. However, the authors estimated that about 30 local authorities may still be levying charges on carers' services. Moreover, carers who are living with the person receiving care, or who are managing their finances for them, may draw on their own incomes to pay the charges of services provided for the person receiving care.

The latest piece of legislation, the Carers (Equal Opportunities) Act 2004 aims to give carers more choice and opportunity to lead a fulfilling life. The implications of the Act are discussed later in the chapter.

The chapter starts with a general look at carers' views and uptake of services, as a preliminary to exploring the interaction between service provision and paid work in respect of first working carers, and secondly, non-working carers. Next, there is a discussion about carers' and professionals' views and experiences of carers' assessments. This is followed by two separate sections looking at what professionals had to say about social services support for carers, and their knowledge of the new Carers (Equal Opportunities) Act 2004. Carers' and professionals' suggestions for change are then detailed, before summarising the key points from the chapter.

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<sup>15</sup> The term 'direct payments' in the context of social care has caused confusion because DWP uses the term 'direct payment' to describe how individuals receive their benefit or pension directly into a bank account. The Department of Health is currently in the process of changing the name of direct payments (DH, 2005).

## 9.2 Carers' views of social services support

The evidence illustrated the wide range of views held by carers about social services support. Carers' opinions varied even amongst those living within the same local authority area, as can be seen in the following quotes from interviewees resident in the one research site:

*'Social services were absolutely marvellous, I can't praise them enough ... I mean they provided far more than I ever expected.'*

(Male carer, employed, 45-54)

*'[home care staff] are very reliable. They come in every day ... they're only off when they're sick.'*

(Female carer, employed, 45-54)

*'There's no point [in requesting help]. They don't deliver. I'm sorry, they're just absolutely useless in my book.'*

(Female carer, not employed, 55-64)

*'The service for the elderly, it really was appalling. ... You know, for anybody who didn't know their way around the system, or anybody who didn't have sufficient confidence to ask, I mean well you despair really for how they would manage.'*

(Female former carer, 55-64)

A common theme that emerged was the apparent failure of social services departments to help carers who were perceived as wealthy and/or 'coping'. This is a phenomenon that has been found in previous research (Wenger *et al.*, 2002), and had the potential to disadvantage professionals who were finding it difficult to hold down a demanding job whilst caring. Lack of support and service provision was an issue for some carers who had resorted to putting in a complaint to their local social services department. Generally, these had been responded to positively (see the case example).

### **Case example of successful complaint regarding lack of service provision:**

A family from an ethnic minority community put in an application for social services support, which was rejected because it did not meet the eligibility criteria. At the time, the family comprised three children with learning disabilities and an elderly parent. Their subsequent complaint was successful, and they were given two social workers and a care package that included home help, day care services and weekend breaks.

### 9.3 Carers without any social services support

Some of the carers taking part in the study were not in receipt of support from social services. This was their choice, for reasons that included:

- carers feeling they were managing and not yet 'ready' for social services help;
- carers feeling that they would be letting their relative down by not doing the care work themselves;
- carers wanting children with special needs to be part of the 'mainstream' world rather than using specialised provision for disabled children;
- care recipients unwilling to accept assistance from paid carers working for independent sector provider agencies, sometimes seen as 'strangers' or 'intruders';
- services regarded as poor quality, inflexible and unreliable;
- charges, and having to pay for services seen as poor, expensive or for tasks carers could do themselves;
- the time taken to organise and oversee service delivery;
- lack of appropriate respite care services;
- not knowing what sort of help was available;
- perceived stigma associated with social services;
- past bad experiences with social services;
- lack of trust and fear of what involvement with social services might lead to.

It is worth following up a number of points raised above. In relation to the issue about care recipients not wanting help from independent sector providers, there were examples of carers who believed that formal support could be beneficial. Consequently, they wished that social workers would try to exert more of an influence and try to overcome the reluctance of the care recipient by, say, pointing out the potential benefits, and suggesting that they tried out the service for a couple of weeks.

Unsuitable service provision were another deterrent to using social services; in particular, carers highlighted the lack of appropriate day care and respite facilities for non-elderly physically disabled adults. Alternative provision that was available, for example, services for older people or people with mental health problems, did not offer interesting or stimulating activities.

For some carers, there was an issue about lack of trust and fear of social services. One interviewee had supported his wife with mental health problems for over 20 years. They were worried that any involvement with social services might lead to his wife being institutionalised and their house, which they owned outright, being sold:

*'Now if we get involved with these people, with medical assessments and one thing and another, I'm afraid as where it might lead to... we really and truly are frightened of them for the simple reason that we don't know the outcome in the future.'*

(Male carer, not employed, 55-64)

Paperwork, bureaucracy and red tape emerged as key obstacles that inhibited carers' use of services. Carers were critical of the very specific, detailed questions that social services asked (e.g. about number of hours caring per week or care-giving activities) that, in any case, tended not to fit with unpredictable and ever-changing care situations related to, say, multiple sclerosis or mental health problems. Dealing with these sorts of issues could take a considerable amount of time, as could waiting for replies to telephone messages.

There was evidence in the study demonstrating the difficulties carers faced in obtaining up-to-date information, endorsing a well documented and long-standing problem (DH, 1999). Carers claimed that social services did not volunteer information about available services or other entitlements, and that it was up to carers themselves to search this out for themselves. This could be quite daunting for carers who did not know who to ask, or who lacked confidence in dealing with people in positions of authority.

## 9.4 Employed carers and social services support

Some of the 43 employed carers in the study received no support from social services at all, yet they still managed to combine work and care – in some cases, working a full 37-hour week. This finding is consistent with previous research showing that only minorities of working carers used services (Phillips *et al.*, 2002), which might suggest that the way in which services are provided – for example, short day care hours, brief home visits rather than sitting services or service provision but without any accompanying transport facilities – do not suit the needs of working carers.

As indicated above, one pattern that emerged was for carers to elect not to receive social services support. However, there were also examples in the data of employed carers who wanted support but who claimed this was not forthcoming, as a consequence of tight eligibility criteria for different services and the failure of some caring situations to meet any criteria. Problems at the health and social care interface are longstanding and can affect carers. For example, one carer – a full-time National Health Service (NHS) employee – who was refusing to take her husband with mental health problems home from hospital until services were put in place to support her, said:

*'...all the consultant is interested in is to get my husband out of hospital so he can have the bed, and all the social services department is interested in is not having to pay out any money... and you just fall between the two.'*

(Female carer, employed, 55-64)

The care packages for working carers who were in receipt of services varied hugely in terms of levels of support, from a weekly visit to a day centre, to daily home care visits, to an extensive 'carer-blind' package (Twigg and Atkin, 1994; Pickard, 2001). The term 'carer-blind' describes a policy whereby a disabled person with a carer is treated in exactly the same way as a disabled person without a carer (Twigg and Atkin, 1994: 150). In other words, the focus of intervention is the care recipient and the carer is supported through the provision of enhanced services for the person looked after.

**Case example of 'carer-blind' package:** The package comprised twice daily visits from home care staff seven days a week, day centre attendance twice a week, and lunches provided for the remaining five days of the week either through meals-on-wheels or a neighbouring residential home that delivered meals to local elderly residents. Charges for the care package were in the order of £330 per month. The support provided to the care recipient enabled the carer to sustain full-time employment as well as to enjoy some leisure time. The carer lived in the rural research site, demonstrating that it is possible for social services departments to overcome problems of rurality (see Chapter 13).

There did not seem to be any significant relationship between levels or comprehensiveness of care packages and the number of hours of paid work that carers were undertaking. For example, there were carers working over 37 hours a week, in touch with their local social services department yet not receiving any actual service provision. At the other end of the scale was an interviewee who worked four hours per week. Her disabled son attended day care every weekday, had regular, frequent respite and used a sitting service one evening a week, so the carer could pursue a long-standing hobby.

Some employed carers were in receipt of direct payments in order to purchase social care. However, these were often not used for support services that would make it easier for them to both work and care. Often, direct payments were used to buy in befrienders or buddies, assistants who would take the care recipient out at weekends or in the evenings. There was evidence that carers lacked information about the availability of direct payments. For example, one parent carer who had only just heard about them did not know whether or not they could be obtained on behalf of disabled children.

There was an underlying issue about social services' ability to respond to carers' changing situations. On the one hand, a few carers indicated that, over time, the care packages provided to care recipients had gradually increased, which in turn helped them to better accommodate paid work. On the other hand, criticisms were raised about speed of responsiveness. For example, one employed carer said she was frequently left '*holding the baby*' and at one point had to take two months off work, mainly because social services were not able to help her with transport to take her father to the hospital in the afternoons to visit his wife. Illustrating how difficult it can be to get hold of information about available services, she had been in touch with the hospital social services, community social services, the local Alzheimer's Society and other organisations, but no-one was able to help or advise until eventually a neighbour told her about a community transport scheme.

The length of time taken by social services to respond to emergencies and unplanned events was a cause of concern for carers, again an issue that has been reported elsewhere (Carers UK, 2005). Assistance that would have been useful included help with lifting care recipients who had fallen, and sitting services to allow carers to leave the house to deal with unexpected emergencies relating to close family members.

As implied at the start of the chapter, carers held mixed views about the quality or adequacy of social services provision. Some working carers praised the support, yet there were those who complained vociferously, and went so far as to suggest that social services support could in fact lead to additional pressures if carers had to spend time checking whether agency staff had done what they were supposed to in terms of turning up, completing specified tasks and staying the full amount of time.

There were only a few instances of carers saying that their social services' support was essential to their ability to sustain paid employment. The lack of childcare for disabled children was frequently raised as a barrier to undertaking work by some interviewees (see Chapter 13). One parent carer was typical of many when she said: *'Really I would say parents like myself probably need [after-school clubs] more than parents with kids in a normal school because they've got their own formal situations.'* (Female carer, employed, 45-54).

Other services that were not essential for paid work but that carers said would make it easier to work and care, tended to focus on very practical help, for instance: help with gardening, cleaning, ironing and shopping; someone to collect prescriptions, or to escort elderly parents for flu jabs; a befriender to take elderly relatives out occasionally. Generally speaking, however, the practical assistance that carers said would be the most helpful is not currently available from social services departments.

## 9.5 Non-employed carers and social services support

Many of the 37 carers who were not in paid employment were also not in receipt of services. The reasons for making this choice varied, and are all included in the list presented earlier in the chapter. Those that were emphasised more than others included: not wanting to let the care recipient down; care recipients being unwilling to accept help from others; charges for social care; inappropriate services; unreliable, poor quality and inflexible services; lack of trust.

The social services provision that non-working carers did receive included home care visits, day care, play schemes, respite care and direct payments. Support was not necessarily conducive to work, for instance, day centre attendance did not cover the full working day and transport was not always available. Some carers who were interviewed for the study drew attention to their lack of knowledge about entitlement to services, which disadvantaged those who were reluctant to ask questions or seek information out themselves. Carers could not always understand why some types of assistance were available but not others, for instance, in one research site, help with housework could be provided but not help with shopping.

Non-working carers' 'wish list' for additional service support again emphasised practical help with tasks such as shopping, ironing and gardening.

Some carers reported that the support they received had decreased over time. For instance, when one carer's husband first came out of hospital five years ago (a point in time when she was still employed) they received 25 hours of home care per week, which had now dwindled to five. This was partly caused by what was now a common problem across all four research sites: a lack of paid care workers. Being able to recruit paid carers, even when in receipt of direct payments, was an issue for both urban and rural carers. At least one (female) carer reported that a key factor in her decision to give up work to care was because of unreliable social services support, and discontinuity in home care staff which confused her mother.

As noted above, charging emerged as an issue for non-working carers. Examples were given of care recipients who had not only disliked their experiences of day care or short breaks, but then had to pay for them. This prompted carers to discontinue using the services. One carer had unexpectedly received a bill for over £300 to cover the costs of three separate weeks of respite care, which she had not realised had to be paid for. Difficulties were also reported in relation to invoices which were inaccurate, in that they covered more hours of paid care than had been received.

It cannot be assumed that interviewees would participate in paid work whilst still caring even if they were provided with increased social services support; indeed, for many non-working interviewees returning to work was unlikely (see Chapter 4).

## 9.6 Carers' assessments

As noted at the start of this chapter, eligible carers are entitled to have an assessment of their ability to provide care. Of all the carers who were interviewed for the study, just over one-quarter (both working and non-working), said they had had an assessment. The remainder had not been assessed (which for some was by choice), did not know or could not remember. A number were expecting to have an assessment fairly shortly. There was wide variability between, and within, the four social services departments in terms of whether carers were, or were not, assessed.

In three of the research sites, assessments were conducted by social workers, whilst in the fourth area this task was contracted out to the local carers centre. The latter assessment process involved a carers worker assessing the carer in their own home, unless they did not want the care recipient to be present and then it would be held elsewhere. Assessments tended to last a minimum of one hour, but because they were so individual, they could extend over several sessions.

Social workers and carers workers taking part in the focus groups stressed that a carer's assessment was about encouraging the carer to recognise themselves in this role, and listening to them. They tended to be guided by the carer being assessed as to the specific content of the assessment, possibly reflecting their belief that many carers did not want to have their lives delved into by professionals. Some practitioners

were more likely to accept what carers had to say about their caring or working situation at face value rather than probe too deeply:

*'If it doesn't seem to be a problem, I don't turn the stone over.'*

(Focus group 3/1.4)

Whilst carers usually wanted their benefit situation to be checked, at the same time they could be cautious about talking about financial matters in general. Social services practitioners in particular tended to avoid getting involved in discussions about finances, mainly because they felt they were not well enough informed themselves. Instead, they would refer carers on for more specialist advice from, say, the Citizen's Advice Bureau.

Government policy (DH, 1999) emphasises the benefits of paid employment for carers, and employment issues are one of the areas that the Department of Health suggests should be covered in a carer's assessment (DH, 2001a). However, there was evidence that professionals were ambivalent about their role concerning carers and paid work. Social workers in two of the research sites, for example, commented that they did not routinely initiate a discussion about employment, although if a carer started to talk about this area of their life then they would respond accordingly. One social worker, who was adamant that social services' role was not to enable people to return to work, summed up the dilemma that social services found themselves in as far as carers were concerned:

*'This may sound very hard-faced, but they're carers and they're a solution to our problem aren't they? 'Cos if we didn't have the carers, then the local authority would be stuck, wouldn't it?'*

(Focus group 1/1.3)

For their part, many carers who were interviewed for the study, were unable to recall whether or not their assessment covered paid work. However, some carers did remember discussing work matters with practitioners who they perceived as supportive and understanding of carers' wishes (especially if they were lone parents) to continue work, or return to work after sick leave.

Social workers spontaneously raised the issue of bureaucracy and the increasing amount of paperwork and form filling, especially in relation to community care assessments. The prevailing view was that the emphasis on performance indicators and star ratings impacted, in a negative way, on the ability of a social services department to be person-centred. They were concerned that the number of carer assessments undertaken on paper appeared to be what counted, rather than the quality of outcomes or the quality of service delivery.

How useful or effective were assessments? There was evidence from the focus groups with social services practitioners that they were sceptical about their value to carers, especially if the services they could access for carers were limited. Whilst they believed that carers wanted someone to listen to them, at the same time, they were

not convinced that carers wanted an assessment that involved a large amount of paperwork. Past experience had taught them that the very term 'assessment' was off-putting; that carers did not understand what an assessment was; and that very often they did not want to take part in yet another assessment, especially if they had been involved in previous ones that focused on the care recipient.

Carers who had been assessed by social services also held mixed views about their value. Some carers thought that their assessment contributed to a care package intended to help them combine paid work and care-giving, but others had the opposite experience. One parent carer had this to say:

*'I always get the response, 'We're not here to help you go to work'; it's a kind of mantra. Well, why not? 'That's not our job, if you want to go to work that's up to you'.'*

*(Female carer, employed, 35-44)*

Other interviewees had thought their assessments were useful at the time, but were then disappointed that nothing happened as a result. And yet others said they were not worth the paper they were written on.

## 9.7 Social services support for carers: the professional perspective

The range of service provision that was potentially available to carers who wished to both work and care included: frequent house calls during the day; respite care and short term breaks; attendance at day centres. According to workers from carers' organisations, however, there were important gaps particularly in relation to help with shopping and housework. The evidence from carers documented above, highlighted how critical these sorts of services were to them, yet they were not provided in some of the research areas.

As already discussed, charges for services can arise as a problem for carers. Social workers gave examples of carers who they felt were themselves increasing the pressure they were under because they were unwilling to pay for services for the care recipient that had been offered and were available. Charging had only recently been introduced in one research area, and carers were thought to be disinclined to spend money on services they judged to be of poor quality or unreliable.

Social services practitioners gave carers whatever information and advice they could, however there were some areas which they commonly said they were not well informed about themselves. Important gaps in practitioners' knowledge related to local employment/training opportunities, and matters concerning welfare benefits, pensions and retirement. Information gaps were overcome by referring carers to other agencies such as the local Citizen's Advice Bureau, Welfare Rights Unit, Jobcentre Plus, carers centre, Age Concern, and condition-specific groups such as the Alzheimer's Society or Multiple Sclerosis Society. However, this meant that

carers might spend a lot of time and effort collecting information from a range of different sources which could be particularly difficult for those who both worked and cared, and did not have spare time during the day. The point was made that social services' reception staff - often the first point of contact for carers - needed to respond in a way that was both encouraging and informative, otherwise there was a risk that carers would lose confidence in the service especially if it had taken them a long time to get in touch in the first place.

Social workers taking part in the focus groups gave examples of carers from their case load who were able to combine work and care. Often, these were carers who needed support to stay in their current employment (or to continue to run their own business) rather than carers who had decided to re-enter the labour market after a period of not working. As well as practical support, there were other ways that social workers could help carers. For instance, one practitioner explained how she had written to a carer's line manager to explain about the responsibilities she had, and the stress she was under, because of caring for her mother, and to reassure the employers that they were working towards providing an appropriate care package.

Ideally, practitioners would try to organise services that were as flexible as possible and reflected not only the care recipient's needs, but also fitted in with those of the carer. This could be challenging because support tended to be more directly linked to the needs of the care recipient than the carer, which had the potential to result in tensions in trying to meet both sets of needs.

Two of the problem areas related to providing care to enable carers to work identified by social workers were: first when care recipients could not be left alone, and secondly when they needed a frequent call (e.g. every hour) for toileting. Practitioners also pointed out that whilst they could provide reasonably effective short-term solutions, it was much harder to provide longer-term care packages for carers who had no 'end date' for ceasing to care but who wanted to continue in work. Carers workers felt that uncertainties over the sustainability of service provision inhibited carers from seeking employment. They also believed that unless services changed the way they traditionally worked, for example, day centres extending the length of time they offered support, then it was not viable for carers to work. Furthermore, it could be difficult to access services because of tight eligibility criteria.

Professionals commented on difficulties surrounding service provision at key transition points from children's services to adult services, and adult services to older people's services. The resulting changes to service provision had the potential to impact negatively on carers' ability to work. Talking about the transition from children's services, one carers worker reported that:

*'Carers who have been in that position describe it as falling off the edge of a cliff: being reasonably well-supported in education and all of a sudden the world comes to an end, the service stops because the child's moved on and there's nothing to take its place.'*

(Focus group 2/3.3)

The list below draws together the wide range of difficulties perceived by social services practitioners and carers workers as constraints on the effectiveness of support for carers, difficulties which were even more pertinent for those carers who wished to both work and care:

- limited resources for adequate care packages to enable carers to work;
- current support not aimed at helping people to work, e.g. inflexible services with rigid starting and finishing times that do not accommodate paid work arrangements; sustainability of support over the longer term; slow levels of responsiveness;
- services that are unreliable and of poor quality; discontinuities/shortages of staff; no night-sitting services;
- tight eligibility criteria to determine levels of need; services that are not accessible enough.

