



Carers, Employment and Services in Scotland: focus on East Ayrshire, Falkirk and Highland

*Sue Yeandle, Cinnamon Bennett, Lisa Buckner, Gary Fry and Christopher Price:
University of Leeds*



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

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

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

In the CES survey, working carers told us that:

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

Key Messages about carers in Scotland

In Scotland 243,672 people have both a paid job and unpaid care responsibilities, supporting a relative, partner or friend who is sick, disabled or frail.

They include:

97,085 MEN (63% of male carers)

and

78,577 WOMEN (35% of female carers)

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

8,097 MEN (5% of male carers)

and

59,913 WOMEN (27% of female carers)

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

56,345 people (23% of working carers) provide 20 or more hours of unpaid care each week

This report focuses on the situation of carers living in Scotland and features detailed information about East Ayrshire, Falkirk and Highland. It uses official statistics and new data from the CES survey to explore the extent of unpaid caring among people of working age, and examines the circumstances of employed carers who live in Scotland and the views of those who took part in the study. There were 290 responses to the survey from carers of working age living in Scotland as a whole (including 60 from East Ayrshire, 63 from Falkirk and 137 from Highland): 86% were providing 20+ hours of care per week and 47% were in employment. 27 of the 134 CES in-depth interviews were with carers in East Ayrshire and Falkirk. This report outlines the support available to working carers in Scotland, highlights innovation and service developments, and offers a contribution to the current policy debate about the role of carers in the delivery of social care in Britain, and about carers' need for support.

About the study

This report is one of a series¹ relating to the Carers, Employment and Services (CES) study conducted in 2006-7 at the University of Leeds, commissioned by Carers UK.

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

The study² included a national survey targeting carers of working age (1,909 responses), and an in-depth study in East Ayrshire, Falkirk and Highland³ and 8 other localities in Britain based on interviews with carers (134), an investigation of local policy and provision relating to carers of working age, and detailed analysis of the 2001 Census⁴.

1. Carers and Employment in East Ayrshire, Falkirk and Highland, Scotland

In this part of the report we consider carers of working age in Scotland (looking in detail at East Ayrshire, Falkirk and Highland), focusing on the growing demand for care, the characteristics of carers of working age, and the circumstances of those carers who are combining their unpaid caring role with paid work.

Demand for Care

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

Changes in the age structure of the population and advances in medicine are increasing the demand for care and drawing more people into unpaid caring roles. In Scotland in 2001 over 802,000 households (37% of all households) contained at least one person with a limiting long-term illness (LLTI). Scotland's population of people aged 75+ is set to increase by 198,000 people (up 53%) by 2024⁵. In this age group 66% of people already report having a LLTI, and 26% are in poor health. These figures have risen since 1991, when 53% of the 75+ group had a LLTI⁶.

The 2001 Census showed Scotland had 480,000 carers providing support for their friends and relatives who needed help:

- 978,400 people in Scotland have a LLTI, among them 433,400 who are also in poor health.
- With age, many older people become frail (88,355 people in Scotland were aged 85 or older).
- Disability and other conditions have increased.

They included an estimated 15,900 parents who identified themselves as carers in households which contained a sick or disabled child⁷.

We estimate that, in Scotland, the care these unpaid carers provide would cost £7.68 billion per year to deliver using paid support⁸. This care would cost £213 million in East Ayrshire, £239 million in Falkirk and £280 million in Highland. Most carers give their help willingly, and wish to work in partnership with health and social service providers; often they enable those they care for to remain at home where they wish to be. All commentators expect demand for care to increase in coming years.

Table 1 Local data on health, ageing and carers

Sources: * 2001 Census Standard Tables, Crown Copyright;
** 2004-based sub-national population projections, National Statistics.

| | East Ayrshire | Falkirk | Highland |
|---|---------------|---------|----------|
| Households containing a person with a LLTI* | | | |
| Number | 20,327 | 23,908 | 30,061 |
| % | 40 | 38 | 34 |
| Increase in people aged 75+ by 2024** | | | |
| Number | 5,000 | 6,000 | 13,000 |
| % | 59 | 59 | 80 |
| Health of people aged 75+ 2001** (%) | | | |
| LLTI | 69 | 67 | 61 |
| Poor health | 29 | 29 | 20 |
| Carers in households with sick or disabled children* | | | |
| | 370 | 500 | 740 |

In 2001, 3.5% of carers in Scotland (almost 17,000 carers) belonged to ethnic minority groups⁹ (Figure 1), a percentage a little below their share of Scotland's total population (5%). This is not surprising, given the younger age profile of ethnic minority groups.

Figure 2 shows all carers in Scotland by age: 2% of carers were under 16 (3% in East Ayrshire and Highland), and 15% were aged 65+, but most were people of working age. In fact two thirds of carers in Scotland were aged 35-64, for many people years in which their career or earnings are very important.

Within Scotland, caring is particularly concentrated in areas of socio-economic deprivation (see Figures 4a to 4c). 21% of carers of working age in Scotland live in workless households (12% of carers providing 1-19 hours of care a week, 27% of carers providing 20-49 hours and 44% of carers providing 50+ hours), compared with 15% of people who are not carers¹⁰.

Figure 5 shows that there are some areas within Scotland in which more than 70% of carers of

Figure 1 Carers in Scotland by ethnic group

Source: 2001 Census Standard Tables, Crown Copyright 2003. Note: Data in this figure are for carers of all ages, and show all carers who identified themselves as belonging to the groups indicated