The range of difficulties that carers wanting to work and care could confront were summed up in the comment below:

*'We provide a service from this time and it finishes at that time and if you want anything outside of that you have to jump through 29 hoops to be able to access it, and even when you do access it it'll only be for a limited period of time 'cos it costs too much money and if you ask for it before the end of the financial year you've no chance, you're better off asking for it after that.'*

(Focus group 4/1.1)

Social workers from all four areas flagged up the potential value of direct payments as a solution to help carers combine work and care. A typical example was of a male carer who used direct payments to employ a personal assistant to look after his wife from Monday to Friday between 9.00 am and 4.00 pm, when he returned home from running his own business. However, there was consensus amongst professionals that direct payments were not suitable for all service users and/or carers, in which case, they had the opposite effect and increased levels of stress. They could be difficult to manage, there was a lot of paperwork involved and there could be a gap between the level of the payment and what the services cost. Because of labour shortages, social workers from both urban and rural research sites stressed that users of direct payments could face similar problems in recruiting personal assistants as those experienced by home care agencies and social services departments looking to employ paid carers.

## 9.8 Professionals' knowledge about the Carers (Equal Opportunities) Act 2004

As noted earlier, a new piece of legislation came into force in England and Wales in April 2005 called the Carers (Equal Opportunities) Act 2004. The Act has the potential to make a large impact on the way that social services and other relevant agencies support carers, especially in relation to work, training and leisure. It made three main changes to existing legislation on carers services: Section 1 placed a duty on councils to inform carers, in certain circumstances, of their right to an assessment of their needs. Section 2 provided that when assessing a carer's needs, councils must take into account whether the carer works or wishes to work, undertakes or wishes to undertake education, training or leisure activities. Section 3 facilitated co-operation between authorities in relation to the provision of services that are relevant to carers.

The focus groups with professionals were held towards the end of the consultation period on the draft policy guidance, which was issued in January 2005. Social services practitioners and carers workers were slightly better informed about the new Act than Jobcentre Plus personal advisers, many of whom had not heard about it before. No one taking part in the focus groups had yet received any specific training for the Act, but delays in offering training might be explained by the fact that the final version of the guidance had not yet been published.

The new Act was viewed positively in the sense that one potential outcome was that social services practitioners might be more proactive, responsive and flexible regarding carers' wishes about education, training and leisure. At the same time, professionals voiced serious concerns about (lack of) resources to back up effective implementation of the new legislation. The main anxiety was that it might serve to raise carers' expectations, which then could not be met. Social workers were particularly worried that the Act might make their job more difficult if they could not provide the services that carers were assessed as needing in relation to these three important areas, and that there might be yet more paperwork.

Staff from carers' organisations felt that imposing duties on local authorities to give carers information about their rights was an important step forward which could help to empower carers. Carers workers speculated that the legislation might broaden their role, as previously much of their work had concentrated on helping carers obtain what they needed in relation to the person they looked after. Now, the new Act presented the opportunity to help carers get support as individuals and in their own right.

Jobcentre Plus personal advisers, once they had been given a short outline of the new legislation, thought that the Act would have implications for them primarily if carers were made one of their target groups. A second potential impact that was suggested was that other interested organisations were more likely to find out what help and support was available for carers from Jobcentre Plus offices.

## 9.9 Suggestions for change

Both carers and professionals proposed changes to service provision that had the underlying aim of helping carers combine work and care.

### 9.9.1 Carers' suggestions for services that would make it easier to work and care

The list below draws together those services that both working and non-working carers said would make it easier for them to combine work and care-giving. Some, but not all, have already been referred to. The suggestions are in no particular order of priority, and similar ones are grouped together.

- Easily accessible, up-to-date information about available services and entitlements.
- Home sitting services; reliable, trained home care staff; quality care in familiar surroundings for older people.
- Practical help with gardening, cleaning, ironing, shopping, preparing meals and running errands.
- Age-appropriate, stimulating day time activities for people with mental health problems; longer day centre hours to cover the full working day.
- After-school clubs for disabled children; social activities or clubs for disabled children; increased allowances for childminders to look after disabled children; childcare for non-disabled children.
- Emergency cover.
- Housing adaptations (such as downstairs toilet) to facilitate a good night's sleep.
- Improved transport in rural areas.

### 9.9.2 Professionals' views about improving support for carers to work and care

Social services practitioners and carers workers made various proposals aimed at improving support to help carers combine work and care. These are listed below; similar ones are grouped together. Personal advisers from Jobcentre Plus offices had few suggestions to make beyond the provision of information and more day care centres/resources for care recipients.

- A well publicised 'one stop shop' information point for (new) carers. This could provide information and impartial advice on: finances and benefits; the full range of options and services available from social services and other support organisations; possibilities for work opportunities from Jobcentre Plus; problem solving and finding solutions; information about what may happen in the future.

- Increased and better quality resources for care recipients, including home care, respite care, night sitting services, increased hours for day centres, low level support that might prevent major investment in intensive support services in the future, and supporting working carers domestically (e.g. home helps) to enable them to work. Services that are not taken away, and/or operate on short-term funding.
- Build up capacity by recruiting more paid carers. This would be helped if the job had more of the characteristics of professional work such as training, job security and paid holidays. More importantly, the pay should be increased to reflect the responsibilities and tasks involved (e.g. medication, dietary intake, skin integrity).
- More use of direct payments to give carers flexibility to employ someone they have chosen and to remove dependence on a service they do not really want.
- More use of new technology, for example assistive technology, monitors and webcams.
- Improve how carers' assessments are undertaken, so that practitioners are more proactive, better trained and have a fuller understanding of important work-related issues for carers.
- Relax eligibility criteria so that care recipients are eligible for services.
- Introduce standards, targets and milestones, with accompanying funding to help attain them and in this way, improve services and/or introduce new services; reinstate the ring-fencing around the Carers Special Grant.
- Increase liaison with, and referrals to, Jobcentre Plus offices, especially if they have a carer-specific worker who can give carers careers guidance and benefits advice.

Training for social services practitioners has the potential to indirectly improve support for carers. When asked about perceived training needs, there was a consensus amongst social workers taking part in the focus groups that training on the Carers (Equal Opportunities) Act 2004 would be helpful. Practitioners felt there was a need to know more about what the new legislation meant and what social services departments expected from them in relation to the Act. They thought it was important not only for all staff who worked with carers to attend such training, but that first line managers also received training otherwise there could be problems with their ability to supervise and monitor their own staff's work with carers.

A further suggestion was for training to improve the way staff undertook carers' assessments, with a view to helping them recognise broader perspectives including carers' aspirations around employment, training or education. In principle, training around welfare benefits was seen as useful, but those social workers who had attended these sort of training courses found they had not learned a lot, partly because the benefit system was so complicated.

## 9.10 Summary of key points

- Carers' opinions on the quality and adequacy of social services provision varied widely, even within the same local authority.
- Many carers (or care recipients) were unwilling to accept assistance from social services.
- There was no evidence of a direct link between the number of hours that carers worked and the levels of social services support received.
- Concerns were raised about social services' speed of responsiveness, in particular their perceived inability to respond quickly and efficiently in emergencies.
- Social services support was generally not essential to the ability of carers to undertake paid work, partly because it did not easily accommodate work patterns.
- Services that would make it easier for carers to work and care included childcare for disabled children, longer day centre hours, and practical help with domestic chores.
- Charges prompted some non-working carers to discontinue using services such as respite care or day care.
- Carers' views on carers' assessments were mixed; some, but not all, had covered work issues; some, but not all, had resulted in additional service provision.
- Social services practitioners were ambivalent about the value of carers' assessments for carers, especially if there was a lack of resources to provide services to meet carers' needs.
- Practitioners did not routinely initiate discussions about employment when they assessed carers.
- Both carers and professionals expressed concerns about the amount of bureaucracy and paperwork involved with carers' assessments and supporting carers (and care recipients) in general.
- Information gaps about local employment/training opportunities, or benefits, pensions and retirement, were overcome by referring carers to specialist agencies, although following up these referrals could then be time consuming for carers.
- Whilst social services departments could provide reasonably effective short-term solutions to help carers combine work and care, it was much harder to sustain this support in the longer term.
- Changing service provision during key transition times when care recipients moved from children's services to adult services, or from adult services to older people's services, could be problematic. The changed/new service support could, in turn, restrict carers' ability to (continue to) work.

- Front-line professionals saw direct payments as one potential solution to problems in providing flexible, good quality care, but there could be difficulties in recruiting staff and they were not regarded as suitable for all carers or care recipients.
- Professionals' knowledge about the new Carers (Equal Opportunities) Act 2004 was limited.
- Training in relation to the new legislation, the broader aspects of carers' assessments and welfare benefits would be useful for social services practitioners.



# 10 Financial support for carers

## 10.1 Introduction

The first chapter gave a brief overview of the welfare benefits that carers may be entitled to. Carer's Allowance (CA) is the main benefit for carers;<sup>16</sup> it is a taxable benefit with a value of £44.35 at the time the interviews for the study were conducted (increased to £45.70 in April 2005). The benefit does not depend on past national insurance contributions. There is an earnings disregard for people working part-time; and weekly earnings can be spread over a suitable period of time.<sup>17</sup> Recipients also receive national insurance credits.<sup>18</sup> The credits protect carers' rights to a basic State Pension and State Second Pension, and may help carers to qualify for Incapacity Benefit (IB) or Jobseeker's Allowance (JSA) in the future. CA is not intended to be the sole means of financial support for carers. Carers not in work can claim income-related benefits and premiums as a safety net and carers in work can claim in-work benefits. If a carer is entitled to a contributory benefit eg IB, that will be their main benefit and if the CA exceeds the IB, then a top-up of the difference is paid. Carers on low incomes may also benefit from a carer premium which is

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<sup>16</sup> Main eligibility criteria are that carers must spend at least 35 hours per week caring, that earnings from paid work must be £82.00 (as at April 2005; £79.00 at the time of the interviews) net of allowable expenses, and that the person cared for must receive Attendance Allowance (AA) or Disability Living Allowance (DLA) at the middle or highest rate for personal care.

<sup>17</sup> There does not seem to be a strict definition of what is meant by a 'suitable' period of time, which is left to the discretion of decision-makers in the CA Unit or a tribunal panel.

<sup>18</sup> Married women who elected not to pay national insurance contributions do not get national insurance credits or home responsibilities protection.

included in applicable amounts for other means-tested benefits such as Income Support (IS). It can be important to claim CA, even though carers might not actually receive it, because it can establish underlying entitlements, for instance carer premium, home responsibilities protection and credits. CA includes additional amounts for adult dependents.

Carers may also be eligible for other benefits from the Government. For instance, carers on a low income may be entitled to housing benefit to help pay their rent, whilst carers receiving council tax benefits will be eligible for a discount. To help make work pay, working carers with incomes below minimum levels set by the Government may also be eligible for in-work financial benefits, for instance working tax credit and Child Tax Credit (CTC).

As a preliminary to discussing carers' and professionals' views and experiences about benefits for carers, some general information is reported about interviewees' access to, and take up of, CA and other benefits.

## 10.2 Carers' views of Carer's Allowance

A total of 28 carers taking part in the study were in receipt of CA. Key sources of information about the benefit and how to apply for it were: carers' and disability organisations; General Practitioners (GPs), district nurses, health visitors and Macmillan nurses; social services practitioners; benefits advisers; job centre staff; the free Benefits telephone help-line; work colleagues and friends. Some carers taking part in the study received help in completing the forms from staff in carers' organisations or social workers because they found them difficult. As one interviewee commented:

*'The form was that thick and, and nothing simple on it. ... You've got to know what this is all about...people that fill them regularly every day, they know, they've been trained to do this...so I went to see [carer's worker] and she filled this form in'.*

(Male carer, not employed, 55-64)

Generally, carers' knowledge about CA was limited. There were some carers – including parent carers – who had been eligible for CA for up to seven or eight years but had not claimed it when they were first eligible because they did not know about it. Other gaps in knowledge included being unaware that:

- the earnings threshold was a net figure and that there were some allowable expenses (especially care-related expenses) that could be deducted from gross earnings;
- it was possible to undertake a limited amount of paid work whilst still receiving the benefit;
- the upper age limit for receiving CA had been abolished.

In addition, carers' knowledge was often out-of-date, so even carers in receipt of CA - and also those who did not get the benefit - often did not know about increases in

the earnings limit.

It was clear from the interviews that CA caused some confusion amongst recipients. For instance, a handful of carers spoke about higher and lower rates of CA. Others were uncertain as to whom CA was aimed at: themselves, or the person they looked after. Hardly any carers knew about Home Responsibilities Protection (HRP). CA was seen as bureaucratic, for instance a number of interviewees talked about the perceived red tape involved in getting CA at the same time as working. Problems were compounded for carers who had unwittingly earned over the threshold and then been overpaid. Carers were confused about the rules in relation to whether or not earnings could be averaged out over a number of weeks.

There was a consensus amongst interviewees that the monetary value of CA was far too low, especially if it was looked on as a 'wage' for care-giving. Interviewees' described the value of the benefit as 'ridiculous', 'rubbish' and a 'joke'. Carers viewed themselves as saving the state a considerable amount of money by enabling the care recipient to remain in the community rather than being placed in residential or institutionalised care. A few carers felt that the benefit should have different rates reflecting how many people were being cared for, or the intensity of caring. The restrictions on earnings were commonly regarded as unfair, with carers pointing out that they would like to earn as much as they could in the hours that they had available to work. This was particularly the case for single people who were the main breadwinners. Interviewees resented not being able to receive CA as well as their State Pension. They were also critical of the prospect of care recipients losing the Severe Disability Premium (SDP)/Addition because they were getting CA.

The remainder of this chapter looks at carers' experiences of CA (and other benefits) according to the following four groups: working carers receiving CA; non-working carers receiving CA; working carers not in receipt of CA; non-working carers not in receipt of CA. Professionals' views and experiences of financial provisions for carers are then documented. Finally, key points from the chapter are summarised. The main focus of the chapter is CA, as that is the principal benefit for carers but discussion of other benefits is included where relevant.

### 10.3 Working carers in receipt of Carer's Allowance

There were ten carers in the sample who were in paid work whilst receiving CA. These individuals – all women – were generally in low paid jobs, such as residential care worker, school dinner lady or filing clerk. In some cases, however, previous careers had included office manager or teacher. Those carers who had taken jobs below their existing skill levels, aptitudes and experience complained that because of the CA restrictions, they were unable to do a job that gave intrinsic rewards such as self-esteem or a sense of worth. However, jobs that paid high hourly rates, such as supply teacher, did not fit easily with the earnings threshold. There was a strong belief that CA should be more flexible to accommodate working additional hours if the opportunity arose.

The general view for this group was that the (then) £79 ceiling on earnings was too low. Interviewees, especially parent carers whose children had started school, indicated that they would be keen to work more hours if the limit was higher. From this point of view, CA was a disincentive to (more) work.

#### 10.4 Non-working carers in receipt of Carer's Allowance

Eighteen carers in the study sample were receiving CA, but not participating in paid work. Few people had been given advice beforehand about the implications of giving up work to care. There were a small number of instances where CA had been an important factor in interviewees' decisions to leave the labour market. As noted earlier, there was a risk involved as these carers were giving up work without knowing whether their claim for CA would be successful or not.

In principle, some carers in this group were interested in some sort of paid work; at the same time, they were anxious about the impact of starting work not only on CA, but also on other means-tested benefits they received such as IS or Housing Benefit (HB). They were also concerned about continuing to fulfil the minimum requirement of 35 hours per week care-giving demanded of CA recipients. Some of the carers who talked about caring as a 'job' felt they would be neglecting their work as a carer if they undertook paid employment at the same time. This was a further instance of CA acting as a disincentive to work.

Some carers in this group had previous experience of working part-time and receiving CA. Similar points were made to those reported earlier, namely that the earnings threshold was too restrictive and that finding a job that paid below the threshold was difficult. For some carers, it was a case of full-time work or no work at all because the scope for working whilst receiving CA was too limited.

#### 10.5 Working carers not in receipt of Carer's Allowance

Some 33 carers were working and not getting CA. Many had jobs in the public sector working for the National Health Service (NHS) or for local authorities, whilst some were employed by voluntary organisations that supported carers or disabled people. Knowledge levels about eligibility criteria for CA amongst carers in this group tended to be quite low, and some thought the benefit was only for carers who did not do any sort of paid work at all. Interviewees in this group were generally fairly high earners with large financial commitments. Many carers still had outstanding mortgages, and/or children they expected to help fund through university, prompting them to claim that they had no choice but to work. The predominant view was that the level of CA and the earnings threshold were both too low, especially for those carers who were the main or sole breadwinner in the household. For these carers, the impact of CA on decisions about whether or not to quit work reflected current and anticipated levels of financial need.

## 10.6 Non-working carers not in receipt of Carer's Allowance

The last sub-group comprises 19 carers who were neither working nor in receipt of CA at the time of their interview. Whilst some were eligible and indeed in the process of applying for the benefit at the time of their interview, other carers would have been no better off receiving CA because they were in receipt of other benefits paid at higher amounts such as the State Pension, IS or IB. A small number of carers had decided not to claim CA because their understanding was that there would be a negative impact on the benefits of the care recipient. These understandings are correct as a disabled person receiving the SDP in IS or Pension Credit will lose entitlement to the SDP if their carer receives payment of CA.

Finally, both working and non-working carers made the point that CA did not easily accommodate mutual flexibility by offering them the opportunity to accommodate employer's needs. For instance, the earnings limit did not offer the flexibility to work overtime, or additional hours to cover for colleagues' sickness or holidays.

## 10.7 Professionals' views and experiences of financial support for carers

The focus groups with professionals covered a range of issues relating to CA and other financial support for carers. There was consensus that many carers did not claim CA because they did not know about it, and, consequently, did not realise that claiming the benefit would in turn help them build up entitlements to a State Pension.

Like carer interviewees, many professionals expressed the view that, on its own, the value of CA was too low to compensate a carer for not working. At the same time, a strong message that emerged from the focus groups was that the benefit system in general was perceived as a barrier that inhibited many carers from taking a job (or working more hours). For instance, participants in one focus group talked about the benefit system being '*a big restriction because we give them too much and make them comfortable.*' (Focus group 4/2.1).

Carers workers pointed out that that the rule whereby carers could not receive CA if they were in full-time education (defined as 21 hours or more a week of supervised study), could also serve as a barrier for carers wanting to improve their employability. However, they described having successfully challenged universities regarding the number of hours an allegedly 'full-time' course actually entailed, with the result that carers on whose behalf they were advocating were able to study at the same time as receiving CA because the amount of 'directed study hours' turned out to be less than 21.

Professionals gave examples of better-off-in-work calculations that they had done for carers as part of their decision-making process to come off benefits and obtain paid work. Often, it turned out that carers were unlikely to gain financially, especially if the job was part-time rather than full-time. Carers could not make work pay because they stood to lose not only CA, but a whole package of benefits as mentioned earlier, such as carer premium, IS, HB and Council Tax Benefit (CTB) – all of which could add up to a significant amount of money. According to focus group participants, ensuring receipt of housing benefit to pay for rented accommodation was one of the main priorities for carers.

A common message to emerge from the focus groups was that people were generally rewarded for working, but for carers the financial rewards were not always sufficient. Whilst the working tax credits that are now available were thought to have made it easier to move from benefits into work, the consensus view was that carers had to enter the labour market at a reasonably high level of earnings to make paid work worthwhile, otherwise the likelihood was that 'ordinary' jobs, in an office say, could make them financially worse off.

Professionals voiced other concerns about CA. For instance, the rigidity of the rules relating to the benefit was thought to be a disincentive to working, particularly in relation to carers' anxieties about unknowingly earning over the threshold. The benefit was thought to be unfair on two counts: it could only be claimed once, even if a carer looked after two or more care recipients; it did not reflect different levels of caring responsibilities, and/or intensity of caring (in the same way that DLA reflected different levels of disability). Theoretically, CA could be claimed after the age of 65. In practice, it was set against the State Pension which meant that whilst older carers might have an underlying entitlement, many stood to lose much, if not all, of it because of the overlapping benefits rule. According to carers workers, some older carers were upset that official recognition of their carer identity was taken away from them simply because they had reached a particular age.

There was general agreement within the various focus groups that benefit issues affecting carers were extensive and complicated to understand. Consequently, calculating benefit entitlements for individual carers could be very complex. Furthermore, complications could arise in relation to rules about paid work where, say, the income of a carer in receipt of CA was in turn topped up by IS. This situation could superimpose different rules in relation to undertaking paid work.

When asked, focus group participants admitted to low levels of knowledge about benefits, and, hence, a lack of confidence in their own ability to provide carers with well-informed advice. As one Jobcentre Plus personal adviser said:

*'I'm afraid to say, you know, but I think I'd be right in saying that Jobcentre Plus staff don't understand all the overlapping benefits so I don't know how the clients are going to.'*

(Focus group 3/2.3)

Reflecting the complexities involved and their own lack of knowledge, professionals had serious reservations about advising carers on benefits and/or general financial matters. Carers workers and social services practitioners tended to give carers a general overview but would then refer them on to a specialist advice centre (for instance, the local Welfare Rights Unit) for more in-depth and detailed advice. Likewise, Jobcentre Plus personal advisers would call on colleagues who were trained financial advisers for further advice.

## 10.8 Summary of key points

- There was a significant non-take up of CA, including amongst parent carers who initially did not know about the benefit.
- There was consensus amongst carers that the earnings threshold was too low and, therefore, restrictive.
- There was evidence that CA might not act as an incentive to work. It could act as a disincentive to work more hours.
- Both carers and professionals regarded the value of the benefit as too low. It tended not to act as an incentive to care.
- Carers had to think about the impact of working not just on CA, but on a package of benefits that might include HB and CTB.
- CA was not flexible enough for some carers, in particular paid work could jeopardise receipt of the benefit because of the rules regarding spreading earnings over a reasonable time period. The earnings ceiling meant that carers who were working were unable to offer employers flexibility by occasionally working additional hours.
- Professionals felt that the benefit system in general was a barrier to paid work for carers. It could be hard for carers to make work pay, especially for carers who stood to lose HB and CTB if they obtained a job.
- Older carers could be disadvantaged by the impact of overlapping benefits.
- Professionals' levels of knowledge about the benefit system were low, and they lacked confidence in their own ability to give carers well-informed advice.



# 11 Workplace policies and practices

## 11.1 Introduction

This chapter reports what study participants had to say about employers' workplace policies and practices for staff with caring responsibilities. The evidence from the literature review (see Chapter 2) showed that flexibility is a key factor in enabling carers to successfully combine paid work and caring. Flexible employment policies and practices include: part-time working; flexitime; job-share; annualised hours; working from home. The new flexible working regulations give parents of children under six, or 18 if the child is disabled, the right to request flexible working, including hours, time and place of work. It is possible that these rights will be extended to other groups in the future.

Other measures that can help carers to remain in work include leave arrangements/entitlements, which can be paid or unpaid. The types of leave arrangements vary in different organisations but include career breaks, special leave, compassionate leave, parental leave and emergency family leave. Whilst carers stand to benefit from legislation and initiatives supporting generic 'family-friendly' policies and work-life balance mentioned at the start of the report, measures specifically targeting carers, such as Carer's Leave, are less commonly found in the workplace. Other potentially useful facilities comprise information packs on caring matters, vouchers to cover the cost of elder care or support for informal networks of carers within the workplace.

The first part of this chapter focuses on issues related to formal employment policies; this is followed by a discussion of informal working practices. After making a number of points relating to self-employed carers, the chapter presents carers' suggestions for how employers could make it easier for them to combine work and care. The penultimate section reports professionals' views of issues related to the workplace; the chapter closes with a summary of the key points.

## 11.2 Formal workplace policies

Many working carers interviewed for the study did not know whether their employer had formal employment policies aimed specifically at carers. In any case, interviewees held opposing views about the value of such policies. There were those who indicated they would like formal policies because they would give certain rights to carers who would then feel less guilty about taking time off or feel that they were asking for favours. Others preferred not to know whether such policies existed in case official policy was less generous than the informal support they already received from their line manager or supervisor.

Some carers working for large employers in the public sector were aware of policies or strategies to help staff with caring responsibilities. One interviewee described how their organisation had invited carers to register this function with their manager (rather than centrally) so it could be taken into account should a problem ever arise. In their view, this was useful because it helped ensure that carers were identified as a specific group, it recognised their existence and it prevented them from remaining invisible. Furthermore:

*'It brought everybody out into the open and you began to realise of course that you weren't the only person, which is always a feeling sometimes, if you have a problem you're the only person with it. But actually you're not.'*

(Male carer, employed, 55-64)

In contrast, there were other carers who worked in environments where staff tended to maintain quite strict divisions between work and home spheres, and whose caring commitments were, therefore, hidden from managers and colleagues.

As noted earlier, formal leave arrangements take a variety of forms. Carer's leave was available in relatively few organisations, but in any case, carers in the study tended to take annual leave rather than carer's leave. Leave was used to escort the care recipient to medical, dental and other appointments that had to be arranged during the working day. This use of leave might reflect the fact that whilst some organisations did have policies that covered emergency health needs for children up to the age of 18, there was nothing for planned appointments. In any case, such 'emergency' leave was often unpaid and carers emphasised that they could not afford that. Carers were aware that (regularly) taking time off, albeit with their supervisor's permission, for hospital and other appointments had the potential to lead to bad feelings amongst other staff especially if the time off was 'informal' and additional to their annual/carer's leave entitlement. Interviewees emphasised how they felt guilty and that rather than abuse any perceived privileges, they would do their best to make up the lost time.

Leave without pay is another option that carers could use to cover (long-term) periods of care, once they had exhausted other forms of leave. Only one or two interviewees had chosen to take advantage of this particular leave provision, which depends to some extent on correctly anticipating the length of time required out of the workplace and the likely trajectory of the care recipient's condition.

Career breaks, which offer the opportunity to take a planned period of time off work without a break in service to fulfil commitments such as (long-term) caring for dependent relatives, are alternative solutions to combining work and care if the time span can be predicted and if they can be afforded. In the event, there was minimal use of this provision by carers in the study, in fact just one carer had actually taken such a break following the birth of her (disabled) son.

Many carers were able to take advantage of flexible starting and finishing times. Confirming the emphasis on flexibility in the national strategy for carers (DH, 1999), there was a consensus amongst both working and non-working carers that flexible working hours were critical to successfully combining work and care-giving. Carers explained how they could tie in work with arrangements for the person they looked after, and flexibility gave them the leeway to build up time off for appointments and other caring-related activities. The following quote is typical of many interviewees:

*'If there was an employer at the moment that wasn't flexible, I wouldn't be able to work for them, I wouldn't be able to.'*

(Female carer, employed, 45-54)

However, not all jobs offered flexible working patterns. For instance, carers who were employed in schools believed they were at a particular disadvantage because they had to be in the classroom at stipulated times: it was not possible for them to arrive late and work late to make up the lost time. Some carers managed to hold down jobs with inflexible working hours by working shifts to fit in with caring responsibilities. There were examples of carers who worked nights, say, in order to be at home during the day time for care-giving, although these sort of working patterns had negative implications for sleep and general health.

Many carers in the study obtained the flexibility they needed to combine work and care by working part-time rather than full-time hours. However, reducing the number of hours worked solved the challenges of combining work and care only when a carer's free time matched the part-time hours that employers wanted to fill. If day centre attendance left a carer free to work between 10.00 am and 3.00 pm, as happened in some instances, but jobs were only available for either all morning or all afternoon, then the problem remained.

Access to a telephone was important (but admittedly less of an issue with the advent of mobile phones). Car parking was raised as an issue by a handful of carers who claimed it would be impossible to work and care if they had to use public transport because of the additional time it would add on to the beginning and end of the working day.

Interviewees emphasised how they tried to reciprocate the flexibility they received from their employers, for instance, by telling them in advance when they were available to work or when they might be able to make up any lost time. One interviewee summed up the mutual dimensions of flexible working like this:

*'They've been brilliant and I know that if I need that time, I could have that time. I mean it's reciprocated...you know, there's been times when I've had to work a twenty-four hour shift because somebody's not come to take over and it's my responsibility to make sure the ward is covered. ...So they know that I will work twenty-four hours a day if I have to but likewise if I need time off, then I can have it. My managers are very supportive of me because they know they get 100 per cent of me when I'm at work.'*

(Female carer, employed, 55-64)

As was pointed out in Chapter 10, because the earnings threshold does not allow for wages to be averaged out over a number of weeks, the scope for working carers in receipt of the benefit to respond to employers' requests for additional hours to cover staff holidays or sickness, say, was very limited.

### 11.3 Informal practices and working arrangements

The study found evidence to support previous research (Holt and Thaulow, 1996; Arksey, 2002) showing that informal flexible practices were widespread, and possibly as significant in terms of successfully combining work and care-giving as formal employment working arrangements. These informal practices varied in type. Reflecting the nature of their job and their level of seniority, some interviewees had the autonomy to arrange their own workload, which could include working in the evenings or weekends.

Some carers recounted how they had reached an agreement about informal working arrangements with their supervisor or line manager. Generally, these agreements worked well for carers, but there was evidence that they could lead to ill-feeling from colleagues (see above). Furthermore, informal agreements were very much dependent on individual line managers and could be lost if the manager concerned left to take up another post with a different company – as one carer found to her cost.

The third type of informality was where carers had the facility to sort out working arrangements amongst their colleagues without reference to their supervisor or manager. A typical example of a general pattern was a carer looking after a husband with mental health problems who would swap shifts and weekend working with colleagues to ensure that she could be at home at potentially vulnerable times. A male factory worker described similar informal adjustments:

*'It was sorted out between the chappies, you know, the management wasn't involved, that was the nature of the way things used to be done. ...We'd done the job long enough to basically make our own arrangements. If extra production was needed, we'd sort it out amongst ourselves what extra hours we'd work.'*

(Male carer, not employed, 45-54)

Finally, it is worth pointing out that family- or carer-friendly employment policies are only beneficial if they are implemented effectively; likewise, carers need managers and supervisors who are sympathetic and supportive of their situations (Princess Royal Trust for Carers, 1995; Arksey, 2002). This was not always the case and there were reports of line managers, and human resources managers, who were unhelpful and generally contributed to the stress that carers were under rather than alleviated it.

#### 11.4 Self-employed carers

A small number of carers taking part in the study were, or had been, self-employed workers. The financially precarious nature of self-employment can be offset against the flexibility it offers in terms of accommodating care-giving. The interviews suggested that for carers who worked mainly on their own, self-employment did indeed help them to work and care. In contrast, people who employed others in small businesses said they found it very difficult to take time off because it was much more of an 'all or nothing' situation.

#### 11.5 Carers' suggestions for successfully combining work and care-giving

The list below details carers' suggestions about what would help them to work and care, provisions that are wholly, or partly, the responsibility of employers.

- Flexibility, and scope to make changes, in relation to days/hours worked, and working at home, to help deal with emergencies and planned appointments.
- Ability to set own timetable.
- Sympathetic managers and colleagues.
- Advice and information about the full range of options available.
- Jobs with particular characteristics, for example: limited number of hours so that earnings would be under the threshold for claiming CA; part-time, close to home; term-time only.
- Guaranteed car parking.

#### 11.6 Professionals' views on workplace policies, practices, opportunities and barriers for carers

Professionals taking part in the focus groups were united in the belief that paid work opportunities were available for carers who wanted to work. However, recent changes in the labour market meant that traditional jobs had been replaced by jobs in the service sector, so the jobs now available were commonly in call/contact

centres, supermarkets and home care agencies. These jobs were typically low paid, unskilled and possibly part-time and/or seasonal. An increasing number of companies operate seven days a week, 24 hours a day. Consequently, it was thought that carers who wanted to work were no longer tied to the 'normal' working hours of 9.00 am to 5.00 pm, and there was scope for them to work during the evenings and/or nights. One view that was commonly expressed was that larger organisations were more likely to be able to meet carers' needs (especially in relation to flexibility, and time off for appointments, or emergencies) than smaller organisations, who did not have any spare capacity, had deadlines to meet and had to make a profit otherwise they would go out of business.

Knowledge about perceived sympathetic or carer-aware local employers, who offered carers the opportunity to work at home, for instance, or flexible hours, was limited. Jobcentre Plus personal advisers, for example, reported that they had little direct contact with employers. On the basis of personal experience or anecdotal evidence, some professionals claimed that organisations in the voluntary or public sectors tended to be more sympathetic and accommodating of carers' needs. This was because they were likely to have introduced policies relating to carers, work-life balance or equal opportunities.

Professionals expressed doubts as to the usefulness of some forms of leave policies. For instance, they hypothesised that a carer looking after someone with dementia might find that the dementia was more severe, and the care recipient more dependent, after a career break or a year's unpaid leave.

Another common theme that emerged in the focus groups related to the potential obstacles that middle management could create for carers if they did not implement policies or give carers information about how the policies worked. As one carers worker said:

*'The policies are all in place, top down all is wonderful, but as soon as you hit middle management level: 'I can't afford to have any staff off, so I'm not going to tell them about this'.'*

(Focus group 2/3.3)

Other perceived barriers that had the potential to make it difficult for carers to combine work with care-giving included organisational policies to move managers around which meant that carers had to repeatedly tell a new person about their caring situation, and did not have the opportunity to build up good relationships with them. For people working in small teams, feelings of obligations to work colleagues, as well as personal pressures arising from one's own values, were highlighted as barriers. Carers workers emphasised how difficult it could be for some carers to receive, or make, telephone calls whilst at work. If they wanted information or advice from an organisation that was only open during the normal working day, for instance, social services or a carers organisation, and telephone calls were frowned upon, then it could be very difficult for carers to even consider working for such companies.

There was evidence that the majority of professionals taking part in the focus groups believed there was a strong case for a combination of both legislation and awareness raising<sup>19</sup> to bring about changes in workplace practices for carers, rather than leave it to the goodwill of employers – who might well be sympathetic towards carers, but at the same time not in a position to accommodate carers' needs because of business demands. Suggested initiatives included:

- policy measures that gave employers certain responsibilities to carers that would encompass paid leave and employment rights regarding flexibility of work and time off (similar to anti-discriminatory practice and equal opportunities, and maternity/paternity leave);
- help for employers to provide more part-time jobs and more job-share opportunities;
- incentives or payments to encourage employers to recruit carers, for example subsidies to employers who recruit carers to cover the costs of any workplace absences;
- 'Carer' symbol for employers meeting stipulated commitments (i.e. a 'carer' equivalent to the Disability Symbol),<sup>20</sup> which might attract carers to work for that particular organisation.

## 11.7 Summary of key points

- Working carers reported benefiting from both formal employment policies and informal working arrangements; for many, these were essential to combining work and care.
- Carers were not always aware whether or not their employers had formal carers' policies.
- Many carers could not afford to take leave if it was unpaid. They tended to use annual leave for appointments and other care-related activities. Few organisations offered carer's leave.

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<sup>19</sup> One carers centre carried out awareness raising talks for local employers, with the underlying aim of improving workplace policies and practices for carers.

<sup>20</sup> See web link: <http://www.jobcentreplus.gov.uk/cms.asp?Page=/Home/Employers/DisabilityServiceshelpforEmployers/DisabilitySymbol> (accessed 30 May 2005). A precedent was set some years ago by employers in the Wearside area of the north east of England who developed a Carers in Employment Charter which commits them to four principles aimed at providing support and information to enable employees to balance their caring responsibilities with their workplace role.

- Flexible starting and finishing times, and the ability to take time off in emergencies and for planned appointments, were particularly important for carers. Informal flexible working arrangements were just as important as formal ones.
- Part-time working was one way to obtain flexibility, but the times carers had available to work were not necessarily compatible with the hours employers wanted to fill.
- Carers were keen to reciprocate the flexibility accorded them by managers if staff were needed to cover holidays or sickness.
- Sympathetic line managers and colleagues were important in helping carers combine work and care successfully.
- Self-employment offered carers the flexibility to accommodate care-giving, but it was more conducive to carers working on their own than for carers who employed other people in their business.
- Professionals believed that employment opportunities did exist for carers who wanted to combine work and caring, but such jobs were typically low paid, unskilled and possibly part-time and/or seasonal.
- Professionals suggested a combination of legislation and awareness raising had the potential to encourage employers to change workplace practices to better accommodate working carers' needs.

# 12 Support to help carers combine work and care from other agencies

## 12.1 Introduction

This report has thus far concentrated on carers' involvement with Jobcentre Plus and social services. Potentially, carers' support networks are more wide ranging and this chapter of the report looks at other agencies with whom carers in the study engaged, primarily from the point of view of how they supported carers who wanted to combine work and care-giving. The first part looks at carers and other voluntary organisations; the second part looks at the National Health Service (NHS); the third part looks at local training opportunities; and the fourth part looks very briefly at how some carers of people with mental health problems have used or been helped by the police. There is then a section on inter-agency collaboration, prior to a summary of the key points.

## 12.2 Voluntary organisations and support for carers

Carers centres provide information, advice and support to assist carers obtain the services they need. Carers held mixed views about them: they had a lot of appeal for some carers, and none at all for others. Parent carers as a group appeared not to get involved with carers centres but instead belonged to organisations that were specific to their child's needs – possibly because they tended to think of themselves primarily as parents rather than carers. In the event, about half the carers in the study were in contact with a range of voluntary organisations. As well as local carers centres, these included branches of disease-specific organisations such as the Alzheimer's Society, the Multiple Sclerosis Society and Headway. Some carers of people with mental health problems belonged to organisations like Rethink and Making Space, as well as regional voluntary sector support agencies providing carers' advocacy services. Carers' levels of involvement varied, from receipt of newsletters to active roles such as volunteer or trustee.

Between them, the four carers centres collaborating with the study provided the following support for carers: information packs; benefits checks; form completion (for Carer's Allowance (CA) and other benefits); telephone help line; training courses (see Section 12.4); referrals for specialist advice (for instance, in relation to benefits or pensions) or services; support groups; carers support programmes; young carers projects; newsletters; leisure activities; awareness raising talks for employers. Two of the centres could access 'one-off' grants for carers that could be used to purchase work on the garden or redecorating/spring cleaning a house - time-consuming activities for carers who combined work and care-giving. As noted above, one of the four carers centres had a contract with the local social services department to undertake carers' assessments (see Chapter 9). Centres were opportunistic: as part of Carers Week 2005, which took the theme of Work, Rest and Play to reflect the 2004 Carers (Equal Opportunities) Act, one centre had decided to organise a special telephone helpline day around opportunities for returning to work, and training provisions.

Carers workers said that a frequent problem related to information and knowledge: carers did not know about available services, what they were entitled to or the right questions to ask. To this end, centres spent a good deal of time and effort in providing carers with relevant information. One estimate was that it could take up to half-a-day to collate a comprehensive information pack tailored to an individual carer's situation and needs. For their part, carers praised the information they received from carers centres about welfare benefits. Non-working carers particularly welcomed being told about CA, and in some cases being given help to complete the application forms (see Chapter 10).