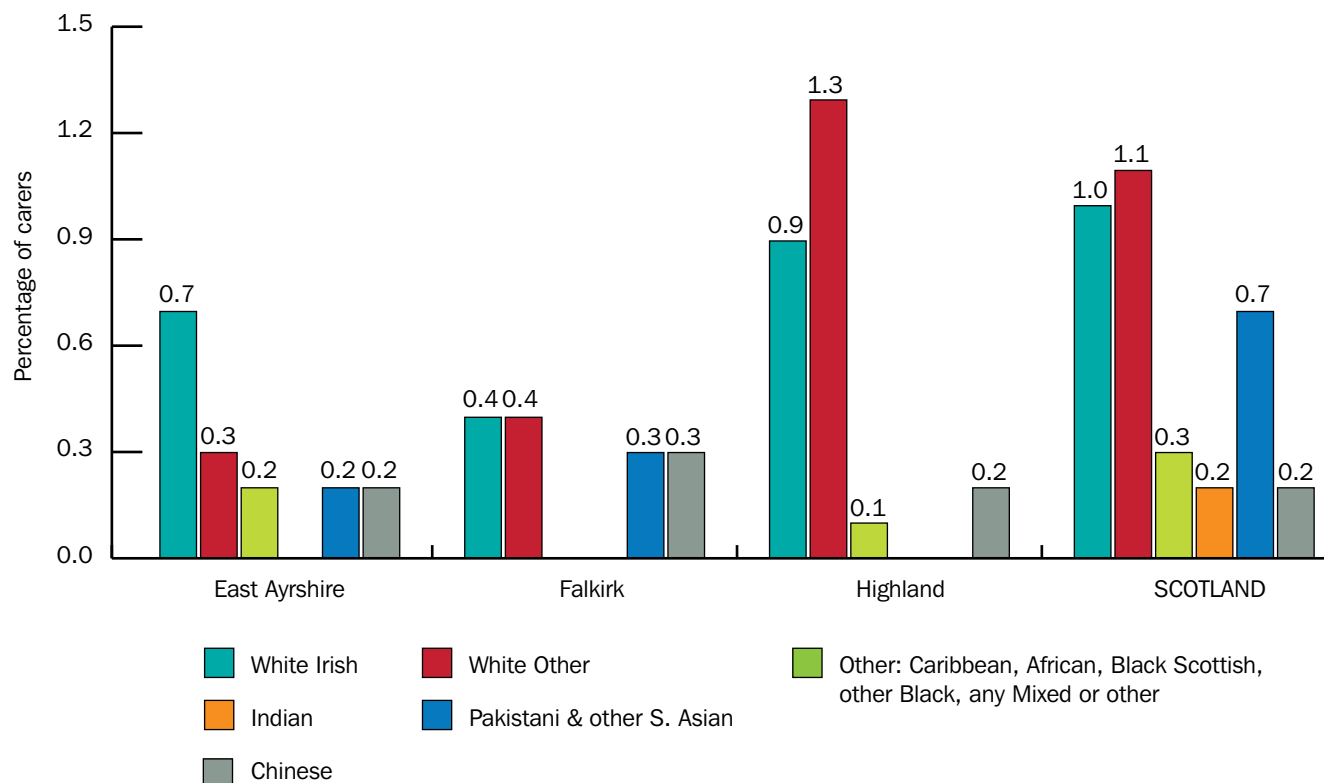
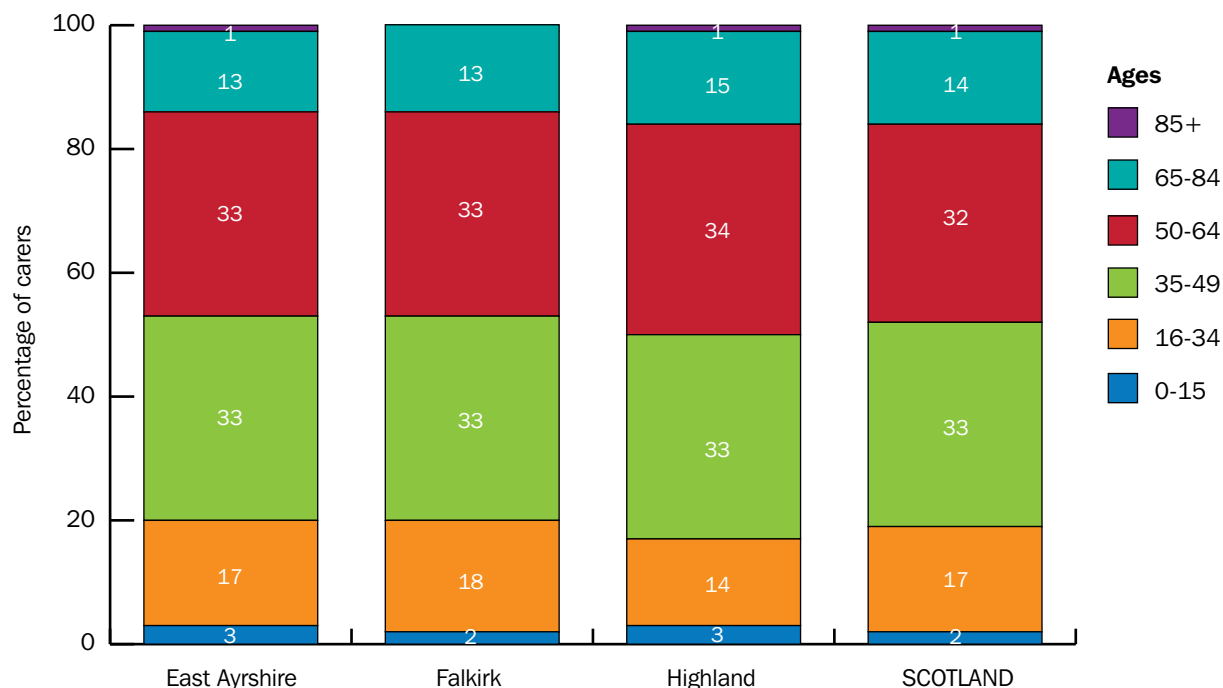


Figure 2 Carers in Scotland by age

Source: 2001 Census Standard Tables, Crown copyright 2003. Note: in Falkirk, 0.46% of carers were aged 85+. For technical reasons, this is not visible in the column in Figure 2 showing the age of carers in Falkirk.



working age are in employment. The likelihood of a carer in this age group also being in paid work nevertheless varies, as shown in the map, between the different districts within Scotland. This situation is likely to reflect both differences in the availability of suitable employment opportunities, differences in the caring needs of the people cared for, and differences in the alternative support and services available locally.

Carers of Working Age

78% of carers in Scotland (almost 374,800 people) are of working age; 41% are men and 59% women. In East Ayrshire and Falkirk, the proportion of carers who are of working age is slightly higher 79% (9,774 people) and 80% (11,870 people) respectively, whilst in Highland it is 76% (14,076 people). Their economic activity status and weekly hours of care are shown in Table 2.

Among people of working age, the likelihood of being a carer rises with age (Figure 3). Among male carers in Scotland, most also hold paid jobs. 55% of men who care for 20-49 hours per week have full-time

jobs, 5% work part-time, and 7% are unemployed and seeking work. 9% care for their family full-time, 4% have retired early and 11% are themselves sick or disabled. Even among those men who have very heavy caring roles (50+ hours per week) 38% are in full-time paid work. However these male carers also have high rates of sickness and disability (19%), and a significant minority care for their family full-time (21%).

Over half (54%) of female carers who care for 20-49 hours per week have paid jobs too. They are fairly equally divided between those in full-time (29%) and those in part-time paid work (25%), while 8% are themselves sick or disabled and 25% care for their family full-time. Among women who care for 50+ hours per week, 16% work full-time and 18% part-time, while in this group 42% care for their family full-time, and 13% are sick or disabled themselves.

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

Figure 3 Percentage of people in Scotland and selected areas who are carers by age and sex

Source: 2001 Census Standard Tables, Crown copyright 2003.

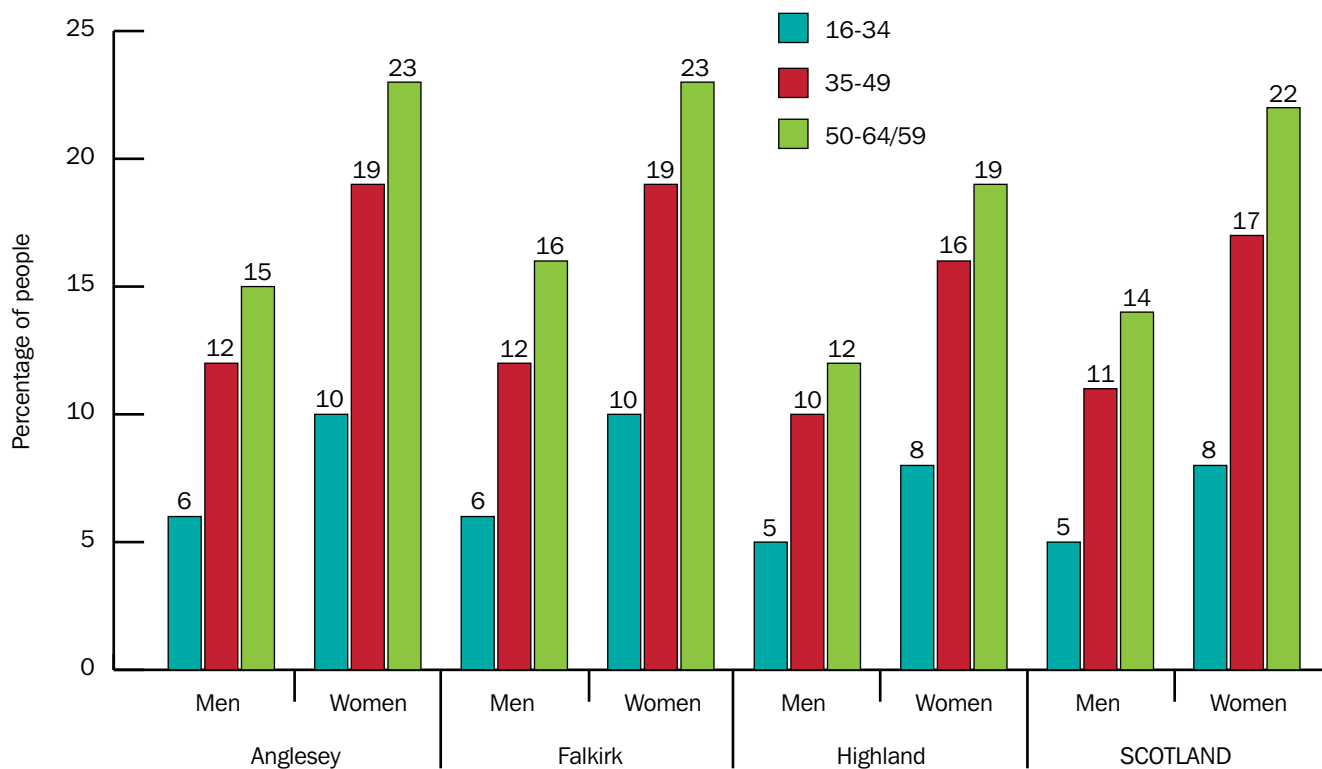


Figure 4a Carers of working age in East Ayrshire by geographical distribution within the area