Carers centres helped employed carers who were struggling to combine work and care by providing a listening ear or access to counselling services. In addition, they gave carers information about available benefits, advocated on their behalf in any dealings with social services, and helped carers gain access to funding for short breaks. Newsletters were seen as a particularly useful way for employed carers to keep in touch, especially for those who found opening hours quite restrictive because of heavy work commitments and who were cautious about asking for any more time off.

Accessibility emerged as an issue from both the interviews with carers and the focus groups with professionals. Carers workers, for example, recognised that it could be difficult for working carers to access their organisation during normal working hours, and one of the centres was planning to offer extended opening hours to cover evenings and weekends. Similarly, employed carers commonly reported that finding the time to take part in courses run by carers centres was difficult, especially if they were held for, say, up to six weeks at specified times.

Carers workers identified three topic areas where further training to learn about new initiatives and/or update their existing knowledge would help them improve their services for carers. These areas were: the new Carers (Equal Opportunities) Act 2004 (see Chapter 9); community care law; welfare benefits (see Chapter 10).

### 12.3 The National Health Service and support for carers

Many carers see General Practitioners (GPs) as their first port of call for advice and information, and signposting to other services (Henwood, 1998). Carers workers were aware of GP surgeries that were identifying carers and creating a database of patients with care-giving responsibilities. Such initiatives have been a Government priority for a number of years now, and there is a performance target in the new General Medical Services contract that came into force in April 2004 whereby a general practice can receive additional remuneration if they initiate carer identification and a mechanism for the referral of carers for social services assessment.

Carers taking part in the study had mixed perceptions of how supportive their GP had been. Some carers described how helpful GPs could be and how they appreciated the additional difficulties faced by carers trying to work as well as care. Interventions by doctors included advocating for increased service provision on behalf of carers with social services, and providing sick notes to cover absences from work for care-related reasons.

**Case example of help from a GP:** An interviewee asked her supervisor for unpaid leave at a time when her caring situation was particularly difficult. The supervisor suggested instead that she went to see her GP to see if she could get a sick note. The carer told her doctor about the difficulties she was having in combining work and caring for a disabled son, as well as elderly parents. The doctor was immediately sympathetic, agreeing that she could not work under those circumstances and willingly gave her a sick note. In the end, she had some three or four months off work.

In contrast, occasional examples were given of doctors not recognising patients' caring role, not providing information about support services and not making referrals to other agencies. Difficulties could arise for carers and care recipients who did not share the same doctor or surgery, especially in relation to information sharing.

As stated earlier, hospital discharge is a time when carers' support needs can be identified and they can be signposted towards services and benefits such as CA, although this does not always happen in practice. A small number of employed carers had relatives in hospital when their interviews for the study took place. Discussions were taking place between them and social services/other agencies about aftercare and support in the community. Whilst they could not be confident that the care package put in place for the person supported would enable them to continue to combine work and care as before, they had made their employment commitments known and were hopeful they would be adequately addressed. The alternative was not to agree for the care recipient to return home, as one carer had threatened (see Chapter 9).

There was very little evidence from the study about the extent to which hospital consultants recognised or supported carers' work commitments. However, one carer (a lone mother) reported that her son's psychiatrist had suggested that he was not getting enough support at home and that she should give up her job – which she subsequently did. A carers worker illustrated the difficulties that working carers typically faced in relation to hospital appointments: consultants running up to two hours behind time in their appointment schedule, and line managers being unsympathetic when the carer finally returned to work.

The evidence is mixed and fragmented: overall, it is difficult to judge how helpful the NHS was in recognising and supporting carers' employment commitments. GPs appeared to be sympathetic and supportive; but the extent to which hospital consultants supported them is less clear.

## 12.4 Local training providers and opportunities

Opportunities for training and updating work skills are important for carers who want to find work, especially for those individuals who have been out of the labour market for some considerable time or whose last job was in a declining industry. However, Jobcentre Plus personal advisers expressed the view that carers taking part in Work Focused Interviews (WFIs) tended not be interested in attending retraining courses to improve their employability. This was because carers did not have the time, and more often than not they had only recently given up work to take on a caring role at the time they attended an interview. In comparison, carers who had been out of the labour market for some considerable time were more likely to be interested in updating their work skills with a view to future employment prospects.

In the last few years, one of the carers centres collaborating with the study had run two groups, in partnership with the local authority social services and education departments, aimed at helping carers find work. Participants in the groups had undertaken work-related activities/courses; confidence building was another important element. Initially, some carers went on to undertake voluntary work, and another embarked on an adult teaching certificate. Over a period of time, four of the seven carers who took part in the first group obtained paid work and a fifth started a university degree course. Reflecting these patterns, the general view was that it could take some considerable time for a carer to gain the confidence and skills necessary to obtain, and sustain, a job. As one of the carers workers involved in the two groups said:

*'What's really important is to recognise that you need those small manageable achievable steps and at the end of that course, the evaluation would have been yes, you know, we learned quite a bit, we had social contact and yes, it was a jolly good time, but in terms of hard outcomes it's much, much too early. But three years down the track, you know, there are those results.'*

(Focus group 2/3.2)

Whilst social services practitioners struggled to identify potential training providers, staff from Jobcentre Plus and carers' organisations were able to name four or five in their respective localities. These included local colleges of further education, learning and skills councils, training providers and Learndirect online learning centres which provide access to e-learning opportunities. Professionals recognised that online learning would not appeal to all carers, but pointed out that this approach did offer flexibility as carers with a home computer could fit learning into their caring schedule and work at a pace that suited them.<sup>21</sup>

Professionals held mixed views about the value of providing training courses purely for carers. Arguments in favour of holding generic courses included achieving the required numbers to make a course viable, attracting people with different perspectives on life to bring something fresh to carers and help widen their social networks, and not putting a carer label on carers. On the other hand, carer-specific courses were seen as beneficial because they provided carers with a 'safe' environment and the opportunity to be with people who shared the same experiences and/or anxieties.

The cost of undertaking retraining was raised by carers workers as a barrier for carers wanting to find work. Carers' organisations could apply for bursaries for carers, however, the criteria were tight and courses had to relate to skills to enable carers to get a job, as opposed to, say, learning to drive to help overcome transport difficulties. Furthermore, whilst recipients of some benefits were eligible for reduced fees, carers in receipt of CA had to pay the full fees.

Professionals made a number of suggestions regarding suitable courses for carers who wanted to find work. One idea was for an initial general course aimed at confidence building and information sharing, to be followed by more specialised courses that were open to all. Another suggestion was to run courses similar to the 1980s Government TOPPS (Training Opportunities) courses for women returners. Participants would be other (former) carers in similar situations who could then support each other. As well as learning new skills, suggestions for course content included invited speakers from different agencies to give participants information about available benefits, services, what to do if the care recipient became ill, pensions and so on.

A third proposal was to run 'access' courses that helped to get carers 'into the system'. One suggestion was a course on, say, 'Computing for the terrified', so carers could learn basic skills in computing and build up their levels of confidence prior to attending a follow-up course at the local college of further education. The final suggestion was for employment-based courses which were actually held on the premises of large employers but run by an external agency; it was thought that attending a course within the workplace could boost confidence levels.

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<sup>21</sup> There is now a small body of research on carers' use of information and communication technologies, showing that age, gender, socio-economic status and caring responsibilities shape carers' use of the Internet (Keeley and Clarke, 2002; Blackburn *et al.*, 2005).

## 12.5 The police force and support for carers

Two carers spontaneously commented on the valuable support they had received from their local police forces when relatives they were caring for went missing. In the case of one employed carer, these sort of incidents occurred whilst she was in work, and the police were instrumental in helping the ensuing search.

## 12.6 Inter-agency collaboration

Recent years have seen increasing Government emphasis given to inter-agency working. One topic discussed in the focus groups with front-line professionals working with carers was to try to determine the extent to which staff from Jobcentre Plus offices, social services departments and carers' organisations collaborated with each other in efforts to support carers around work and retirement issues.

Effective joint working requires a certain level of knowledge about the roles and responsibilities of relevant organisations. However, the evidence from the group discussions suggested there were some important information gaps in relation to knowledge about what local organisations existed and the type of services they provided.

Jobcentre Plus offices appeared to be the most isolated; personal advisers had little knowledge of, or contact with, social services or carers' organisations. Likewise, there appeared to be very low levels of knowledge amongst social services staff and carers workers about Jobcentre Plus services in general, and the type of support available to carers in particular. Not surprisingly, then, direct communication between professionals from social services and/or carers centres and personal advisers was very limited. Whilst a few of the former said that they occasionally suggested to a carer that they visited a Jobcentre Plus office and to that end gave them the appropriate telephone number, generally speaking they did not know what services were offered or how personal advisers could help carers interested in finding work. Those who were slightly better informed had generally acquired their knowledge second-hand from carers who had told them about their experiences, or had some personal experience themselves of visiting a Jobcentre Plus office.

Whilst referrals to (and from) Jobcentre Plus were minimal, there was one positive example which demonstrated the value of effective collaboration. One of the carers centres had asked their local Jobcentre Plus for help to keep a client with dementia in employment. They had arranged for transport to take him to work, which in turn allowed his wife who looked after him to keep her part-time job. The carers worker was:

*'...astounded by the help they did give. It was offered rather than dragged out of them!'*

(Focus group no 3/3)

The focus group discussions suggested that social workers and carers workers had limited awareness of available services from The Pension Service, which is also part of Department for Work and Pensions (DWP). What knowledge there was tended to be derived from leaflets publicising information forums and drop-in centres, although there was one example of a carers centre that had invited The Pension Service to give a talk to their volunteers on pension credits. This event came about, in part, as a result of having a named individual in The Pension Service to contact, a link which facilitated more effective collaborative working.

In contrast, social services practitioners and carers workers had developed effective working relationships with each other. Other local organisations that staff from both types of agencies knew about, and/or made referrals to, included Crossroads – Caring for Carers, Age Concern, and carers groups attached to disease-specific bodies such as the Alzheimer's Society, Stroke Association, Parkinson's Disease Society or the Multiple Sclerosis Society. The local Citizen's Advice Bureau, benefits advice centre or law centre were also used to help with the more specialist issues relating to finance or legal matters.

As just noted, there was clear evidence that Jobcentre Plus personal advisers had little, if any, knowledge about local carers centres. They were more aware of social services provision, but in some cases that was as a result of personal dealings rather than through professional channels of communication. Personal advisers were keen to help carers, though, and those who knew relevant telephone numbers (e.g. if they were available on desktop computers) would pass these on. The point was made that advisers themselves would appear more credible when giving out telephone numbers if they could answer carers' queries about what services were offered and how the organisation in question could help them.

There was a consensus amongst personal advisers that obtaining information about social services provision, say, or locating a specific contact name could be difficult unless the adviser was involved with a particular group of customers, as was the case for, say, a disability employment adviser working with disabled people. Then, networking happened automatically and levels of knowledge about social services and disability organisations increased. Otherwise, it was more a case of learning about other organisations by serendipity rather than in any structured way. This was seen as difficult for generic personal advisers who were tied to their desks by electronic diaries, did not see many carers, and did not have the opportunities to build up networks or relationships with social services or carers' organisations.

In relation to the 'image' problem noted earlier (see Chapter 8), one view put forward by Jobcentre Plus staff was that they were seen as the 'poor relations' by, say, social workers and probation officers. Not being highly regarded in a professional capacity could then be a further obstacle in relation to networking and collaborative work with other local service providers.

A common theme to emerge from virtually all 12 focus groups was a desire by participants to learn more about the concerns and services of the two other types of organisations taking part in the present research with a view to increasing knowledge levels and also encouraging more collaboration and cross-referrals.

Finally, it is worth mentioning what the various groups of professionals said about collaborative working with the NHS. Some social workers reported working quite closely with primary healthcare staff. For instance, they received referrals from GPs concerned about a carer's capacity to continue caring, or were in contact with health visitors about carers on their caseload. Carers workers tried to exploit training opportunities for primary healthcare staff in their protected learning time programme. They did not find this an easy task, however; indeed, one worker described this as '*flogging a dead horse.*' (Focus group 3/3.1). Carers workers also undertook presentations and attended meetings with GPs, district nurses and health visitors with a view to getting information about services available in the voluntary sector in general, and for carers in particular, included in the handbooks of primary care staff. Personal advisers commented on strategies that had been deployed in the last two years to help reduce the levels of Incapacity Benefit (IB) claimants, which encompassed networking with organisations, including GP surgeries.

## 12.7 Summary of key points

- Not all carers wanted assistance from carers centres; those who were in touch were generally very positive about the information, advice, form filling and other services they received.
- Carers centres indirectly helped carers remain in work by helping reduce stress levels through a variety of means, including: listening, counselling, advocacy, referring to social services and accessing short breaks.
- It could be difficult for carers who worked (full-time) to access carers centres' services because office hours were the same as their working hours.
- Carers centres helped non-working carers by signposting them to available benefits, and helping them to complete claim forms for CA.
- The evidence was limited, but there were indications to suggest that carers' employment commitments were more likely to be recognised and supported by GPs than hospital consultants.
- Front-line professionals held mixed views regarding the enthusiasm of carers to attend retraining courses. Carers who were keener were more likely to have been out of the labour market for some time.
- Whilst some professionals were in favour of carer-only training courses, others believed that generic courses were more beneficial to carers.
- For some carers, the police were an essential support when the person they were supporting went missing.
- Inter-agency collaboration between Jobcentre Plus, social services departments and carers' organisations was limited, in part reflecting important information gaps about what organisations existed to support carers and what services they offered. Jobcentre Plus staff were the most isolated professional group; personal advisers' knowledge of the support provided by carers centres and social services was very limited.

## Part 5

Important issues for  
different groups of carers



# 13 Carers and diversity

## 13.1 Introduction

This part of the report concentrates on different types of carers, and tries to tease out any issues about caring, work and retirement that are particularly distinctive or relevant to specific sub-groups. Many points have been raised earlier in this report under the relevant topic area, for instance financial support for carers, social services provision or workplace policies and practices. The groups looked at are, in order: parent carers of disabled children; ethnic minority carers; rural carers; unsupported carers; carers of different ages; and former carers. These groups have been selected because the literature suggests they might face particular issues, or there is policy interest in them.

## 13.2 Parent carers of disabled children

There were over 25 parent carers in the study sample looking after children whose ages ranged from four years to 37. Some parent carers had two (and in one case, three) disabled children; others were looking after elderly parents or spouses as well as a disabled child. Family circumstances also varied widely, for example quite a number of interviewees were lone parents. There were examples of families where the mother was the main breadwinner and (initially) the father stayed at home to look after the disabled child.

Most of the parent carers who took part in the study had children who were disabled from birth, and the majority of parent carer interviewees were female. As reported in the literature review (see Chapter 2), the literature suggests that mothers of disabled children tend to stay out of the labour market longer than mothers of non-disabled children (Baldwin, 1985; Kagan *et al.*, 1998). The experiences of parent carers taking part in the present study varied and included some who had returned to paid work soon after their disabled child was born; others who had returned to work when the child (and/or other children) started school; and yet others who had purposely chosen to stay at home whilst all the children in the family were still at school. There were carers who were not taking part in paid work, but instead were

involved in voluntary work such as school governor or welfare rights/parental adviser. Two parent carers were looking after children who had developed mental health problems in their mid to late teens; both their working lives had been disrupted because of care-giving. Their adjustments included giving up work for a time, before changing to less demanding jobs.

Some factors had the potential to make it easier and more manageable to work and care. As far as workplace practices were concerned, these included flexible working hours, convenient shift patterns and working locally to reduce travelling time. Interviewees were not asked directly about their experiences of the new rights under the Flexible Working Regulations entitlements. However, no carers spontaneously mentioned this Government initiative, suggesting they did not know that parents of disabled children under 18 could request flexible working such as changing hours or working from home.<sup>22</sup>

Active support from partners, other family members (for example, grandparents and other children) and friends was important in helping parent carers to work. So, too, were childminders, although childminders and nurseries able to accommodate disabled children were few and far between. Social services provision such as day centres was important for some parent carers of adult children.

**Case example of how a parent carer managed to combine work and care:**

This carer managed to work and care more or less continually following the birth of her disabled child (now 37). She worked opposite shifts to her husband and also weekends. She had help from friends and neighbours, as well as colleagues with whom she could swap shifts to avoid inconvenient early starts and to cover emergencies. In spite of all this support, she still found working and caring exhausting, and at one point took six months' sick leave. As well as the negative impact on her health, she saw very little of her husband.

The evidence suggests that parent carers spent time searching for the right job to suit their particular family circumstances. Factors that they took into consideration included hours of work, term-time-only working, and distance from home. A trained nurse, for example, who took a higher education course which then led to her 'dream' job deliberately did not look for work in a hospital because she did not believe she would get the flexibility she needed in a nursing environment.

There were particular problems for parent carers wanting to combine work and care. Difficulties relating to changed/new service provision at key transition points have already been discussed (see Chapter 9). Uncertainties about a disabled child's shift from junior school to secondary school, or from secondary school to training college made decision-making about whether, and when, to start work problematic.

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<sup>22</sup> One professional taking part in a focus group who was also a carer of a disabled child did know about this entitlement, and had found the option to take unpaid leave during the school summer holidays very helpful.

Parents did not know how well their child would settle in, or how long this process would take. With regard to training college, they did not always know which college their child would go to, for how many days a week and what the transport arrangements would be. There was also the possibility that employed carers might have to give up work if the new care arrangements were not compatible with their hours of work. As stated earlier in the report, parent carers missed the support of older children who had now left home but who had previously covered the time between the end of the school day and the end of the working day (see Chapter 5).

Parent carers, both working and non-working, were asked what would make it easier for them to both work and care. Their suggestions are:

- shorter school holidays;
- after-school clubs, social activities and clubs for disabled children; additional allowances for childminders of disabled children; childcare for non-disabled children;
- after-day centre provision;
- flexible and reliable paid carers (via direct payments); one-to-one care for disabled teenagers;
- flexible working practices; sympathetic colleagues and supervisors;
- the right job in terms of hours, term time only and close to home;
- a benefit system sympathetic to part-time workers.

### 13.3 Ethnic minority carers

This section concentrates on the material relating to the 15 carers taking part in the study from ethnic minority communities. The literature indicates that carers from ethnic minority communities are disadvantaged in terms of social services provision (SSI, 1998b) and under-represented as far as carers' assessments are concerned (Arksey *et al.*, 2000; Hepworth, 2001). Twelve of the 15 carers were female. Eleven lived in the inner city area (Site 2), and the remaining four in the declining industrial area (Site 4). The amount of formal and informal support carers received ranged from no help whatsoever to a considerable amount. Just five of the 15 carers were in paid employment. Four of the five worked for over 30 hours per week, and estimated their care-giving responsibilities were between 20 and 25 hours per week. The fifth carer both worked and cared for fewer hours.

Ethnic minority carers made similar points and observations to other carers. Staying at home with young children, for instance, was seen as important by some interviewees, who were planning to return to work but not until their children had finished school. Decisions about taking on a caring role centred on responsibilities and obligations towards elderly parents.

Poor health was a specific issue for ethnic minority carers. Over half of this particular sub-sample perceived that their own health was poor, more often than not

reporting that health problems were related to care-giving. Some carers gave their poor health status as the primary reason why they were unable to take part in paid work.

Interviewees' opinions about help from social services ranged from genuine praise to strong criticism. Two carers had put in complaints in the past, which in both cases had led to improved services. One person described how for a long time she could not get respite care for her young son. This was because her social services department had a policy about placing children in a similar cultural setting, and they did not have enough black respite workers. Eventually, the child went to a white foster carer which worked out satisfactorily. The interviewee regretted the lengthy delay, and believed that the situation could have been resolved much earlier if only the social worker had asked her, as the parent, what sort of arrangement she would like. This same carer had been admitted to hospital on two different occasions through stress and fatigue; her experiences with social services prompted her to believe that carers received no help until they were actually in crisis yet at the same time, social workers were not prepared to devise contingency plans to deal with emergencies.

Only one ethnic minority carer was unable to read or speak English. However, she reported (via an interpreter) that this did not cause any undue problems when dealing with social services as she would always request an interpreter who spoke her language, and/or would take one of her children with her who would translate on her behalf. Likewise, a relative had completed the application form for Carer's Allowance (CA) on her behalf and whilst she now received the benefit, at the same time she knew nothing whatsoever about it.

Levels of knowledge about important aspects of paid employment had been an issue for other carers in the past. For instance, an interviewee who took up residence in the UK in her early 20s explained how, when she first arrived, she knew nothing about income tax and national insurance contributions. Her understanding gradually improved having worked for over 15 years in the clothing industry, but new situations could still be troublesome. For instance, after receiving a pensions forecast, she wrote to ask for a clearer explanation because she did not understand the one she had been sent.

To sum up, health problems were more prevalent in this small sub-sample; some ethnic minority carers had experienced difficulties in accessing services and/or lacked knowledge about matters related to welfare benefits and paid work.

### 13.4 Rural carers

This part of the report focuses on the interview material from the carers living in the rural area (Site 3). There were 20 rural carers, 17 women and three men. Ten female carers were working for employers as well as care-giving; a further two who were working and caring were self-employed. Another female carer was on a five-year career break. The remaining four female carers, and the three male carers, were not working.

The interviews with rural carers raised many common issues, for example in relation to priorities and accommodating work and care, that emerged in the accounts of carers from the other three research sites and these will not be repeated again.

Carers from rural areas can find it even more difficult to obtain advice, help and assistance than carers in urban areas (DH, 1999). Levels of help available to them, from both statutory and voluntary organisations, can be relatively low, and services may be difficult to access, involving long journeys to day centres or hospitals. For people without their own car, getting to work can be difficult in areas where public transport is limited or even non-existent.

As far as rural carers in the present study were concerned, one carer was exceptional in that her disabled husband was provided with carer-blind services (see Chapter 9). Without this enhanced service provision, the carer was adamant that she could not have worked as many hours as she did (i.e. 30 hours per week) – work that could also involve spending time away from home. Other carers, both working and non-working, received lower levels of support. It could be difficult for people living in remote villages to recruit local paid carers, even if in receipt of direct payments to fund such services.

Some carers had no social services support whatsoever. This was often by choice, because the care recipient (or the carer) was unwilling to accept help from outside the family and/or unwilling to pay charges. Carers had concerns about the quality and reliability of service provision; non-working carers tended to express opinions that were more negative about social services than did working carers.

The predominant difficulty that emerged as distinctive to rural carers related to poor public transport, and having to travel long distances to work and/or to hospital appointments. If work was not available in the immediate locality, then this could make it harder for carers to combine work and care. This presented carers with a dilemma, in that it could mean that owning a car was less a matter of choice and more an expensive necessity. However, the cost of running a car was not necessarily financially worthwhile for those carers who were restricted in terms of the number of hours they could work, or who were on low rates of pay.

### 13.5 Unsupported carers

'Unsupported' carers, i.e. carers in receipt of neither CA nor social services provision, were specifically targeted for the study because of policy interest.<sup>23</sup> Across the four research sites, 25 carers received no statutory support in recognition of their care-giving role, either through the main benefit for carers or from social services. Thirteen of the 25 unsupported carers were in paid employment, and 12 were not. The reasons why both working and non-working carers decided not to accept any help from social services have been detailed earlier in the report (see Chapter 9).

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<sup>23</sup> Some of these carers were in receipt of other welfare benefits.

These included: carers or care recipients being unwilling to accept social services assistance, services regarded as poor quality, unreliable and inflexible; social services charges for services; lack of appropriate services; fear and lack of trust in social services.

As far as not getting CA was concerned, this is understandable for the 13 employed carers. They were not eligible because they earned over the earnings threshold (see Chapter 10). But what made it possible for them to work and care without any statutory support? The answer to that question is two fold: flexibility and supportive colleagues (see Chapter 11). The majority of unsupported carers were in jobs with flexible working practices, so they had leeway in terms of starting and finishing times. Some carers had also been able to make individual arrangements, for instance one person had arranged to work at home after 3 o'clock every day so as to be there when her disabled daughter returned from school. A rural carer worked weekends, and was able to take her husband to work with her. Carers also had supportive managers and colleagues, and were able to make their own informal arrangements to cover care-related activities.

There were 12 non-working carers who did not get CA. Instead, eight of the 12 received other benefits, which included Incapacity Benefit (IB), Income Support (IS), Jobseeker's Allowance (JSA) and Widow's Pension (WP). Some of these carers were also in receipt of an occupational pension. They might possibly have had underlying entitlements to CA but for one reason or another were not receiving any benefit support as carers. A further three carers derived their income from other sources, in one case from rents from property and in the other two cases from an occupational pension and a private pension. The twelfth carer, who had been made redundant from a job in a declining industry and could not get alternative permanent work, described his dislike of having to sign on every two weeks to claim JSA. Gradually, this process added to his already depressed state and he decided to start claiming his private pension which meant that he could no longer get the benefit.

### 13.6 Carers of different ages

The age range of carers taking part in the study was 28 to 64; 33 carers were 49 years or less, and 47 carers were aged between 50 and 64. As noted in Section 13.5, professionals had mixed views about whether or not age influenced carers' decisions about working (see Chapter 6).

The data from the interviews with carers were examined with a view to identifying what impact age had on undertaking a caring role. Close scrutiny indicated there was no strong evidence to suggest a significant association or relationship between age and deciding whether to care. Just over one-quarter of the sample had started caring in their 20s which meant that in life-course terms, they were in the early stages of their employment careers. The majority of these were parent carers, for whom there was little question but that they took on the additional responsibilities of looking after a disabled child. On the other hand, there were also individuals who,

it could be argued, had made more of a conscious decision to take on a caring role at a relatively early age. This group comprised carers who had married someone who was disabled or suffered from a chronic condition such as arthritis, or who had a disabled child from a first marriage. There were also a few individuals who had taken over care-giving for siblings because the previous carer (a parent) had died.

The impact of care-giving on younger carers' subsequent labour market participation varied. Some parent carers had chosen to stay at home with their children whilst they were still at school. Others had been able to sustain paid work whilst caring, for instance by taking jobs that fitted in with school hours, and/or by having additional support from other family members, friends and social services.

Over one-third of carers interviewed for the study had started caring at the age of 45 and over. This might have been to look after a spouse, elderly parent(s) or sibling. Carers varied as to where they stood in relation to the labour market when they took on care-giving responsibilities. Some were in paid employment, others were self-employed and yet others were not in work. At the time of interview for the study, some carers had successfully managed to combine work and care over the subsequent years. This had been accomplished either with or without help from social services and, for some carers, involved a change of career or job to one that afforded more flexibility, say, or involved part time hours or a different location (see Chapters 5 and 9). Others had stopped working, but for a wide variety of reasons and it would be misleading to assume that carers only stopped working to take on full-time caring role. To recall points made in Chapter 4, quite a number of carers had stopped work for reasons beyond their control, for example they were made redundant, they lost their job because the company they worked for went bankrupt or they had become disabled or suffered a chronic illness themselves and had taken early retirement.

It was not clear from the interviews with carers how service provision at different times or stages in caring, or employment pathways, might have been more or less useful. In any case, the timing of service interventions would also reflect carers' personal perceptions of stress and burden, and coping strategies to deal with these (see Nolan *et al.*, 1996, for a discussion of stress and coping and their implications for care-giving).

### 13.7 Former carers

The research literature (Nolan *et al.*, 1996) describes a range of emotional and practical difficulties that carers experience when caring ceases, for instance if the care recipient enters nursing or residential care, or dies. This can also be a time when support from statutory services is minimal.

The evidence from the interviews with carers about issues relating to people whose care-giving activities had ceased was limited. Just three people (two women and one man) who took part in the study were former carers. The male carer had stopped

caring when his wife left him some two or three years previously to live in a different town with another close relative. Some years before that, however, he himself had taken early retirement from the National Health Service (NHS) as a result of an accident at work.

In contrast, the two female carers had continued to combine work and care until the person they were looking after had died. This meant that the issue of a subsequent return to the labour force was not relevant. One person was able to continue actively working with the help of family and colleagues. However, the second person took 12 months' unpaid leave at one point, before returning to work on reduced hours. Whilst at that point in time she did not want to give up her professional career entirely, because of her own health problems she had since decided to take early retirement.

Professionals from all occupational backgrounds taking part in the focus groups said that generally speaking they were not involved with former carers to any great extent. For instance, if the care recipient died or entered long-term care, then the carer was no longer classed as such and they would then leave a social worker's caseload. Jobcentre Plus personal advisers would only see former carers if they had made a claim for a different benefit such as JSA, in which case discussions would focus on future work rather than past caring activities. It was not clear to what extent advisers would recognise the particular needs of former carers, for example, in relation to low levels of confidence or self-esteem, or loss of contact with the labour market. Carers workers said that older former carers might continue their contact with carers' organisations via carer support groups, but carers below state pension age were more likely to break the links.

At the same time as facing a possible gap in support from statutory services, former carers could also find they lacked important resources once their care-giving ceased. Professionals spontaneously talked about carers' loss of confidence, their very small social networks and consequent loneliness, and their lack of identity because their caring role had come to an end. Financially, they could be much worse off because their own, and the care recipient's, benefits stopped. There could also be an impact on their ability to get out and about if the care recipient had been entitled to a Motability vehicle and this had been returned. In the words of one carers worker:

*'When bereavement happens, everything else just piles up. All the problems come out, everything, and it's like you've got three more hurdles for every one that you had before.'*

(Focus group 2/3.3)

The Government is keen to encourage and support former carers back into the labour market (DH, 1999). Given that former carers can suddenly confront a huge void of time, especially if the person they have cared for has died, then in principle this space could be filled by paid work. However, there was a consensus that former carers could find it very difficult to re-enter the work force when the caring situation

changed, especially if the care recipient had died. Workers from carers' organisations talked about carers being 'rudderless' and having to cope with grief and a complete loss of identity. A number of examples were given of people who, after caring for 30 or more years, suddenly found themselves without any social or financial resources, yet at the same time they had lost all confidence in themselves and believed they had no skills that were of any value to an employer. Carers workers in particular believed that it took carers a long time to overcome the barriers into the labour market, if indeed they wanted to return to work. This aspiration could not be assumed, as one carers worker explained:

*'I mean some of the carers that come to the [support group] that are under sixty-five are just so relieved not to be carers any more that they do actually go to various things, cyber centres and things like that, but it's more for pleasure than to actually return to work. I think it's just such a relief. And also I think caring takes such a toll on their own health that we often find people then start hospital, 'cos they've got their own major health problems.'*

(Focus group 1/1.4)

Remarks from Jobcentre Plus personal advisers showed their sensitivity to issues related to bereaved former carers who were still grieving. One adviser recalled a telephone conversation with someone whose wife had died just three weeks earlier:

*'I think he's still in shock to be honest with you from the phone call I had with him the other day, I don't think he knows what planet he's on at the moment. It's very, very early days and I think we need to make sure that you're not pushing people too soon.'*

(Focus group 4/2.2)

There was a feeling that training courses aimed at improving confidence and motivation, together with careers advice, would make it easier for carers wanting to return to the workplace. Professionals generally felt there was a need to develop similar training opportunities for both former carers and carers who wanted to return to work whilst still caring. These were discussed in the last chapter in the report so will not be repeated again.

## 13.8 Summary of key points

- Carers are often thought of in generic terms, but in reality, carers are diverse and heterogeneous, reflecting socio-demographic characteristics and other factors such as the condition of the care recipient, the nature of the caring relationship, and locus of care.
- Although difficult, parent carers could work and care if they could find jobs that fitted in with care-giving responsibilities. For parents of school-age disabled children, that usually meant being able to work school hours and term-time-only. The lack of after-school care for disabled children was a large barrier. Unlike parents of non-disabled children, combining work and care can continue to be difficult, or become more difficult, as children grow up.

- Few ethnic minority carers both worked and cared. Many ethnic minority carers experienced poor health, which was a common reason for not working.
- Rural carers faced difficulties in respect of having to travel long distances to work, and/or hospital and other appointments. Poor public transport made it more important to own a car, but this could be expensive and not necessarily financially worthwhile for carers whose earnings potential was low.
- Formal and informal flexible working practices, and sympathetic colleagues, were important in enabling unsupported carers to both work and care.
- There was no strong evidence of a significant association or relationship between age and deciding to take on a caring role. Some carers had started on a caring role in their 20s, either as a parent or spouse carer, when they were in the early stages of their working life. Others began caring in their 40s and 50s at a time when some, but not all, were in paid work.
- Professionals had little involvement with former carers, yet this was a time when their social and financial capital could be very low and they needed help to return to the labour market, if that was their wish.

Part 6  
Conclusion



## 14 Conclusion

This final chapter draws together the main findings from all three elements of the research: the literature review, the in-depth interviews with carers and the focus groups with professionals working with carers. To recall, the study was designed to help ascertain what can be done to assist carers to remain in work, or to return to work during or after an episode of caring. The formal objectives of the research were to:

- identify and review previous research on the relationships between carers and the labour market, including the decisions that carers make about caring, paid work and retirement;
- understand the decisions that carers make about care, work, retirement and pensions and the factors that influence those decisions;
- explore the work and retirement aspirations of carers;
- consider the effectiveness of the support available to carers in enabling them to remain in, or return to, work.

As a preliminary, it is worth drawing attention to the strengths of the study. The literature identified what was already known about carers, employment and pensions. We built on that work (and our own existing knowledge) when designing the topic guides for the fieldwork in the empirical parts of the project. The literature review also identified some important gaps in the existing evidence base and areas where more research is required. The strong points of the new empirical research lie in the richness of data generated through in-depth interviews with a diversity of carers, including unsupported carers, and focus groups with professionals. In this way, different perspectives from a range of key stakeholders were brought together to bear on the research areas under investigation.

The 80 carers who took part in the study covered a wide range of employment and caring circumstances. Consequently, the research presents insights derived from carers who varied in terms of gender, age and ethnicity, as well as different caring relationships and labour market situations. Whilst we cannot claim that the sample was representative of the carer population as a whole, the work is strengthened by

the fact that many of the experiences and opinions reported by study participants are consistent with evidence from previous research, as well as with the findings from the focus groups with front-line professionals.

### 14.1 Carers' aspirations and decisions around care-giving, work, retirement and pensions

Most of the non-working carers taking part in the new empirical research were already out of the labour market before they started caring. This was often because of their own poor health status, or for reasons beyond their control such as redundancy. In other words, only a minority of carers gave up work to take on a full-time caring role. This finding is consistent with evidence from the primary research reports included in the literature review that only a minority of non-employed carers gave up work because of their caring duties. On the other hand, and again endorsing evidence from the literature, carers who were in work made great efforts to remain in work as long as possible, trying out alternative measures such as: taking advantage of (formal and informal) flexible working arrangements and leave entitlements; reducing the number of hours worked; reducing distances and time spent travelling; and changing jobs. These solutions to make it easier to combine work and care involved a lot of hard thinking and decision-making by carers.

One of the most important themes to emerge from the interviews with carers, and also the focus groups with professionals, was the complexity of carers' decision-making about work and care. Generally, decisions (or non-decisions) tended to be on-going and subject to review rather than a one-off decision making event. Carers' decisions were (seen as) the result of combinations, or clusters, of factors rather than one single dominant one. Such factors might have been out of their control, coincided purely by chance, and/or could be contradictory. Whilst carers might have attempted to make reasoned decisions about caring, working and retirement, these were very likely to be undermined by a variety of uncertainties and unknown factors, and/or external constraints. These varied widely, and included: their own health, and also that of the person looked after; the outcome of critical transition points such as disabled children changing from one school to another, or school to college; sustainability of service provision; and long-term job security. There was no strong evidence from the interviews of a significant association or relationship between age and deciding to take on a caring role. However, the literature review showed that, statistically, the risk of becoming a carer among people below state pension age does increase with age.

Factors influencing decisions about work and care that were identified in the present study were wide-ranging, and were broader than those described by Mooney *et al.* (2002) in the literature review. They include: financial factors (household incomes and mortgages; pensions; welfare benefits); health and well-being; personal factors (identity; freedom and independence; commitment to career); work-related issues (supportive employers; working hours; finding the right job; flexibility; reliability;

working hours; retirement/redundancy packages); support services (general service provision; childcare provision; charging); factors related to the care recipient (commitment to care recipient; care recipients' wishes and needs); distance and travelling times.

Different groups of carers had different priorities reflecting whether or not they worked, and if so, the number of hours worked. Carers who worked 30 hours or more per week wanted to continue caring for as long as it was reasonably possible, but at the same time they had a strong attachment to the labour market. They were very committed to remaining in paid employment, and unwilling to scale down their career/work ambitions. Financial commitments, particularly in respect of outstanding mortgages, were key motivating forces as was the desire for a full pension in the future. Generally speaking, those carers who had been with the same employer for many years were not inclined to risk starting a new job in a different organisation. This was because they had no way of knowing how sympathetic new supervisors and colleagues would be to their care-giving requirements, or the scope for (formal and informal) flexibility. These findings are consistent with the literature review, which found that length of job tenure was longer among carers than among non-carers.

Some carers confronted difficulties relating to distance and the amount of time spent travelling, which could be even more of a problem for extra-resident working carers who could face considerable logistical difficulties. However, the sorts of measures adopted could be particularly expensive – and add to existing financial burdens – as they might involve moving house, combining two homes, building an extension or buying neighbouring property for the care recipient to move into.

As the literature review highlights, substantial caring duties are more compatible with part-time than with full-time employment, and male carers much less likely than female carers to work part-time hours. Reflecting these patterns, some female carers in the present study had decided to reduce the number of hours they worked as a way to better combine work and care-giving, although this option did not seem to be attractive, or available, to male carers.

Carers who currently worked less than 30 hours per week tended to have a less tenuous hold on the labour market and they were less likely to be influenced by financial factors. Qualifying for the State Pension was seen as an additional benefit of continuing to work, rather than a crucial motivating factor. In contrast, their health status was an increasingly important influence for those carers working under 30 hours a week. Some carers deliberately decided to compromise and take jobs below their skill levels and experience as a way to reduce levels of stress. This decision was often taken unwillingly, but reflected carers' perceived lack of choice. By default almost, any desires to maintain their chosen career, or previous professional identity, were being eroded. Reflecting these health concerns, the aspirations of carers in this group were circumspect and emphasised the need to obtain a job that was right in terms of hours, demands, location and (for some people) involved term-time-only working. This was particularly the case for parent carers of disabled children who tended to tailor paid work around caring requirements.

Having adopted a strategy of reducing the number of hours worked per week, carers could eventually reach the point where no other adjustments to their working patterns were possible. It was then that carers might start to consider giving up work altogether in the future, especially if, for whatever reason, no alternative care was available (or wanted) to help the care recipient and/or their own health was (still) poor. The value of Carer's Allowance (CA), the main welfare benefit for carers, tended not to have any significant impact on decisions about whether to leave work to care, although it did deter some carers with extensive financial commitments from considering giving up employment.