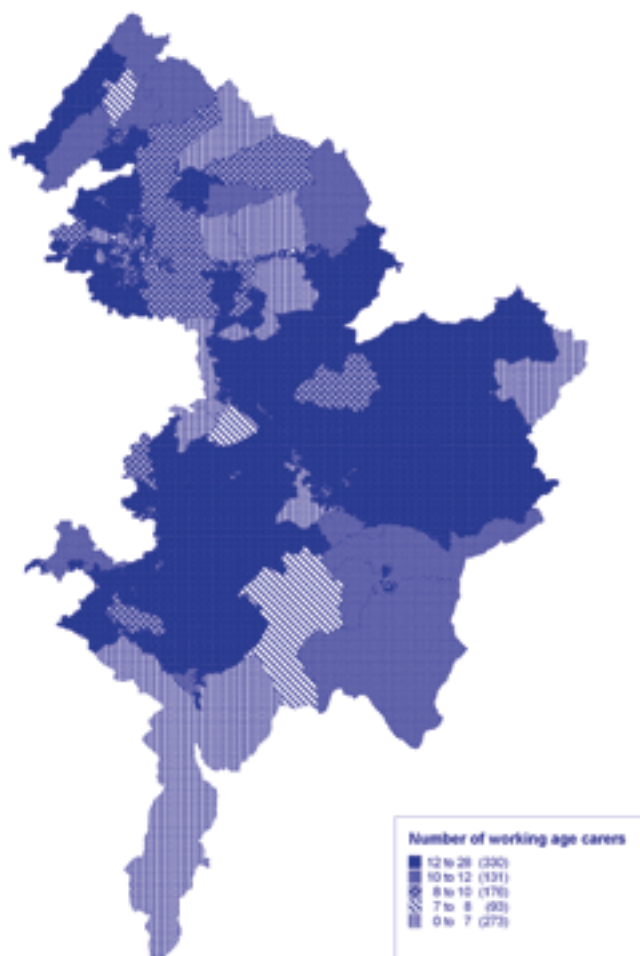


Figure 4b Carers of working age in Falkirk by geographical distribution within the area

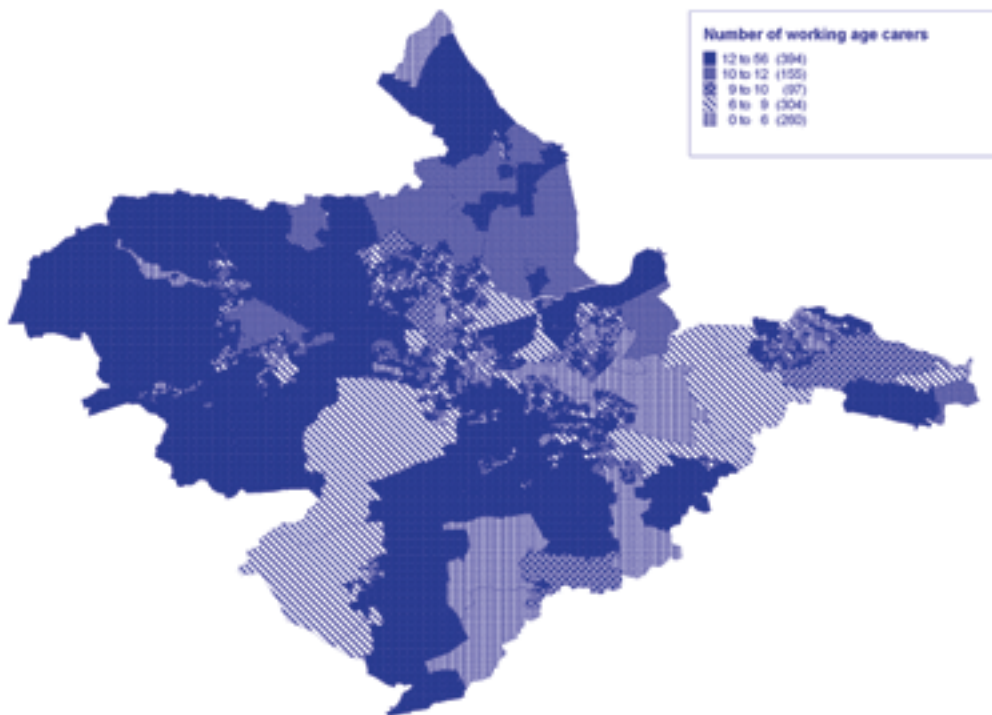
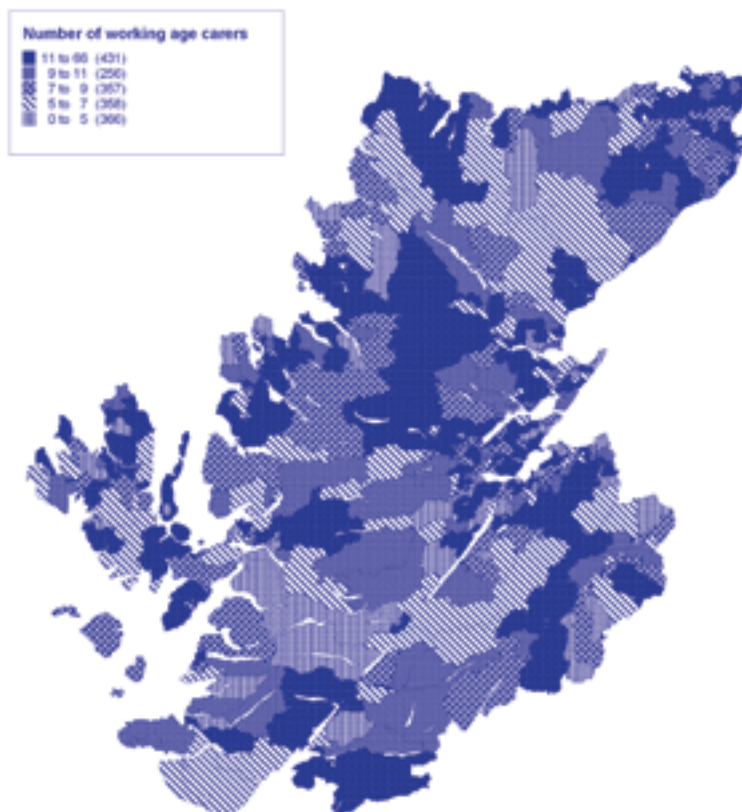


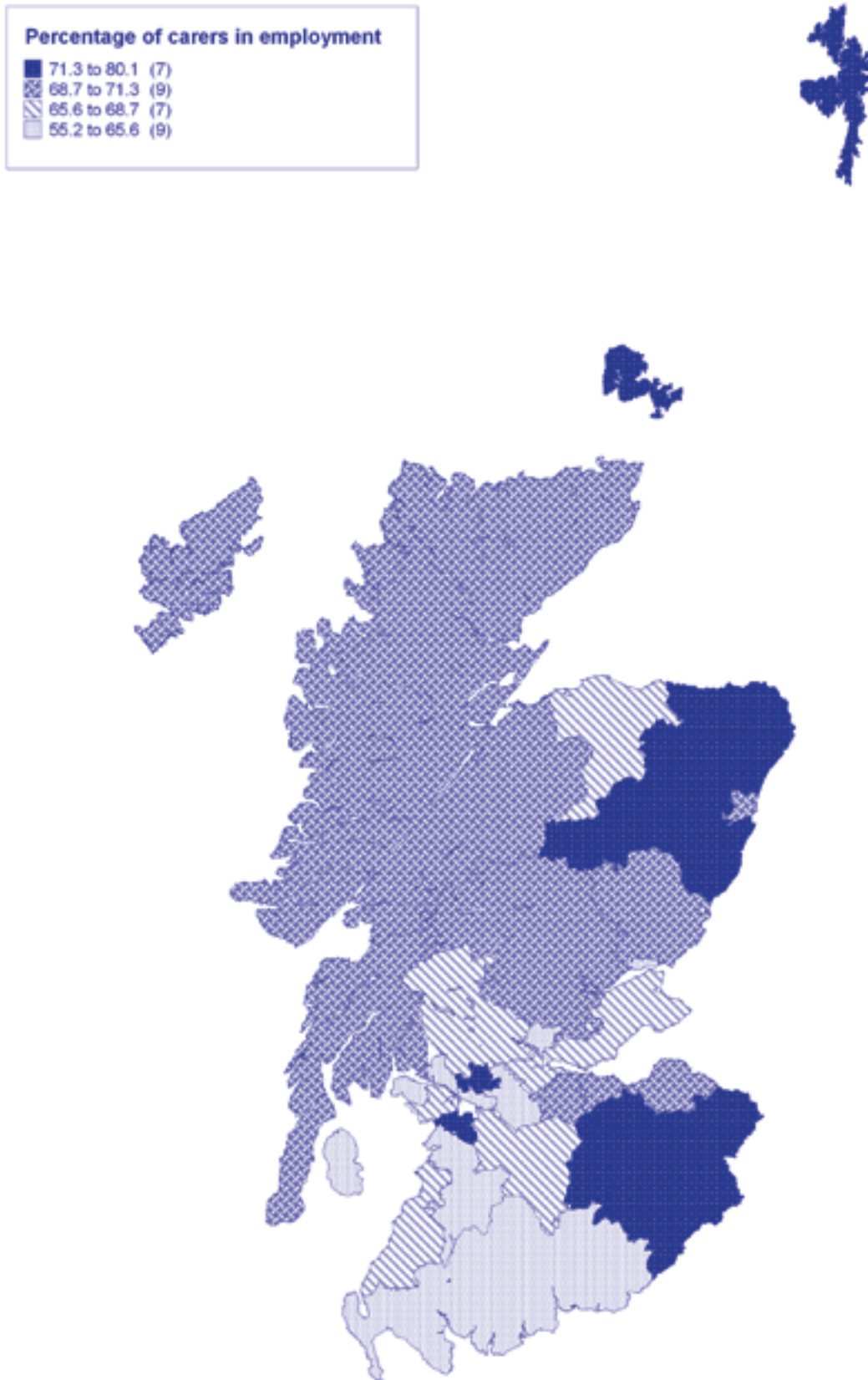
Figure 4c Carers of working age in Highland by geographical distribution within the area



Source for Figures 4a-4c: 2001 Census Area Statistics, Crown Copyright 2003. This work is based on data provided through EDINA UKBORDERS with the support of the ESRC and JISC and uses boundary material which is Copyright of the Crown; 2001 Census, Output Area Boundaries, Crown Copyright 2003. Note: In the key, figures in brackets indicate the number of Super Output Areas (each approximately 615 households) in the relevant category.

Figure 5 Carers of working age who are in employment: SCOTLAND

Source: The source for this figure is as for Figures 3a-3c.



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Table 2 Carers of working age in East Ayrshire, Falkirk and Highland by sex, employment status and weekly hours of care

Source: 2001 Census Standard Tables, Crown Copyright 2003.

| | Men (16-64) | | | | | | Women (16-59) | | | | | |
|----------------------------------|----------------------|----|-----------------------|----|---------------------|----|----------------------|----|-----------------------|----|---------------------|----|
| | Caring 1-19 hours | | Caring 20-49 hours | | Caring 50+ hours | | Caring 1-19 hours | | Caring 20-49 hours | | Caring 50+ hours | |
| | | % | | % | | % | | % | | % | | % |
| EAST AYRSHIRE | | | | | | | | | | | | |
| All of working age | 1,2,568 | | 512 | | 907 | | 3,603 | | 853 | | 1,346 | |
| In full-time work | 1,851 | 72 | 275 | 54 | 331 | 36 | 1,479 | 41 | 220 | 26 | 200 | 15 |
| In part-time work | 115 | 4 | 20 | 4 | 31 | 3 | 1,098 | 30 | 199 | 23 | 213 | 16 |
| Unemployed | 162 | 6 | 45 | 9 | 73 | 8 | 148 | 4 | 40 | 5 | 34 | 3 |
| Permanently sick or disabled | 180 | 7 | 58 | 11 | 174 | 19 | 143 | 4 | 40 | 5 | 34 | 3 |
| Looking after home/ family FT | 25 | 1 | 54 | 11 | 187 | 21 | 457 | 13 | 244 | 29 | 612 | 45 |
| (Early) retired | 94 | 4 | 20 | 4 | 63 | 7 | 56 | 2 | 18 | 2 | 39 | 3 |
| FALKIRK | | | | | | | | | | | | |
| All of working age | 3,363 | | 623 | | 985 | | 4,513 | | 1,018 | | 1,387 | |
| In full-time work | 2,456 | 73 | 343 | 55 | 404 | 41 | 1,981 | 44 | 283 | 28 | 217 | 16 |
| In part-time work | 138 | 4 | 28 | 4 | 37 | 4 | 1,346 | 30 | 260 | 26 | 247 | 18 |
| Unemployed | 158 | 5 | 42 | 7 | 42 | 4 | 146 | 3 | 23 | 2 | 34 | 2 |
| Permanently sick or disabled | 198 | 6 | 64 | 10 | 204 | 21 | 182 | 4 | 86 | 8 | 174 | 13 |
| Looking after home/ family FT | 30 | 1 | 55 | 9 | 177 | 18 | 513 | 11 | 277 | 27 | 587 | 42 |
| (Early) retired | 203 | 6 | 40 | 6 | 77 | 8 | 101 | 2 | 27 | 3 | 38 | 3 |
| HIGHLAND | | | | | | | | | | | | |
| All of working age | 4,151 | | 648 | | 1,113 | | 5,573 | | 958 | | 1,683 | |
| In full-time work | 2,976 | 72 | 382 | 59 | 425 | 38 | 2,232 | 40 | 273 | 28 | 280 | 17 |
| In part-time work | 332 | 8 | 36 | 6 | 74 | 7 | 2,011 | 36 | 265 | 28 | 340 | 20 |
| Unemployed | 235 | 6 | 48 | 7 | 80 | 7 | 145 | 3 | 41 | 4 | 36 | 2 |
| Permanently sick or disabled | 164 | 4 | 59 | 9 | 153 | 14 | 150 | 3 | 61 | 6 | 171 | 10 |
| Looking after home/ family FT | 36 | 1 | 59 | 9 | 243 | 22 | 637 | 11 | 235 | 25 | 736 | 44 |
| (Early) retired | 214 | 5 | 20 | 3 | 95 | 9 | 130 | 2 | 20 | 2 | 38 | 2 |

Working Carers

We know from the 2001 Census that across Britain, carers are found in all occupations and in all industries, making working carers an important part of virtually every workforce throughout the whole economy. The occupations of employed men and women in East Ayrshire, Falkirk and Highland (indicating their level of unpaid care responsibility) are shown in Figures 6 and 7. Carers who provide 20 or more hours of care per week are more strongly concentrated in lower level jobs than other workers, a picture also seen at national level. Both male and female carers are more likely to work in 'routine' occupations, and less likely to work in managerial or professional jobs, if they care for 20+ hours per week.