Once carers had left the labour market, their aspirations and motivation levels to return to paid work (especially whilst still caring) were not strong. Factors influencing decisions included their own health, the needs of the care recipient and financial implications in terms of possible future claims for welfare benefits. In essence, they were wary of taking any actions that might threaten or destabilise what were often already quite complicated and fragile (caring) situations. They had adapted to, or accepted, their current circumstances and were disinclined to make any changes unless the caring situation changed.

Carers' own ill-health had prompted some people to retire early. Similarly, those who were still employed were nonetheless likely to consider taking early retirement in the future if their own health was poor, or the health/condition of the care recipient was deteriorating and they could be called on to provide more care. In contrast, some carers anticipated working beyond state pension age. For most people, this sort of decision was more likely to reflect financial pressures and/or inadequate retirement incomes, rather than genuine enjoyment of paid employment.

The value of CA was seen as derisory by both carers and front-line professionals. Some carers were employed whilst also getting CA. Their decisions about jobs had to take account of the strict earnings threshold, which meant that they had little choice but to engage in low paid, unskilled work. Because the regulations attached to the benefit restricted how much they could earn, by default they also put constraints on the number of hours carers could work.

As is common in the population as a whole, it was not in the nature of many carers to plan ahead and make (additional) financial provisions for retirement, even if they could afford to. There were additional reasons for carers not to plan in advance, though, which were more specific to care-giving. An important one was carers' lack of time. This, coupled with low levels of knowledge about pensions, inhibited rather than encouraged any detailed consideration of financial provisions for retirement. Many carers prioritised managing or resolving day-to-day financial pressures, which was far more critical to them than putting money aside for when they retired – an event that in some cases was many years away. Other reasons for not planning ahead were not knowing whether adult disabled children would still be at home or living independently, or whether carers would be called upon to contribute towards the costs of residential or nursing home care for elderly parents (even though in theory, they should not have to) – two issues that had financial implications.

Information is a prerequisite to making well thought out decisions. Frequently, however, carers did not have information to help them in decision-making around pension planning and income, or at other important times. For example, carers did not always know about CA until they had already made the decision to leave work. Neither were they aware of service provision in general, or how social services could help them remain in work in particular.

## 14.2 The effectiveness of support to enable carers to remain in, or return to, work

The evidence from the empirical research illustrated that carers can be supported by a range of organisations from the statutory and voluntary sectors. The first point to make, therefore, is that all agencies need to be carer-aware, and as one would expect, that was the case for the social services departments and carers' organisations taking part in the study. In comparison, personal advisers from Jobcentre Plus had a more limited understanding of carers' issues.

Maximising opportunities for inter-agency collaboration is a key message in the new Green Paper on *Independence, Well-being and Choice* (DH, 2005), as well as the Carers (Equal Opportunities) Act 2004 which insists that carers' assessments consider work, training and leisure activities and provides for the necessary co-operation between local authorities and other bodies to help achieve this. The study found that inter-agency collaboration between staff from Jobcentre Plus, social services and carers' organisations was limited. As a result, professionals had low levels of understanding about the services that the other two organisations offered to carers, and how they could help carers wanting to work and care. Personal advisers from Jobcentre Plus were the most isolated group.

The literature review draws attention to the fact that it is important to recognise that whilst carers are perceived to be a coherent or homogeneous group, in reality they are quite the opposite. Differences between carers relate to gender, age, ethnicity, geography, and type/nature of care-giving responsibilities. To be effective in helping carers remain in, or return to, work, support services must address the full range of carers' needs which in turn reflect individual circumstances and caring situations.

Jobcentre Plus services and Work Focused Interviews (WFIs) are two routes back into employment although very few carers in the sample had ever obtained a job through a job centre, and none recently or whilst they were caring. Whilst carers doubted that they could find a job to meet their particular requirements, personal advisers took an opposing view claiming that jobs were available. These jobs were primarily in the service sector, and tended to be part-time, low paid and possibly seasonal. As such, they could also have problems attached to them for carers thinking about moving from benefits to work, for instance, earning enough to make work pay and carers being disinclined to want to go through the process of reclaiming welfare benefits if work proved unsuccessful.

Overall, carers were positive about the information and advice they received from Jobcentre Plus personal advisers. The better-off-in-work calculations were particularly useful in making decisions about whether or not to apply for a particular job. One weakness that was identified in interviews with carers related to advisers' perceived lack of knowledge about caring in general, and the impact of caring on carers' ability to work in particular. Personal advisers themselves acknowledged they did not have in-depth knowledge about care-giving, and one suggestion from both carers and professionals to improve Jobcentre Plus' services for carers was to introduce advisers with specialist training in carers' matters.

Those carers who had been called for a WFI in relation to a claim for CA (or other benefit) did not appear to find them particularly useful. Discussions tended to last little more than ten or 15 minutes, and did not lead to any change of mind on the carer's part. Carers arrived for WFIs not necessarily fully understanding their purpose, especially as, generally speaking, they had already made the decision not to return to work until their caring situation had changed.

Personal advisers' views on WFIs for carers reflected organisational priorities, for example the fact that carers were not a key group in the same way that Incapacity Benefit (IB) recipients were. Advisers tended to take their lead from the carer participating in the interview. They were more likely to focus on how Jobcentre Plus could help carers in the future when their caring situation changed. From this point of view, advisers used the interviews as an awareness raising exercise about Jobcentre Plus' activities rather than as an opportunity to talk about job prospects in the shorter term.

One or two carers who still had some (limited) attachment to the labour market but were struggling to hang on to this, had approached job centres for help in the past, but their efforts to get a more suitable job had been thwarted because they were already in work (see Chapter 8). They found it hard to understand this sort of negative response. Personal advisers did not appear to follow up comments about caring responsibilities in interviews with people claiming benefits other than CA.

Training courses were one way for carers to improve their employability and prepare for a return to the work force. Suitable courses were provided in a range of different settings, but whether carers had the time or freedom to attend them was a different matter, especially if they lasted over a number of weeks. Furthermore, 'hard' outcomes in terms of obtaining a job could be months or even years away, especially for those carers who were far from being 'job-ready'.

As far as the effectiveness of financial support for carers was concerned, professionals had strong views about the benefit system and its impact on carers. Some saw it as overly generous, especially for those carers in receipt of other benefits, for example, Housing Benefit (HB) and/or Council Tax Benefit (CTB). In these instances, it was thought, the value of the carer's (or household's) total benefits package could be quite high. Carers stood to lose the whole package if they embarked on paid work and came off benefits. It was believed that, potentially, some carers needed to

obtain work with relatively high earnings, otherwise it could be very hard for them to make work pay and be financially viable. However, in reality, low paid carers are entitled to HB, CTB and Working Tax Credit (WTC) (including the childcare credit).

Turning now to support from social services, the evidence suggested that current service provision did not particularly help either working carers or carers who wished to return to work. From this point of view, it was not the most critical factor in enabling carers to combine work and care. In theory, carers' assessments are one vehicle for identifying carers' needs and providing subsequent support. The importance of focusing on carers' wishes in relation to paid work is emphasised in the practitioner's guide to the Carers and Disabled Children Act 2000 (DH, 2001a), but this opportunity could be lost. The evidence from carers indicated that not all carers had been assessed, and not all of the assessments that had taken place had covered employment issues. Social services practitioners confirmed that assessments they conducted did not routinely cover carers' aspirations or needs in relation to paid work. Their general approach was to take a lead from the carer being assessed. A small minority of staff did not think that it was their responsibility to support carers' employment. Overall, social workers were ambivalent about the value of carers' assessments, especially if the resources to provide subsequent support were limited. Whilst service provision could generally be provided on a short-term basis for working carers, there were issues about the sustainability of support for the longer term.

There was no evidence of a direct link between the number of hours that carers worked and the level of social services support received. Even if carers (or care recipients) were willing to use social services help, more often than not, carers had to accommodate their working patterns around service provision rather than the other way round. This reflected the restrictions on available time to work imposed by day centres' short opening hours, say, transport difficulties or lack of after school clubs for disabled children. Perceived inflexibility and unreliability also inhibited (working) carers from using social services. Those carers who received direct payments to purchase social care were in a somewhat better position as they had more control over paid carers, timing and so on. However, this was not necessarily the solution as carers (and social services practitioners) in both urban and rural research sites reported recruitment difficulties.

Social services' speed of responsiveness was an issue for working carers, particularly in relation to an emergency or unplanned event when they needed help immediately. Additional practical help with domestic chores, childcare for disabled children and longer day centre hours were all services that carers reported would make it easier for them to work and care. Other services included reliable home care staff, home sitting services and easily accessible, up-to-date information about available services and entitlements.

Carers' centres and other voluntary organisations provide additional means of support for carers. By no means all carers wished to have direct contact with carers centres, but many appreciated their newsletters and knowing that there was an

opportunity to contact them should the need ever arise. Carers praised the information and advice they received. Particularly useful services related to being told about available benefits and/or being helped to complete application forms for CA.

None of the carers centres taking part in the study was currently involved in an employment-related project for carers, although they had run them in the past with some success – including helping carers obtain paid work. Carers centres were important in helping carers remain in work by helping reduce stress levels through providing listening services, counselling, advocacy, referral to social services and access to short breaks. Employed carers could find it difficult to visit carers centres because opening times tended to clash with when they were in work, but carers workers in one research site were about to pilot opening outside normal working hours.

The study provided strong evidence that neither personal advisers, social services practitioners nor carers workers felt competent to provide detailed advice about pensions; the benefit system was also seen as very complex, and, again, professionals were wary about giving advice. Consequently, they were likely to refer carers to other agencies who could offer expert help. This meant that carers might have to spend a lot of time trying to access information, not only from social services, carers centres and Jobcentre Plus, but from other organisations too. Given the fragmentation of information, professionals from all occupational backgrounds suggested that a one-stop shop information and advice point for carers was needed to save carers time, and provide them with full information at critical decision-making points.

Both formal employment policies and informal working arrangements were perceived as essential by carers and professionals to enable them to work and care, thus endorsing evidence from the literature review. Flexible starting and finishing times, and the ability to take time off in emergencies and for routine appointments, were particularly important. Annual leave was also helpful for appointments and other care-related activities; unpaid leave was not popular with carers – generally speaking, they could not afford it.

When employers' formal policies were supplemented by informal flexible working practices, for instance the opportunity to swap shifts with colleagues, employers' support was yet more effective. In addition to formal entitlements, as the literature review also showed, having a supportive manager or supervisor who would respond sympathetically to carers' difficulties in combining work and care, could make a big difference to carers' ability to (continue to) combine work and care. Carers benefited from managers with individual discretion to interpret policy in different ways, and to their advantage, but at the same time this could cause resentment with other colleagues. Furthermore, if the manager left the organisation then that concession could come to a speedy end. Front-line professionals speculated that a combination of legislation and awareness raising had the potential to encourage employers to introduce carer-friendly working arrangements.

In principle, carers were keen to reciprocate the flexibility shown to them by managers and work extra hours to help cover holiday absences or periods of sickness. Generally, this was not feasible for carers in receipt of CA because the inability to average out wages over a number of weeks meant they risked earning over the threshold. Those carers who inadvertently earned more than was allowed then faced considerable paperwork, and even tribunals, to resolve the situation.

The Government has consistently emphasised the importance of the National Health Service (NHS) in supporting carers, for instance General Practitioners (GPs) and other primary care professionals are seen as particularly well placed to provide carers with up-to-date information and advice, and to make referrals to other agencies (DH, 1999). The findings from this study suggest that carers' employment commitments were more likely to be recognised and supported by GPs than hospital staff. Hospital discharge provided an opportunity for carers to make their work commitments known, so that appropriate support could be put in place. The evidence was limited, but carers were aware that they could be caught up in the struggle between hospital staff, who wanted to discharge patients as soon as possible, and social services, who could struggle to provide adequate community care packages for the care recipient.

There was little help available from social services departments to former carers who were keen to return to work, yet people who had ceased care-giving were vulnerable and often lacked the resources to take the initiative themselves.

In sum, the study demonstrates that it can be very challenging for carers to combine work and care. Those carers who are able to manage this dual role can only achieve this with great difficulty, and frequently at the expense of their own health. Sustaining paid work could be particularly important for older carers given that their opportunities to obtain another job if they quit work to care are likely to be significantly reduced.

Carers' immediate and longer-term financial situations are put at risk if they have to reduce the number of hours they work, and/or give up work entirely. The regulations for CA can have the effect of pushing carers into low-paid work if they want to maintain some sort of attachment to the labour market. There is an important issue about the timing of help and advice for carers in that it might be more effective later in a carer's caring career and after, rather than straight after giving up work. Current Department for Work and Pensions (DWP) policies are poorly timed and do not engage with the totality or overall situation of carers; integration into wider support networks and/or organisations would be helpful. WFIs for carers tend to concentrate more on carers' future employment prospects and how Jobcentre Plus can help. Whilst social services support and direct payments have the potential to help carers combine work and care successfully, this is not borne out in reality. Carers hold low opinions of the services available, and/or the sort of practical help they want is not available. Where available, employers' formal and informal policies can help working carers fit their care-giving responsibilities around their work commitments.

Many of the issues raised in the study have relevance not only to DWP but also to other Government departments such as the Department of Health, the Department for Trade and Industry, and the Inland Revenue. For instance, carers' ability to retrain, find or return to work involves many different factors, including complex income issues, substitute care, confidence building and specialist counselling. Thus, an effective strategy to support carers to combine work and care needs to engage all relevant agencies – Jobcentre Plus, social services departments, carers centres, GPs/hospitals and training providers – and create closer networks between them so they can operate as a 'whole system'. At the local level, the new Carers (Equal Opportunities) Act 2004 offers a framework for improved inter-agency collaboration in order to take more account of carers' needs concerning employment matters.

### 14.3 Gaps in evidence

Finally, the literature review identified a number of gaps in the existing evidence base about carers, employment and retirement:

- Much of the literature on the impact of caring on employment is derived from general purpose household surveys, unrepresentative questionnaire surveys, and qualitative studies. What is missing from the literature is an up to date, large-scale, nationally representative survey of carers. Such a survey would make it possible to examine in depth a wide range of issues that are specific to carers. It would quantify the number of carers in particular situations and examine statistically the relationships between these situations and the 'risk factors' that associated with them.
- The literature of caring among minority ethnic groups is growing, but important gaps remain. In particular, we appear to know relatively little about how the difficulties of balancing informal care and employment may impact differently upon people from different ethnic groups.
- Many of the studies about carers and employment were conducted in the 1980s and 1990s. However, there have been important changes in the labour market and in expectations about employment, particularly in relation to women, in recent years, which highlights the need for more up-to-date research.
- Similarly, there are relatively few up-to-date analyses available about the impact of care-giving on earnings, personal and household incomes, and pension entitlement.
- Another gap is about carers and self-employment. We appear to know relatively little about whether, how and to what extent, self-employment is easier to combine with substantial caring duties than paid employment.
- Another important gap in the existing evidence base is about the role of services provided by Jobcentre Plus, social services departments and voluntary organisations in helping carers with substantial care-giving duties to remain in, or take up, paid employment. This study has provided important, new qualitative insights into these issues, but there remains a need for quantitative evidence.

- Little is known about return to work among economically inactive carers when the caring episode comes to an end. It would be helpful to know, for example, about what may be done to help people make the transition from carer to worker.
- There is a need for more up to date research on CA recipients. The only survey of CA recipients was conducted in the late 1980s when it was known as Invalid Care Allowance (ICA) and is long out of date. We know relatively little about the circumstances and needs of recipients of this benefit. Also, research is needed on the take-up of this benefit and in particular upon how it might be improved.
- We know relatively little about the experiences of carers who have chosen to take career breaks, unpaid leave, or unpaid carers' leave. Topics of interest here include: how the different leave options work for carers; what it is like to make an informed estimate of how long they are likely to need off work, whether that is correct, too long, not long enough; what it is like to make the transition back into work; what financial impacts there are, in both the short-term and the longer term.
- It would be helpful to know the extent to which carers of disabled children use their rights to request flexibility for a child up to the age of 18; and the extent to which employers grant them their request.
- An important gap in existing evidence is the role that voluntary work plays in carers' lives. Is it a substitute for paid work, such that carers then don't want to take that next step into employment because it gives carers the flexibility (and identity) that some employers cannot give them? To what extent is voluntary work a step on the pathway to employability and paid work? Similar issues arise in relation to vocational training.
- Given the fragmentation of information, it would be helpful to understand the different times in carers' working and caring careers when information and advice would be useful to help them make important decisions such as giving up work to care and returning to work after/whilst care-giving.
- Research on carers often measures the intensity of caring in terms of hours per week. It would be helpful to know more about carers with more episodic or intermittent care responsibilities and the impact this has on decisions about employment.



# Appendix A

## Research methods

### A.1 Literature review

For the purpose of the literature review, ‘carers’ were defined as people who provide unpaid care for sick, disabled or frail elderly people. The recipients of their care include chronically sick or disabled children, spouses, elderly parents, other relatives, friends or neighbours. Childcare and foster caring was excluded from the remit of the review and the study more generally. The study focused on adult carers below state pension age.

The aim of this part of the study was to conduct a narrative review of the existing evidence base. It was not, therefore, intended to be a ‘systematic review’ in the sense that the term has begun to be used in the health and social sciences (Torgerson, 2003). However, the review aimed to be transparent and systematic in its methods. It covered both qualitative and quantitative studies.

In order to identify publications to be included in the review, the research team carried out an extensive literature search through academic, policy and professional databases, relevant internet sites of carers’ organisations and Government departments, following up the references in cited publications, and contacting leading researchers in the field. The list of databases and websites searched are shown in Tables A.1 and A.2, respectively. The key words used in the literature search are shown in Figure A.1

### Figure A.1 Search terms used for the literature search

Employment or work or job or work-focused interview or WFI or retirement or pension or income or earnings or poverty or benefits or Carer's Allowance (CA) or Invalid Care Allowance (ICA), or older workers, or decision making, or aspirations

**and**

Carer or caring or care-giving or caregiving or informal care or unpaid care or caring responsibilities or partner of benefit recipient, or couple, or household, or marriage

The geographical coverage of the literature search included the UK, or England, or Scotland, or Wales, or Northern Ireland. Because of time and resource constraints, only articles published since 1985 were included. Articles on research conducted on non-UK countries and comparative studies were excluded from the review at the reference retrieval stage. Very short (1-2 pages) articles were also excluded as not containing enough information to appraise the quality of the research.

Over 150 full-text publications and reports were retrieved. All retrieved publications were subjected to research quality evaluation to decide whether their findings should be included in the review. This was undertaken using a tool (see Table A.3) that was an extended version of one devised for a systematic review by Croucher *et al.* (2003). Only those publications that passed the quality appraisal were included in the review. The *Endnote* software package was used for bibliographical search and management of the references.

### Table A.1 Databases searched for evidence review

1.	ZETOC	British Library's table of contents service indexing journal articles and conference papers
2.	IBSS	International Bibliography of Social Sciences
3.	ELSC (CAREDATA)	Electronic Library for Social care
4.	ASSIA	Applied Social Sciences Index and Abstracts
5.	ISI Web of Knowledge	Social Science Citation Index
6.	SCIENCE DIRECT	An electronic collection of science, technology and medicine full text and bibliographic information
7.	REGARD	An ESRC funded database service for social science
8.	JSTOR	The Scholarly Journal Archive
9.	INGENTA	Comprehensive collection of academic and professional publications.
10.	CSA Sociological Abstracts	The database of international literature in sociology and related disciplines in the social and behavioural sciences.
11.	National Research Register	A database of ongoing and recently completed research projects funded by, or of interest to, the United Kingdom's National Health Service (NHS).