The CES survey was designed to explore the circumstances of working age carers in more depth. It obtained responses from 1,909 carers, including 812 working carers. 350 respondents were carers living in Scotland (including 75 in East Ayrshire, 70 in Falkirk and 174 in Highland). While not fully representative of all carers in Scotland, the information provided by these carers gives some insight into carers' circumstances and into what combining work and care is like for someone living in Scotland (Table 3).

- 22% of carers in Scotland told us their health was 'not good' (26% of our whole GB sample).
- 75% of carers in Scotland had been caring for 5 or more years (68% of our GB sample).
- 86% of carers in Scotland provided 20+ hours of care per week (82% of our GB sample).
- 37% of carers in Scotland were struggling to make ends meet (33% of our GB sample).

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

- Services are too expensive (34% compared with 33% of our whole GB sample).
- They do not like the way services are organised (26% compared with 31% of our whole GB sample).
- There are no suitable services in their area (41% compared with 32% of our whole GB sample).

- Services are not reliable (31% compared with 30% of our whole GB sample).
- Services are not flexible (47% compared with 46% of our whole GB sample).
- Services are not sensitive to needs (41% compared with 44% of the whole GB sample).
- They do not know what is available locally (35% compared with 31% of our whole GB sample).
- The cared for person does not want to use services (46% compared with 37% of our whole GB sample).

In Scotland, 151 respondents were carers of working age (16-64) who were not currently in paid work (including 30 in East Ayrshire, 37 in Falkirk and 76 in Highland). Of these:

- 27 had retired from a paid job (7 in East Ayrshire, 6 in Falkirk and 13 in Highland).
- 12 were looking for work (1 in East Ayrshire, 6 in Falkirk and 4 in Highland).
- 89 were looking after home and family full-time (20 in East Ayrshire, 17 in Falkirk and 48 in Highland).
- 20 were themselves sick or disabled (3 in East Ayrshire, 7 in Falkirk and 10 in Highland).
- Over a third (37%) would prefer to be working (29% in East Ayrshire, 35% in Falkirk and 43% in Highland).

Working carers in the CES survey in Scotland included:

- 109 men and 22 women.
- 66 people working FT and 56 people working PT.
- 67 people caring for a sick or disabled child.
- 31 people caring for a partner or spouse.
- 27 people caring for a parent or parent-in-law.

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

Figure 6 Men in employment by caring responsibilities and socio-economic group: Scotland and selected areas

Source: 2001 Census SAM¹⁰. Note: Data in this figure are for men aged 16-64.

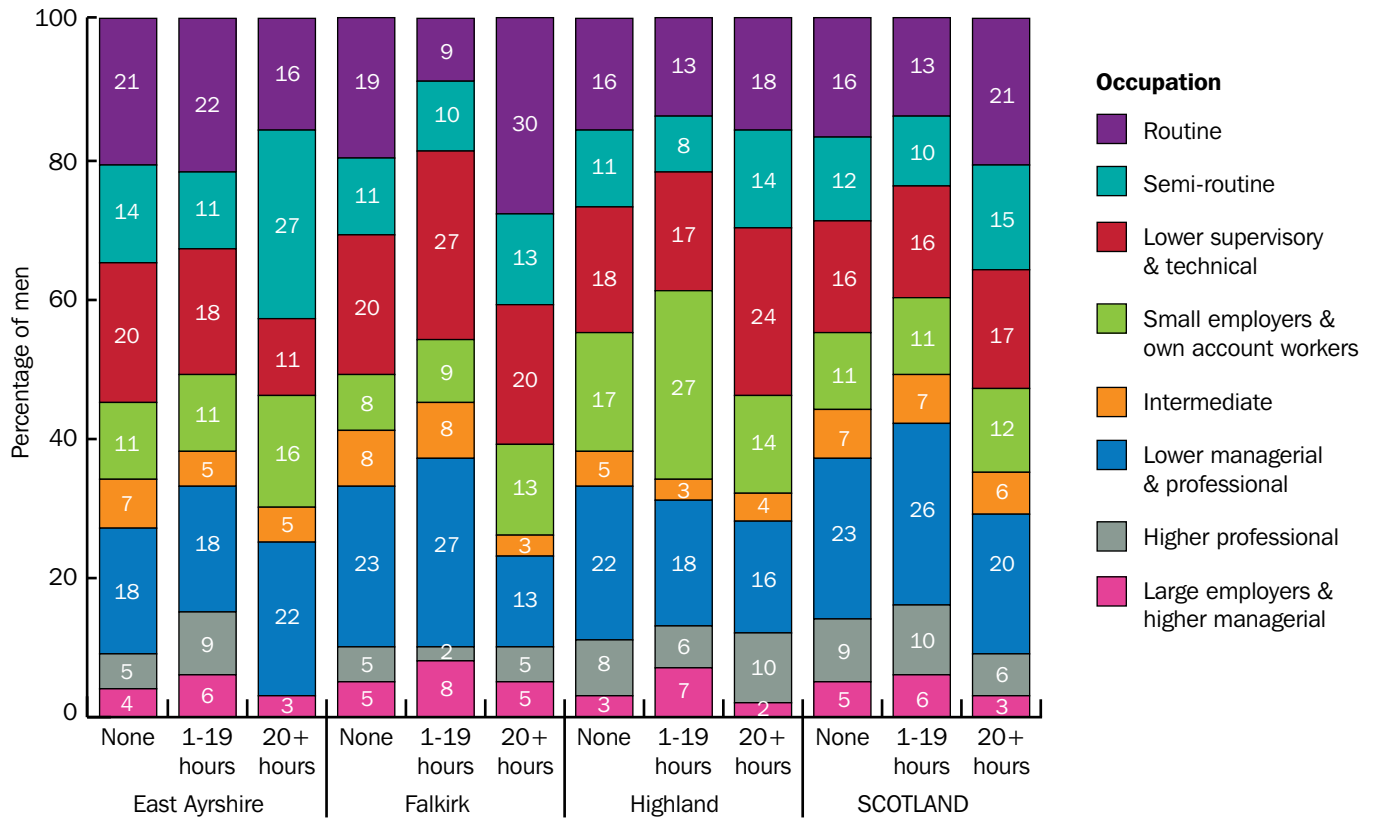


Figure 7 Women in employment by caring responsibilities and socio-economic group: Scotland and selected areas

Source: 2001 Census SAM¹⁰. Note: Data in this figure are for women aged 16-59.

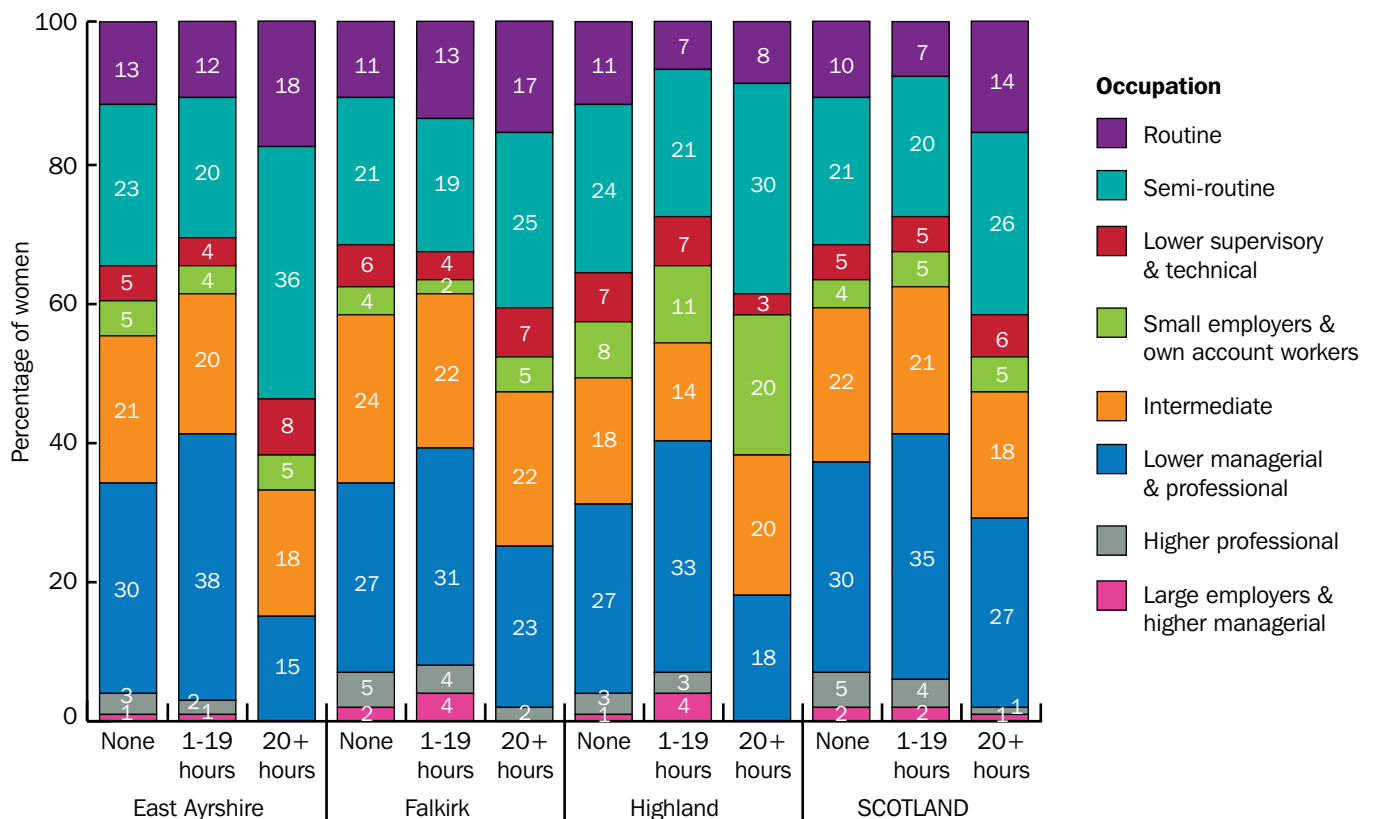


Table 3 Responses of Scottish carers in the CES Survey

Source: CES Survey, University of Leeds 2007.

| | East Ayrshire | Falkirk | Highland | Scotland |
|--|---------------|---------|----------|----------|
| Scottish respondents – number | 75 | 70 | 174 | 350 |
| Carers whose health is 'not good' (%) | 9 | 23 | 39 | 22 |
| Carers who have been caring for 5+ years (%) | 71 | 77 | 79 | 75 |
| Carers who provide 20+ hours of care a week (%) | 81 | 81 | 90 | 86 |
| Carers who are 'struggling to make ends meet' (%) | 27 | 41 | 43 | 37 |
| Carers' use of services limited because: | | | | |
| Services are too expensive (%) | 25 | 26 | 46 | 34 |
| They do not like way services are organised (%) | 19 | 29 | 33 | 26 |
| There are no suitable services in the area (%) | 15 | 27 | 65 | 41 |
| Services are not reliable (%) | 22 | 25 | 37 | 31 |
| Services are not flexible (%) | 41 | 44 | 53 | 47 |
| Services are not sensitive to need (%) | 26 | 40 | 53 | 40 |
| They do not know what is available locally (%) | 27 | 24 | 45 | 35 |
| The cared for person does not want to use services (%) | 35 | 34 | 57 | 46 |

Combining Work and Care

Many carers in Scotland are working carers: in 2001 97,085 men and 78,577 women were combining care with full-time employment (63% and 35% of male and female carers respectively), while a further 8,097 men and 59,913 women were providing unpaid care while working part-time (5% and 27% of male and female carers respectively). Table 4 shows working carers' employment status in Scotland, and Table 5 shows the views of those working carers in Scotland who took part in the CES survey.

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

I've just given up work, and this is one of the reasons why. There is a lot of work involved in just sorting things out – mundane, basic things.

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

I think the people that I deal with are actually very good. The quality of the people whether it's the doctor or the social worker are very good. I just feel they're restricted in what they can actually do...

For most, a job was a financial necessity; some also valued their paid work as a break from caring. Many reported that the demands of caring left little time for other aspects of life, including spending time with other family members or children:

We've never been able to go on holidays...it's really sad because I don't have any time for him [her other child] because I'm pulled in so many directions. I try my best to do everything for everybody.

They described their experiences in ways which highlight both what can be achieved when carer support is flexible and responsive, and the problems which carers face when the services received do not provide the carer with appropriate support to get on with their 'normal' lives:

It [home care paid for by Direct Payments] lets me get on with my work without having to worry

Figure 8 Men in employment by caring responsibilities and employment status: Scotland and selected areas

Source: 2001 Census Standard Tables, Crown Copyright 2003. Note: Data in this figure are for men aged 16-64.

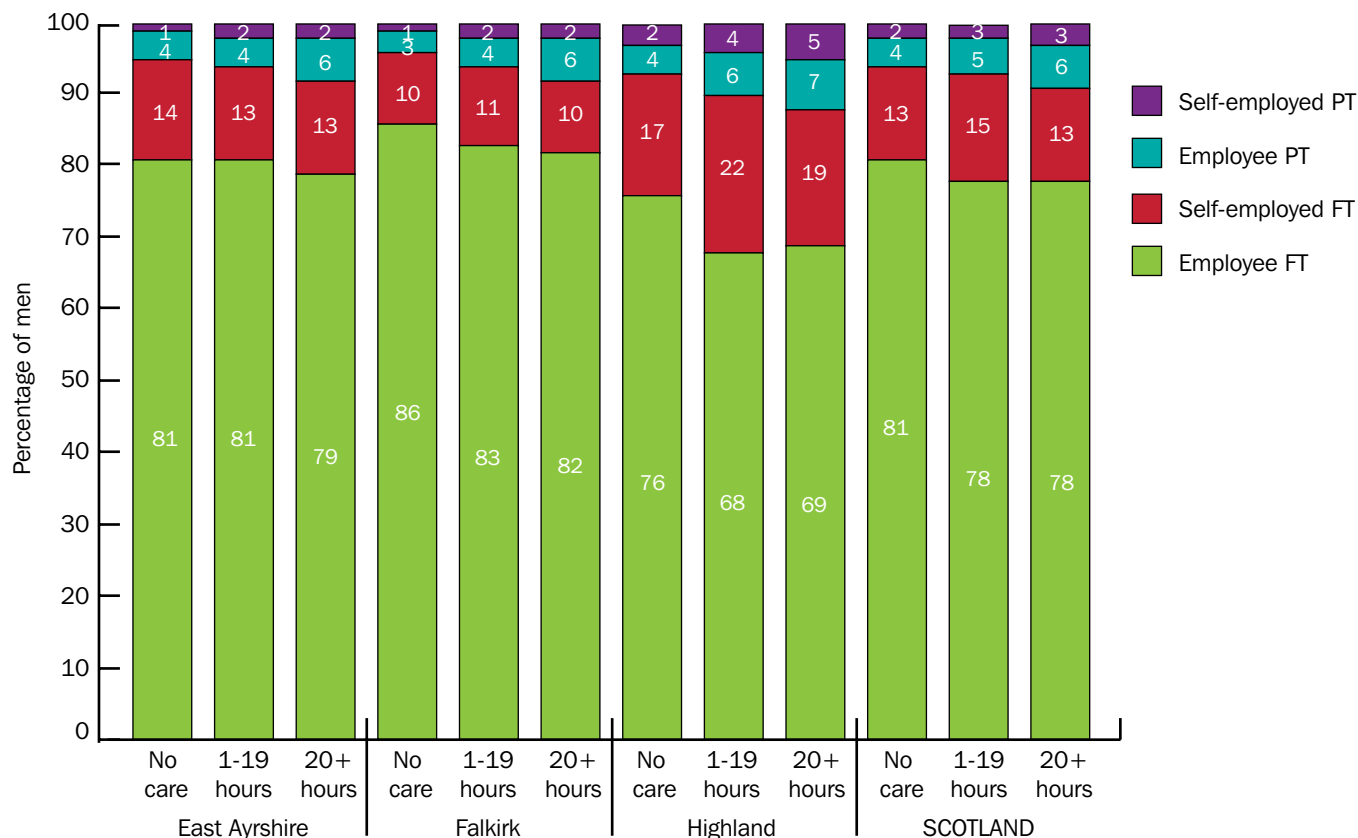


Figure 9 Women in employment by caring responsibilities and employment status: Scotland and selected areas

Source: 2001 Census Standard Tables, Crown Copyright 2003. Note: Data in this figure are for women aged 16-59.