**Table A.2 Internet sites searched for evidence review**

1.	Equal Opportunities Commission
2.	Audit Commission
3.	The Stationary Office <a href="http://www.statistics.gov.uk">www.statistics.gov.uk</a>
4.	DWP research reports collection
5.	Joseph Rowntree Foundation
6.	Carers UK
7.	Princess Royal Trust for Carers
8.	Age Concern (England, Scotland and Wales)
9.	Chwarae Teg (a Charity aimed to support, develop and expand the role of women in the Welsh economy)

**Table A.3 Quality appraisal criteria**

No.	Aspect	Criteria	Assessment	Comments
1	Research questions	Are the research questions clear?		
2	Study design	Is the study design appropriate to answer the research questions		
3	Sampling (quantitative)	Is the sample representative of the population from which it has been drawn? Is the population appropriate for the research questions?		
3	Sampling (qualitative)	Is the sample size adequate for the analysis undertaken and is the sample drawn from an appropriate population for the research questions?		
4	Data collection	Was the data collection rigorously conducted and is it adequately described to ensure confidence in the findings?		
5	Data analysis	Was the data analysis rigorously conducted and is it adequately described to ensure confidence in the findings?		
6	Reporting	Are the findings clearly and accurately reported?		
7	Conclusions and recommendations	Do the conclusions and recommendations follow logically from the findings?		

Possible assessments: Yes, No, ? [= unclear], DK [= insufficient information], NA [= not applicable]

## A.2 Qualitative research

### A.2.1 Research sites

Fieldwork took place in four research sites, selected to reflect different labour market situations, namely:

- a high labour demand area (Site 1);
- an inner city area (Site 2);
- a rural area (Site 3);
- a declining industrial area (Site 4).

In addition, the four research sites had to meet other criteria:

- have an integrated Jobcentre Plus office;
- have a well-established carers centre run by the voluntary sector;
- not be an existing DWP research area.

The NOMIS website,<sup>24</sup> which is one section of the Office for National Statistics (ONS) website, was used for the selection of potential research sites. NOMIS contains local authority labour market statistics, including details of unemployment (per cent of Jobseeker's Allowance claimants; GB average = 2.5 per cent) and 'job density' (ratio of jobs per adult resident; average = 0.8 jobs). 'Job density' was used as a proxy measure for high labour demand.

Site 1, the high labour demand area, is in the North West of England. As would be expected, the unemployment rate is lower than the national rate. Site 1 has a strong, long established services sector, particularly in commerce, retailing and tourism, which is complemented by an expanding manufacturing base. It is also a major centre for local government and public sector administration.

The inner city area, Site 2, is in the East Midlands. It has smaller than average proportions of its workforce working full-time, part-time or in a self-employed capacity. In addition, it has a higher percentage who are unemployed. Manufacturing is the largest source of employment, and the occupational structure is heavily biased towards manual labour. Just over 35 per cent of people are from ethnic minority communities, mainly Asian.

Site 3, the rural area, is also situated in the North West. Tourism is important to the economy. Latest available statistics show that average male wage rates are 6.5 per cent below the GB average, whilst wages rates for women are 12 per cent below the GB average.

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<sup>24</sup> [www.nomisweb.co.uk](http://www.nomisweb.co.uk)

The declining industrial area, Site 4, is located in the North. The local economy is showing signs of revival, for example, the number of jobs available has increased in the last three years and the unemployment rate is falling although it is still higher than the average for England and Wales. Slightly under ten per cent of people are from ethnic minority communities.

## **A.2.2 Interviews with carers**

### *Gaining access to carers*

We accessed carers in the four research sites through wide-ranging sources:

- DWP's CA database;
- databases held by the local Jobcentre Plus offices;
- the local social services departments;
- the local carers centres;
- local employers, in both the public and private sectors;
- snowballing.

We aimed to interview a total of 80 carers below state pension age, ideally 20 carers from each of the four research sites. The sampling strategy was intended to reflect the prevailing gender division in care-giving, and within each of the four sites our target was 12 female carers and eight male carers. We proposed to break down each of these two groups by age, i.e. 'below state pension age' (18-54 years) and approaching retirement (55-64 years). The intention was to include slightly higher proportions of men and women carers approaching retirement than would be expected in the general population of carers below state pension age because little is known about carers' pre-retirement decision-making, and because post-retirement provision is a core DWP responsibility. Within the study sample for each site, we were also seeking five or more 'unsupported' carers who were not in receipt of CA or social services provision (they might have received other welfare benefits, though).

To help achieve diversity in the study sample, across the full sample of 80 carers we then aimed to recruit pre-specified target numbers of:

- carers in different employment situations, i.e. in full-time work; in part-time work; not in work;
- carers in receipt of CA, and carers not in receipt of this benefit;
- carers who had attended a Work Focused Interview (WFI) at their local Jobcentre Plus office;
- carers looking after disabled children, spouses/partners and elderly relatives;
- carers from ethnic minority communities.

As the recruitment period progressed, difficulties in recruitment led to a review of priorities and the original target numbers were revised in order to complete the interviews within the allotted time. The figures for the final sample are shown in Table A.4.

Ethical approval from an NHS Research Ethics Committee was not required as any NHS professionals who took part in the research did so in their role as a carer, and were accessed via carers centres or snowballing rather than directly through the NHS.

### *Data collection*

Interviews with 80 carers living in the four different research sites were conducted between September and November 2004. The majority of interviews were face-to-face, but for practical reasons some 13 were undertaken over the telephone. We do not consider these suffered any loss of data quality (and were easier for carers to arrange). In 11 instances, interviews were conducted with care recipients present. This arrangement was generally by choice, but in a few cases unavoidable. One interview with an ethnic minority carer involved an interpreter. Interviews lasted one hour on average. All interviewees were asked questions about: the caring situation; past and current training and employment experiences; retirement planning and financial provisions; Jobcentre Plus and WFLs; social services provision; and CA. See Appendix B for the full topic guide. The interviews were semi-structured and discussion was wide ranging around the key topic areas. Interviewees were particularly encouraged to talk about decision-making in relation to the above issues.

### *Data analysis*

The interviews were all tape-recorded, with permission, and transcribed in full. The data were entered into a database designed specifically for the project. This proved an efficient tool with which to organise the interview material according to the key research questions and analytic themes. It also facilitated searching and retrieving information from different sub-groups of carers within the interview sample.

A rigorous analysis similar to the 'Framework' technique (Ritchie and Spencer, 1994) was conducted, with a view to highlighting the full range of perceptions, beliefs, experiences and behaviours described by the respondents, as well as the factors that underpinned them. Interviewees' accounts were compared, and commonalities, anomalies, patterns and explanations within the data identified.

### *Profile of carer interviewees*

Table A.4 gives details of the full study sample of 80 carers according to research site area. Three of the carers had stopped caring in the last year or so, in two cases because the person they were looking after had died and in the third case because the couple had separated. As shown in the table, in each of the four sites there were more female than male carers; the majority of carers were over the age of 45. The final sample included 15 carers who belonged to ethnic minority communities from countries from Asia, the Caribbean and Egypt. Exceptionally, one interviewee originated from

Germany. Ethnic minority carers were clustered in two research sites, the inner city area (Site 2) and the declining industrial area (Site 4). The inner city area had the highest proportion of carers who were not working. Carers living in the declining industrial area spent fewer hours per week caring in comparison with carers in the other three sites. Nineteen carers were extra-resident carers; an additional seven interviewees were both co-resident and extra-resident carers. Just over half the carers in three of the four research sites were in receipt of social services provision (the exception being the inner city area). Far fewer carers were in receipt of Carer’s Allowance in the declining industrial area compared to the other sites. There were comparatively more unsupported carers living in the high labour demand area (Site 1). It is important to note that the characteristics of the samples were not ‘representative’ of the four localities as it was a purposive, and not a representative, sample.

**Table A.4 Study sample**

	Site 1 (n=16)	Site 2 (n=19)	Site 3 (n=20)	Site 4 (n=25)
<b>Gender</b>				
Female	11	13	17	17
Male	5	6	3	8
<b>Age</b>				
25-34	1	3	2	1
35-44	2	3	3	4
45-54	4	6	7	11
55-64	9	7	8	9
Ethnic minority carers	-	11	-	4
<b>Economic activity status</b>				
Working 1-15 hours	3	0	7	1
Working 16-29 hours	3	1	4	6
Working 30+ hours	3	3	2	10
Not working/taken early retirement	7	15	7	8
<b>Number of hours caring per week*</b>				
1-19	1	1	1	3
20-34	4	5	3	9
35-49	3	7	8	5
50+	7	5	8	7
<b>Locus of care*</b>				
Carer’s household	10	15	12	14
Other private household	3	3	5	8
Both	2	0	3	2
<b>Support</b>				
In receipt of Carer’s Allowance	5	10	8	5
In receipt of statutory services	9	10	11	15
Unsupported carers	7	5	6	7

\* Figures do not include three former carers.

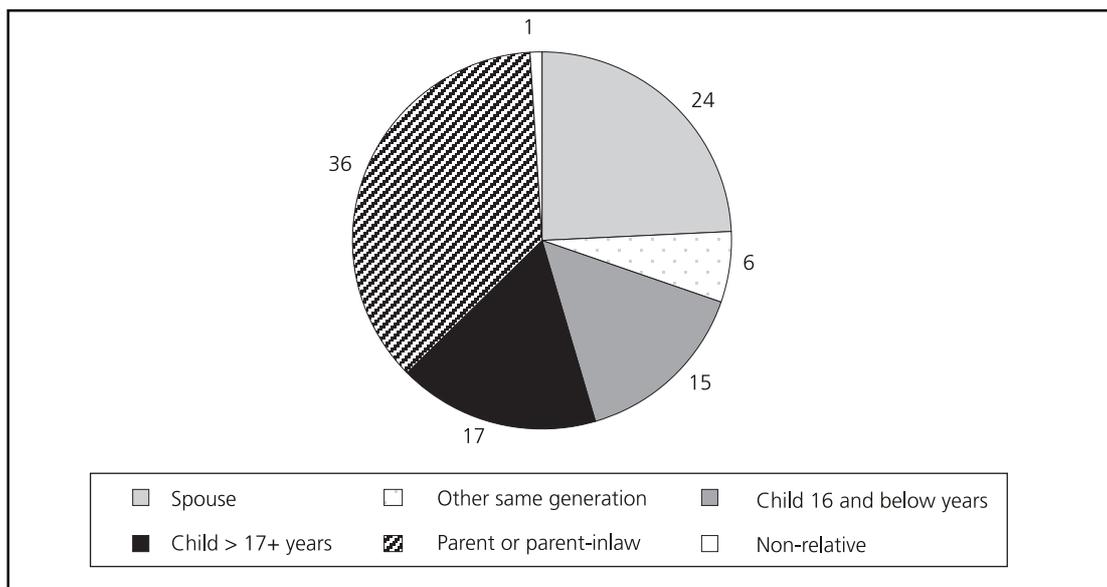
Table A.5 shows the economic activity status of all carers in the sample. Carers identified as 'working' include those interviewees who saw themselves as members of the labour market, but at the time of interview might have been on prolonged sick leave or in the middle of a career break. Reflecting previous research (Hutton, 2000; Maher and Green, 2002), female carers rather than male carers were in jobs that involved working part-time hours.

**Table A.5 Economic activity of carers in the study sample**

Economic activity status	Men	Women
Working 1-15 hours	-	11
Working 16-29 hours	-	14
Working 30+ hours	6	12
Not working/Taken early retirement	16	21
All	22	58

The 77 current carers in the sample looked after a total of 99 individuals (see Figure A.2). Some 19 carers were responsible for two or more care recipients. As shown in Figure A.2, the majority of care recipients were parents or parents-in-law. As far as children were concerned, the majority were disabled from birth but a very small number had developed mental health problems in their teens. Only one carer was looking after someone she was not related to.

**Figure A.2 Breakdown of care recipients (n=99)**



### **A.2.3 Focus groups with front-line professionals**

The research design included holding focus groups with front-line professionals who had direct contact with carers from social services departments, Jobcentre Plus offices and carers' organisations in each of the four research sites. The aims of the focus groups were to:

- examine the effectiveness of the support currently available to carers in enabling them to remain in, or return to, work;
- explore what additional forms of support could be provided that would help carers.

#### *Gaining access to professionals*

We used our existing links with social services and carers centres to access relevant professionals from the respective organisations. Invitation letters, which made clear that taking part in a focus group was voluntary, and information sheets about this stage of the study were distributed to appropriate members of staff by our liaison officers in the different organisations. We were keen to widen participation, and carers centres were encouraged to invite staff from other organisations, such as Crossroads - Caring for Carers or the Alzheimer's Society, who worked with carers. Participants in one focus group also included volunteer workers.

The procedure for organising the focus groups with Jobcentre Plus personal advisers was somewhat different. The initial contact with the relevant Jobcentre Plus office was made by our research manager at DWP. We were given contact details for the relevant local manager once this was agreed. At that point, we contacted managers to start making arrangements for the personal adviser focus groups.

Altogether, some 59 professionals took part in the focus groups. The number of people taking part in each one varied between three and seven. Nine of the 12 groups involved five or more participants.

#### *Data collection*

The 12 focus groups were held over a four week period, starting in mid-March 2005. Different members of the research team facilitated the groups. This was primarily for logistical reasons, as the discussions were held over a comparatively short period of time. Five of the focus groups involved a second researcher to support and observe the facilitator. Again, this was not always possible for practical reasons, or did not seem necessary for those groups where the numbers were small.

An outline topic guide had been circulated previously so focus group participants were aware of the areas to be covered in the discussions. The full topic guide, agreed with DWP beforehand, had six main sections: awareness of issues relating to carers' combining work and care-giving; views of the impact of local labour market characteristics; awareness of, and opinions about, the effectiveness of current service

provision; suggestions for improving support and service provision for carers; the new Carers (Equal Opportunities) Act 2004; and support and training for staff working with carers. See Appendix C for a copy of the full topic guide. The focus groups lasted between 60 and 90 minutes.

### *Data analysis*

The data analysis for the focus groups followed a similar pattern to the approach used for the interviews with carers. The discussions were tape-recorded, with permission, and transcribed in full. The data were then entered into a second database specially designed for the purpose. The subsequent analysis drew out professionals' experiences of working with carers, and their opinions about a full range of issues relating to carers and paid work. The accounts of professionals with different occupational backgrounds were compared; and consistencies, anomalies and patterns within the data were identified.

### *Profile of professionals taking part in focus groups*

Professionals taking part in the focus groups covered a wide range of occupational backgrounds. Some had personal experience of care-giving, both in the past and currently.

Social services practitioners included:

- social workers in teams responsible for carers, children with disabilities, adults, older people and people with mental health problems
- social workers in Access, Intermediate Care and Transition teams
- social workers based on hospital sites
- a planning and performance manager.

Whilst some practitioners were involved with carers who both worked and cared, others reported that the majority of their case load comprised carers who tended to think that paid work was not an option that was open to them, generally because of the intensity of their care-giving responsibilities.

Jobcentre Plus staff included:

- personal advisers for IB, Income Support (IS), Jobseeker's Allowance (JSA);
- a lone parent adviser;
- Disability Employment Advisers;
- an external adviser team officer.

As well as two voluntary workers, staff from carers' organisations included:

- carers centre managers and carers workers with a range of responsibilities, including development and support worker, information and website development worker, finance and administrative co-ordinator, primary health care liaison co-ordinator, volunteer co-ordinator;
- carers workers from local branches of the: Alzheimer's Society; CVS; Crossroads - Caring for Carers; the Red Cross; and a mental health project.



# Appendix B

## Topic guide for interviews with carers

## **CARERS' ASPIRATIONS AND DECISIONS AROUND WORK AND RETIREMENT**

### **Topic Guide for Interviews with Carers**

#### **Aims of the interviews:**

- **To understand the decisions that carers make about care, work, retirement and pensions; and the factors that influence those decisions.**
- **To explore the work and retirement aspirations of carers.**
- **To consider the effectiveness of the support available to carers in enabling them to remain in or return to work.**

#### **Interviewer's Introduction**

- SPRU is an independent organisation.
- The research is funded by the Department for Work and Pensions, to provide information about the experiences and views of carers of ill or disabled people or the elderly. By 'carers' we mean carers of ill or disabled people, or the elderly (to distinguish from children and child care).
- Explain that all the information provided will remain confidential, and that the report will be written in such a way that no individuals will be able to be identified.
- Explain discussion will have no effect on any benefits or services, or any dealings with DWP, Benefits Agency, social services, etc.
- The issues to be covered will relate to your caring responsibilities, paid work, experiences of benefits, support and services, and plans for retirement.
- The discussion will last around one and a half hours – if there is any need for breaks for either carer him/herself, or because of the care needs of the person supported, then that is OK.
- Any questions or concerns?
- Check informed consent.
- Ask for permission to use tape-recorder.

## **SECTION 1: CARER'S CIRCUMSTANCES AND CARE-GIVING SITUATION**

### **FOR ALL CARERS**

#### **PERSONAL DETAILS**

Can I first of all check your:

- age
- marital status
- employment situation
- who you care for (if not providing care, why not; when did caring responsibilities stop)
- when started caring; has caring been continuous or intermittent
- legal status (e.g. UK resident, asylum seeker)

(some of this info will be available from the completed screening tool)

#### **HOUSEHOLD COMPOSITION**

I'd like to know who else lives in the household with you. What do they do?

- Paid work/voluntary unpaid work/out of work
- Education/training
- Disabled/long term sick
- Retired

#### **CARE RECIPIENT**

Can you tell me who you look after?

- Relationship
- Age
- Where lives (if extra-resident, how far away)
- Diagnosis
- How long been ill/disabled; sudden or gradual onset
- Nature of condition: stable; fluctuating; remitting
- Treatment routines

### **CARE-GIVING RESPONSIBILITIES**

I'd like to know about what is involved in looking after (care recipient).

- What sort of tasks
- Frequency and patterns, e.g. particular days when do certain things
- Hours spent caring per week
- (Un) Predictability of care-giving
- Impact of treatment routines on carer
- Any help from other relatives/friends/neighbours; who does what

### **DECISION-MAKING ABOUT BECOMING A CARER**

One of the things we're interested in is how people reach the decision they do. Did you make a conscious decision to become a carer?

- What factors influenced that decision?
- Was anyone else involved?

### **HEALTH PROBLEMS**

#### **Have you any health problems of your own?**

- Related to caring
- Independent of caring

Do these affect your ability to care? In what way?

### **HOUSEHOLD SOURCES OF INCOME/ASSETS**

I'd like to ask a few questions about household finances.

- Sources of income (wages, benefits, direct payments, Independent Living Fund)
- Applied for Carer's Allowance; outcome
- Estimation of weekly household income (after tax)
- Own or renting house; is mortgage paid off
- Other assets (e.g. business, if self-employed)

Overall, what has been the impact of care-giving on your income and savings?

## **SECTION 2: EMPLOYMENT HISTORY AND DECISION-MAKING ABOUT WORK**

### **FOR ALL CARERS**

#### **EDUCATIONAL AND TRAINING HISTORY**

We'd like to know about your qualifications and employment history. First of all, can you tell me briefly about any qualifications you have, or training courses that you've been on?

- What for?
- When; at the same time as caring?
- Led to any formal qualification

#### **EMPLOYMENT HISTORY**

I'd like to know about what paid work you've done in the past (where appropriate, concentrate on period just before care-giving began).