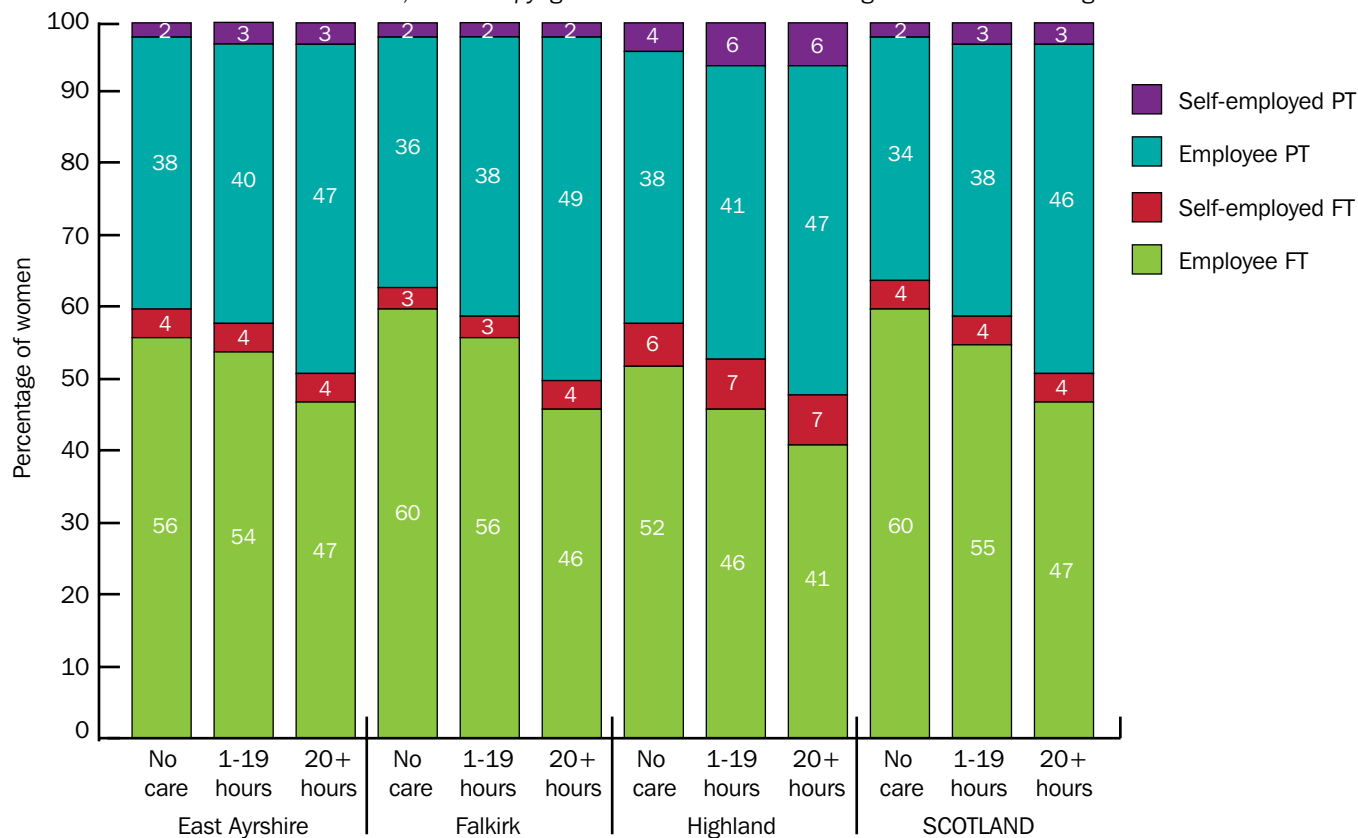


Table 4 Carers in employment in Scotland and selected localities

Source: 2001 Census Standard Tables, Crown Copyright 2001.

| | East Ayrshire | Falkirk | Highland | Scotland | Great Britain |
|-----------------|----------------|----------------|----------------|-----------------|--------------------|
| Men full-time | 2,457 (62%) | 3,203 (64%) | 3,783 (64%) | 97,085 (63%) | 1,199,263 (65%) |
| Women full-time | 1,899 (33%) | 2,481 (36%) | 2,785 (34%) | 78,577 (35%) | 791,168 (33%) |
| Men part-time | 166 (4%) | 203 (4%) | 442 (7%) | 8,097 (5%) | 123,669 (7%) |
| Women part-time | 1,510 (26%) | 1,853 (27%) | 2,616 (32%) | 59,913 (27%) | 716,583 (30%) |

Table 5 Combining work and care

Source: CES Survey, University of Leeds, 2007.

| | East Ayrshire | Falkirk | Highland | Scotland | Great Britain |
|---|---------------|---------|----------|----------|---------------|
| % in paid work agreeing that: (number=) | | | | | |
| <i>I have adequate services to enable me to work</i> | 28 | 24 | 49 | 122 | 786 |
| <i>My employer is carer-friendly and I feel supported at work</i> | 46 | 50 | 57 | 55 | 58 |
| <i>I rely on family and friends to enable me to work</i> | 72 | 75 | 81 | 79 | 70 |
| <i>I am considering giving up my job</i> | 25 | 29 | 51 | 37 | 39 |
| <i>My caring responsibilities do not affect my job</i> | 39 | 21 | 16 | 24 | 22 |

and I know if there's anything at all they'll phone me. It takes a bit of weight off your shoulders for a few hours a day, so you can go about your normal business.

If they had got me day care before now, I wouldn't even consider putting my father in a home. Because the only thing wrong with my father is boredom. He's not got any interaction with adults his own age.

JOYCE'S EXPERIENCE

Although I must admit that my work has been understanding, it still puts a strain on me. I'm maybe getting away from my work or maybe not doing the full amount of work I should be doing - but it's still there. When you go back you're trying to catch up.

Barbara has been caring for her elderly father for

several years with the support of her sister. Her father lives alone, close by, and she visits him daily to prepare evening meals and keep him company. As Barbara works full time in a town nearby she is reliant on her sister and an outreach worker to check on her father at lunchtime. The family have tried using home care services but they did not find the arrangement appropriate, given her father's dementia. With home care workers only spending 15-20 minutes at a time in the house, her father was easily confused and Barbara felt more time and patience was needed. Although she feels very well supported by her employer's flexible working practices, Barbara is always trying to catch up lost hours, contributing to her high level of stress. She acknowledged that in the future, she may have to reduce her hours if her father's condition worsens.

Jess's EXPERIENCE

If I had been able to work all the days that I could without taking time off for appointments and things then I might have been [better off]. But the fact is there were several days – sometimes a week here and there – that I had to take off, and I wasn't getting paid for it.

Jess has three children under the age of 11, two of whom have care needs. Jess is also a single parent and is struggling to make ends meet and access appropriate services. The only family she has close by are her mother and father, but they are not always able to provide her with help as they are elderly themselves. Jess's situation is made more problematic by her severe asthma, which has left her hospitalised on more than one occasion, and she is concerned about a lack of appropriate emergency respite services in the area. All of Jess's children attend school but she feels she needs more support, and has made a number of unsuccessful attempts to secure more help. This has contributed to her leaving her paid job to concentrate on organising medical appointments and accessing services. In the end, her children's

many hospital appointments and her own ill health have made sustaining paid work difficult. As Jess was not paid for the days when she was absent from work, she now finds herself in serious and mounting debt.