- What the job(s) was, and who for
- What work involved
- Hours worked
- How long ago; impact on care-giving, if working and caring at the same time
- Why left job; because of care-giving
- Ever not got a job because of care-giving

#### **PAST DECISION-MAKING**

Has there been anything related to work (or a training course) that you decided not to do because of your care-giving? What factors did you consider when you made that decision? Was anyone else involved in reaching that decision, e.g. care recipient?

Has there been anything related to work (or a training course) that you decided to do because of your care-giving. What factors did you consider when you made that decision? Was anyone else involved in reaching that decision, e.g. care recipient?

#### **JOB CENTRE SUPPORT**

Have you ever talked to anyone at your local Job Centre about work, and what help the Job Centre could give you?

- Usefulness
- Suggestions for improving service to customers generally
- Suggestions for improving support to customers who are carers in particular

## **FOR CARERS CURRENTLY IN WORK**

### **CURRENT JOB**

I'd like to ask about your current job(s) now.

- Employed/self-employed (if self-employed, is this because of care-giving responsibilities)
- Type and size of employer
- Type of work
- Responsibilities
- Hours of work; scope for flexibility
- Permanent/temporary contract
- How long in job; started at a time with/without caring responsibilities
- Told new employer about care-giving commitments when first interviewed
- Since told line manager/work colleagues about care-giving commitments
- Impact of care-giving on job
- Anything related to work that decided not to do because of impact on care-giving
- Anything related to work that decided to do to accommodate care-giving
- Impact of these decisions/changes on: career prospects; earnings; pension; care-giving; person cared for
- How important is job, and why

### **CURRENT EMPLOYER**

I'm interested to know about your current employer's support for staff with care-giving responsibilities.

- Formal policies, special leave or working arrangements
- Ever taken advantage of them; how worked out in practice
- Attitude of personnel manager/line manager

### **COMBINING WORK AND CARE-GIVING**

Has anyone else been involved in your decision to combine care and work?

Thinking about combining work and care-giving, what difficulties do you experience?

What sort of things help you to overcome these difficulties?

- Work-related factors, e.g. employer's attitude, flexible hours, time off, supportive work colleagues
- Support from social services
- Support from family, friends, neighbours
- Support from cared-for person

Is there anything that might make it easier for you to continue combining care-giving and paid work?

Is there anything that might make it impossible for you to continue combining care-giving and paid work?

How do you think combining employment and caring has improved your performance at work?

Does combining employment and caring improve the quality of the care you are able to give? In what way(s)?

Thinking about this from the other point of view, do you think that combining employment and caring has detracted from your performance at work?

Does combining employment and caring detract from the quality of the care you are able to provide?

## **THE FUTURE**

How long do you think you will be able to continue combining work and caring?

Can you foresee having to make any changes in your current job to help you manage to both work and care?

Do you have any plans regarding your job if your caring situation changes?

## **FOR CARERS CURRENTLY UNDERTAKING VOLUNTARY/UNPAID WORK**

### **CURRENT JOB**

I'd like to ask about any voluntary or unpaid work that you do.

- Who for; type and size of 'employer'/sponsor
- Type of work
- Responsibilities
- Hours of work; scope for flexibility
- How long doing work; started at a time with/without caring responsibilities
- Told sponsor about care-giving commitments when first started

- Since told sponsor/work colleagues about care-giving commitments
- Impact of care-giving on work
- Anything related to work that decided not to do because of impact on care-giving
- Anything related to work that decided to do to accommodate care-giving
- Impact of these decisions/changes on: career prospects; earnings; pension; care-giving; person cared for
- How important is voluntary work, and why

### **CURRENT SPONSOR**

I'm interested to know about your current sponsor's support for staff with care-giving responsibilities.

- Formal policies, special leave or working arrangements
- Ever taken advantage of them; how worked out in practice
- Attitude of personnel manager/line manager

### **COMBINING WORK AND CARE-GIVING**

Was anyone else involved in your decision to combine voluntary work and care-giving?

Thinking about combining voluntary work and care-giving, what difficulties do you experience?

What sort of things help you to overcome these difficulties?

Is there anything that might make it easier for you to continue combining care-giving and voluntary work?

Is there anything that might make it impossible for you to continue combining care-giving and voluntary work?

How do you think combining voluntary work and caring has improved your performance at work?

Does combining voluntary work and caring improve the quality of the care you are able to give? In what way(s)?

Thinking about this from the other point of view, do you think that combining voluntary work and caring has detracted from your performance at work?

Does combining voluntary work and caring detract from the quality of the care you are able to provide?

## THE FUTURE

How long do you think you will be able to continue combining voluntary work and caring?

Can you foresee having to make any changes in your voluntary work to help you manage to both work and care?

Do you have any plans regarding your voluntary work if your caring situation changes?

## **FOR CARERS NOT CURRENTLY IN PAID WORK (i.e. neither working for an employer or self-employed)**

### **LAST PAID OR VOLUNTARY WORK**

I'm interested to know a bit more about your last (paid/voluntary) work.

- Who for; type and size of 'employer'/sponsor
- Type of work
- Responsibilities
- Hours of work; scope for flexibility
- How long doing work; started at a time with/without caring responsibilities
- Why left; if related to care-giving, what could have been done to help stay in the job

### **RETURNING TO PAID WORK**

Do you have any plans to look for (more) paid/voluntary work? How important is paid work to you? Why?

- Want to work and care at same time; why
- What kind of job opportunities exist in area for people with similar skills/ experience
- What kind of job would like (whilst still caring)
- How easy or difficult to get this sort of job
- Taken any steps towards getting a job

What do you think might prevent you from taking a job while still caring?

- Personal factors
- Work-related issues
- Care-giving responsibilities
- Finances/benefits

What factors might help you to combine paid work and care-giving?

- Work-related issues
- Service provision; support from family and friends

Have you taken any steps to find out about possible work opportunities? What did you do? What was the outcome of these enquiries?

What information or help would you find useful to enable you to find paid work while caring?

Overall, how do you feel about not having paid work at the moment? Does it affect the quality of the care you are able to give?

If you can envisage a time when you have fewer caring responsibilities, would you look for a job or voluntary work then?

- How easy or difficult to get this sort of work
- Taken any steps towards getting this work

### **SECTION 3: ONLY FOR THOSE CARERS WHO HAVE BEEN INVITED FOR A WORK-FOCUSED INTERVIEW**

I'm interested to know about the discussion you had about your work prospects with someone from the Jobcentre (i.e. a WFI).

- When; how did timing relate to other key events; usefulness of timing
- Accept, waived or deferred; why
- Understand purpose of discussion beforehand
- Helpfulness of discussion
- Followed up any of the information/advice given
- Impact of discussion on decision to work
- Made any further appointments with Jobcentre Plus adviser
- Suggestions for making the WFI more helpful for carers

### **SECTION 4: SERVICE SUPPORT**

#### **FOR ALL CARERS**

#### **SERVICES RECEIVED**

I'd like to know about the services you receive to help you or the person you care for.

- Different services provided, and who for
- Service providers

- Frequency
- Charges; impact of costs of services on decisions about paid work

### **CARER'S ASSESSMENT**

Have you ever had a discussion with a social worker about your own needs as a carer (officially called a carer's assessment)?

- Helpfulness
- Coverage of paid work issues
- Attitude of practitioner towards combining work and care-giving
- If not, why not? Likelihood of asking for one in the future?

### **CARERS' ORGANISATIONS**

Do you know about [local Carers Centre] or other organisations for carers?

- Had any contact; why
- Usefulness of any information or help received, especially any concerning combining paid work and care-giving

## **SECTION 5: CARER'S ALLOWANCE**

### **FOR ALL CARERS**

Moving on, I'd like to ask you about a benefit called Carer's Allowance.

- If and when heard of it
- What know about it

*Then explain if necessary:* Carer's Allowance used to be called Invalid Care Allowance. It is a benefit for people caring for someone who receives Attendance Allowance or Disability Living Allowance. You can claim Carer's Allowance if you are caring for someone for at least 35 hours a week. If you work, you must earn less than £79 net of allowable expenses a week and if you are studying you must be studying less than 21 hours a week. Some carers who qualify for Carer's Allowance may not actually receive it because they are already receiving another benefit. Carer's Allowance can now be claimed if you are over 65 (nb: the upper age limit was abolished in 2002).

- Applied for Carer's Allowance? Establish eligibility status (some people may have applied and established entitlement but not actually receive CA because already receiving another income benefit.)

### **FOR CARERS WHO HAVE APPLIED FOR CARER'S ALLOWANCE**

Why did you apply for Carer's Allowance?

You can earn up to £79 a week (net of work-related expenses) and also receive Carer's Allowance. Did you know about this when you applied for Carer's Allowance? Did this affect your decision to apply?

When you receive Carer's Allowance, you also get your national insurance contributions credited. Did you know about this when you applied for Carer's Allowance? Did this affect your decision to apply?

### **FOR CARERS IN RECEIPT OF CARER'S ALLOWANCE**

Do you know that it is possible to earn more than £79 per week and that some or all of the cost of care to the care recipient can in some cases be an allowable expense?

Do you know that you can undertake part-time study without it affecting your entitlement to Carer's Allowance?

Thinking back to what you said earlier about decisions about work, to what extent did knowing about Carer's Allowance, and being able to earn up to £79 net, influence your decision to work/not to work?

### **FOR CARERS WHO HAVE NOT APPLIED FOR CARER'S ALLOWANCE**

Not everyone is eligible for Carer's Allowance. Is that why you haven't applied for Carer's Allowance?

Have you asked anyone for advice or information about whether you'd qualify for Carer's Allowance?

Would you consider applying for Carer's Allowance in future, if your circumstances changed?

Have you heard of Home Responsibilities Protection? (HRP is not a pension but a scheme that helps to protect your basic State Pension. You may be able to get it if you spend at least 35 hours a week looking after someone who receives Attendance Allowance or Disability Living Allowance).

## **SECTION 6: RETIREMENT PLANS**

*(Note that the wording of these questions may need adjusting depending on whether interviewee is part of a couple and the employment status of the other partner)*

### **FOR ALL CARERS, WHETHER APPROACHING RETIREMENT AGE OR YOUNGER**

#### **RETIREMENT PLANNING**

The final thing I'd like to talk to you about is planning for retirement, and in particular how carers decide what's the best thing for them to do. Have you made any plans for retirement?

- What are plans; what happens to care-giving activities; who plans involve; timescale
- When started planning, and why
- If not done any planning, why not
- Main factors that influenced planning

### **FINANCIAL PROVISION**

Can you tell me what financial provision you (and your partner) have made?

- Pension provision?
- Other provision?

Do you think that caring will have/has had an impact on your pension/income after you retire? **Probe fully but carefully!**

How adequate do you think the funds you have available be to support your retirement?

Since you started caring, have you (and your partner) sought any information about your pension(s)?

- What sort of information
- Who from
- How helpful
- What information or advice about retirement planning or pensions would be useful

### **FOR CARERS CURRENTLY IN PAID WORK**

I'd like to know about the factors that have influenced your plans for retirement.

- Relative importance of future financial situation and pension compared to other factors in decisions about combining work and care-giving
- Influence of caring commitments on decisions made in future about retirement
- Considered taking early retirement; why; why not; when; financial consequences
- Considered working beyond state pension age; why; why not; when; financial consequences
- Any information/advice that has been helpful in making these sort of decisions

### **FOR CARERS NOT CURRENTLY IN PAID WORK**

When you stopped paid work, did you consider how your pension might be affected?

Could you afford to retire because you were entitled to start receiving your pension?

And have you sought any information about your pension since then? How useful?

Have you taken any steps to protect or continue contributing to your pension since you stopped work?

### **FOR CARERS WHO HAVE NOT WORKED WHILE CARING**

Since you started caring, have you (or your partner) sought any information about your pension(s)?

- Who from?
- How helpful?
- Did timing of information seeking coincide with timing of decisions around caring and/or employment?
- Have you taken any steps to protect or continue contributing to your State Pension?

### **SECTION 7: FOR EX-CARERS (i.e. who have stopped caring in past few weeks because cared-for person has died/entered residential care/moved away)**

I'd like to talk to you about any plans for work now that your caring responsibilities have changed.

- Any plans to change your training activities/work/seek paid work? What? Do plans relate to any changes in financial situation?
- *If no plans to seek paid work/change current work* – Does the change in your caring responsibilities affect the retirement and pension plans we talked about earlier?
- *If does plan to seek paid work/change current paid work* – Have you sought any information or help in relation to these plans to change/seek work/training now your caring responsibilities have changed?

How has your financial situation changed now that you have ceased caring?

What do you think are the main barriers to changing/seeking work now that your caring responsibilities have changed?

What kinds of help would be most useful to you now in seeking/changing paid work given that your caring responsibilities have changed?

**SECTION 8: CONCLUDING REMARKS**

Is there anything we've not discussed about caring and paid work that you would like to add?

**Thank you very much for taking part in the study. As I said before we started the interview, all the information you have given me will remain confidential. Would you like us to send you a short summary of our report? We anticipate that this will be available next autumn (2005).**

**Give £20 gift; get signed receipt**



# Appendix C

## Topic guide for focus groups with professionals

## Carers' Aspirations and Decisions Around Work and Retirement

### Topic Guide for Focus Groups with Professionals

#### Aims of the focus groups:

- To examine the effectiveness of the support currently available to carers in enabling them to remain in or return to work.
- To explore what additional forms of support could be provided that would help carers.

#### 1. Broad introduction

- Thank you for agreeing to take part in the focus group.
- I am (...) and this is (...) from the Social Policy Research Unit (or SPRU) at the University of York. SPRU is an independent organisation. We do research on behalf of Government agencies and departments, research councils and charitable organisations.
- You should all have seen the information leaflet about the research. Just to remind you, however, this discussion group has been organised as part of some research that has been commissioned by the Department for Work and Pensions. The purpose of the research is to provide information about the experiences and views of informal carers. By 'carers' we mean carers of ill or disabled people, or the elderly, rather than parents caring for non-disabled children.
- The Department for Work and Pensions is interested in this because it wants to learn more about the relationship that carers have with the labour market and in particular their attitudes to, and decisions about, caring, paid work and retirement.

#### 2. The set-up of the focus group discussion and breaking the ice

- Before we start, I just want to say a few quick words about the set-up of the session today.
  - The session will last for 90 minutes until (...). (For Carers Centre group: Please let me know at the end of the discussion if you have incurred any expenses for attending the group so we can reimburse you.)
- As you know, we are going to tape record the discussion. However, everything said and done in the group is confidential and will only be used for the purposes of this research. Nothing that you say will be attributed to you by name.

- Please do not hesitate to put your own viewpoint or experiences forward, even if that means disagreeing with someone else.
- Try to avoid more than person speaking at a time as it will be hard for the person transcribing the tape.
- My role is to ask the questions and make sure that everyone has the opportunity to contribute. (... 's) role is to take a few notes, make sure the tape recorder is working correctly and that things go smoothly.
- Does anyone have any queries or concerns about the times or the ground rules? Please tell me now.
- I'd like to have a brief 'getting to know' you session, because even if you all know each other, we don't know you. Please could each of you say quickly who you are, what your job/position is and how you come into contact with carers.
- (When finished going from each group member) Thank you, now moving onto our first subject.

### 3. Topics for discussion

#### **3.1 Awareness of issues relating to carers' combining work and care-giving**

Aim: to explore professionals' experiences with dealing with carers and employment, their subjective perception of the (different) groups of carers and their needs.

- **Past experience:** Can you think back over the last 12 months or so to discussions you have had with carers about working and caring.
  - What is your impression of the importance of paid work for carers? Are there any specific issues or problems that carers raise? (*Probe: issues related to lack of confidence, length of time out of labour market, welfare benefits; other financial provisions.*)
  - How did you deal with them? What sort of advice or support did you provide? Did you signpost carers on to any other support agencies? Which?
- **Perception of different groups of carers regarding combining work and caring**
  - Have you found that there are any particular groups of carers who need specific or special types of help to support them in combining work and care-giving? Why these groups? What are their particular needs? (*Probe: parents of disabled children, carers of people with mental health problems, carers of particular ages or professional background*).

- **Perceptions of the groups of carers regarding returning to work while caring**
  - In your experience, which carers do you think are most likely to want to return to paid work? Under what circumstances?
- **Perceptions of the needs and aspirations of former carers**
  - For some people, caring is relatively short-term and they may wish eventually to return to paid work. In your experience, what do carers want to do after caring, and when?
- **To sum up this section**
  - Based on your experiences of working with carers, what do you think are the most important barriers that prevent carers from working? (*Probe: caring responsibilities, benefit system, health, age, motivation.*)

### **3.2 Views of the impact of local labour market characteristics**

Aim: to understand professionals' perceptions of the impact of the local labour market situation on carers ability and attitudes to work.

- What do you know about good local employers for carers who want to work? What makes them good? Can you give us some examples of what you view as 'good practice' and why?
  - Are there any specific features of this area/locality that you think create particular difficulties or good opportunities for carers seeking to combine work and care-giving?

### **3.3 Awareness of, and opinions about, effectiveness of current service provision**

Aim: to explore professionals' awareness of, and perceptions about, the effectiveness of the support currently available for carers.

- **Knowledge of availability of support:** What information, help and practical support is available to help carers wanting to combine work and care-giving:
  1. From your organisation?
  2. In the locality more widely
    - Do you know what support other organisations like (social services, JobCentre Plus, PRTC carers centre) provide for carers?
    - Are there other agencies to whom you refer carers or tell carers about? Do you refer to any national organisations as well as local ones?

If not mentioned, ask specifically about training: Are any training opportunities available, perhaps for carers who have been out of the labour market for some time and want to return?

- **Financial support**
  - To what extent do you think that the financial provisions available for carers are adequate? (NB: concentrate on the whole package of benefits, rather than just Carer's Allowance)
- **Pensions**
  - Where can carers go to ask for information and advice about plans for retirement, or pensions? Which agencies do you signpost carers on to for advice or support about pensions?
  - Do you think there are any specific issues about pensions that are only/ especially relevant to carers? And if so, is there a case for tailoring advice specifically for carers?
- **Effectiveness of current support**
  - In your view, how effective is the help that is available for carers wanting to combine work and care-giving/return to work? (*Probe for the potential impact of retraining on job prospects?*)
  - Are there any barriers for carers to access the help? (*Probe for the problems they have experienced in contracting and/or communicating with carers (e.g. carers are too busy to get into your office easily.)*)

### **3.4 Suggestions for improving support and service provision for carers**

Aim: to explore professionals' ideas about additional help and support for carers.

- **Suggestions for helping to combine work and caring**
  - What additional help, information or advice do you think would help carers already in work who then start a caring role (e.g. someone in their late 40s or early 50s who starts to look after an elderly parent which is an increasingly common situation)
- **For getting back in work while caring**
  - What additional help, information or advice do you think would help people who are already caring, but are keen to get back into the work force, for instance the mother of a disabled child?
- **For returning to work for former carers**
  - And lastly, what additional help, information or advice do you think would help people whose caring situation changes such that they no longer have caring responsibilities and want to return to paid work (for instance, the person they were looking after might have gone into independent living, residential care, or died)?

- **Any other organisations?**

- Are there any other (types of) organisations that are well placed to support carers back into work, but that tend to be overlooked (for example, local training providers)? How could they help?

### **3.5 New legislation**

Aim: to explore professionals' expectations regarding the changes in their work practice after the Carers Act comes into force.

- The Carers (Equal Opportunities) Act 2004 comes into effect on 1 April. One of the duties placed on local authorities is that consideration must be given to whether the carer works or wishes to work, wishes to study or have some leisure activities, when carrying out a carer's assessment. What implications do you think this new legislation will have for your organisation and the work that you do with carers?

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