These two examples illustrate the importance of high quality, accessible services – both in improving quality of life for individual carers and their families, and in enabling carers to participate in paid employment, contribute to the support of their families, and put their skills to work in the formal economy where securing an adequate labour supply is an increasing problem for some local employers.

In England, Wales and Scotland, many carers in the CES study lacked confidence in the ability of statutory agencies to respond quickly and appropriately to their situation, and, because of this and other problems in securing support, some were at risk of giving up work.

We turn next to arrangements for supporting carers of working age, especially those who are in paid employment, both in Scotland and in the localities studied in detail in our research.

2. Support for Working Carers

Policy context in Scotland

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

The legislation and policy now in place in Scotland secures carers' right to leave from work to deal with emergencies and caring crises; their right to request

flexible working arrangements; and their right to a Carers Assessment which acknowledges their desire to work as well as to care (Figure 10). These recent changes have placed new statutory obligations on local authorities, employers and others.

In Scotland the debate about the need to modernise social care services outlined in the 1998 White paper¹¹ has increased the prominence of carers' issues and the effective delivery of carers' services through the statutory obligations placed on health services: the Kerr report *Building a Health Service for the Future* (2005) highlighted the significance of carers in supporting and reducing health service intervention, particularly in the areas of emergency admissions, hospital discharge and managing

people suffering from long term conditions. In its response, the Scottish Executive emphasised that the NHS must change, from the current position, where 'carers are undervalued', to one where 'carers are supported as partners'¹². Supporting carers is a central theme in Scottish health care policy. Ministers took up powers granted by the *Community Care and Health (Scotland) Act (2002)* to request that Scottish NHS Boards produce Carer Information Strategies, detailing how they provide carers with the information and training they need for their caring role, alongside building 'carer awareness' training into professional schemes. In addition, to secure service delivery improvements, joint management systems and joint commissioning and assessment processes between staff in NHS primary care and local authorities have been established by the *Joint Future* policy, delivered by the Joint Future Unit in the Scottish Executive.

Central to driving forward change at local level are the Local Improvement Targets (LITs), agreed by local partnerships, to deliver four National Outcomes for Community Care, issued in March 2004 by the Executive. One of these four areas, 'Better involvement and support for carers', encourages the development of carers' strategies, a flexible range of services 'fit for purpose', clear signposting to a range of care packages, and support for individuals and carers' groups. Local partnerships in Scotland have already made some progress towards the setting of LITs as part of the development of their local joint performance management frameworks.

In line with the national Carers Strategies in England and Wales, Scotland's *Strategy for Carers (1999)* was accompanied by an annual allocation of funding to local authorities to help them deliver better support for carers. The allocation has been in the form of Grant Aided Expenditure (GAE) which has not been ring-fenced, and has been increased each year since 1999. In addition, in June 2007 the Scottish Government allocated a single grant of £400,000 to support a young carers' festival and to develop training for carers in the skills they need to carry out their caring tasks¹³. At the local level, it is unclear how GAE has been divided between services such as carers' centres and respite services, as most authorities have not been required to report this level of detail to the Scottish Government. However,

where they did not already exist, many authorities have now established carers' centres or projects¹⁴.

Older service users in Scotland and some of their carers have benefited from the Scottish Government's approach to charging which differs from that in England and Wales: upholding the Scottish Labour Party's manifesto promises, free personal care for people aged 65 and over was introduced through the *Community Care and Health (Scotland) Act 2002*¹⁵. All charges for personal care in the community for older people were lifted, and a flat rate payment for residential care was introduced. This policy was identified as a 'success' by the Care Inquiry Report (July 2006)¹⁶, which recommended its continuation, while nevertheless noting that half of all local authorities were operating a 'waiting list' for free personal care.

A significant difference for working carers in Scotland is the absence of a statutory duty on local authorities to promote equal opportunities and in so doing uphold their right to enter or remain in paid employment and training, although the *Community Care and Health (Scotland) Act 2002* prompts local authorities to 'consider' carers' employment when conducting Carers Assessments. The in-depth planning document *Care 21: the future of unpaid care in Scotland (2006)* also highlights the issue of carers and employment. Based on the views of 5,000 carers consulted in 2004-2005, it called for a national carers' awareness campaign, targeting employers. As yet, the Scottish Executive has not made any firm commitments in response.

Although across Scotland local agencies have been innovative and resourceful in responding to the carers' agenda, delivering new forms of support for carers, especially employed carers, has often been affected by resource constraints, organisational blockages, and the lack of statutory and monitoring requirements. In the workplace, and elsewhere, developments have sometimes also been affected by out-of-date attitudes towards carers, or by ignorance of the ubiquity, importance and necessity of carers' roles.

Policy developments in East Ayrshire

East Ayrshire has a well developed voluntary sector infrastructure for carers. The East Ayrshire

Figure 10 Main legislative / policy developments affecting carers in Scotland since 1995

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

| Development | Key change for carers* |
|---|---|
| Carers (Recognition and Services) Act (1995) | Introduced the concept of a Carers Assessment. |
| Strategy for Carers (1999) Scottish Executive policy document | Stressed that enabling carers to combine paid work and care was a priority for government, in line with 'Caring for Carers' the UK National Strategy issued in 1999. |
| Employment Relations Act (1999) | Gave employees the right to 'reasonable time off' to deal with emergencies. |
| Changes to Invalid Care Allowance (now known as Carer's Allowance) (2000) | Amendment to the <i>Social Security Contributions and Benefits Act 1992</i> , which included extending carers' benefits to people aged 65 and over. |
| Employment Act (2002) | Gave employed parents of disabled children under the age of 18 the right to request flexible working arrangements. |
| Community Care and Health (Scotland) Act (2002) | Recognises unpaid carers as key partners in the provision of care, and gives them the right to an assessment in their own right. Guidance for NHS Boards on the development of Carers Information Strategies. Free personal and nursing care for people aged 65 and over in both domiciliary and residential settings. Places a duty on local authorities to offer Direct Payments to all disabled people, including those with mental illness and learning difficulties and parents of disabled children. |
| Care 21: the future of unpaid care in Scotland (2006) Planning document | Recommends a national awareness campaign about employed carers, targeting employers. |
| Work and Families Act (2006) | Extended the right to request flexible working arrangements to all carers in employment, from April 2007. |
| Pensions Act (2007) | Recognises carers' situation, for example by reducing the number of qualifying years needed for a full basic State Pension; introduces a new carers' credit for those caring 20+ hours a week for someone who is severely disabled. |
| Revised National Carers' Strategy (2008) | The UK government's consultation process began in 2007. |

Carers Centre opened in 1996, and the number of registered carers using its services has grown to over 3,000¹⁷. In 2003, it became a registered charity with a voluntary Board of Directors which has continued to include a number of carer representatives. 35% of its core funding is provided jointly by the Council and NHS Ayrshire and Arran¹⁸. A range of other sources including the Lloyds TSB Foundation, the Department of Work and Pensions and the Big Lottery have allowed it to develop specialist services and to pilot new approaches. Some of these services are discussed in more detail below.

The first East Ayrshire Carers Strategy (1997-2001) anticipated and addressed priorities arising from the Scottish Executive's National Carers Strategy (1999); in particular it focused on the introduction and expansion of Carers Assessments as part of the new process of Single Shared Assessment which involved social workers and community health providers, and the provision of more and better respite care and carers breaks.

East Ayrshire Council's involvement in the *Joint Future for Carers Project*, a partnership initiative between Carers Scotland and the Coalition of Carers in Scotland, funded by the Scottish Executive, fed into the development of its second Carers Strategy (2004-2007)¹⁹. In this partnership East Ayrshire was one of four pilot authorities which undertook training and capacity building activities to enable carers to fully participate in local service planning processes. A Carers Strategy Group was formed in 2003 comprising equal numbers of carers and representatives from the statutory sector, chaired jointly. It produced an action plan based on the priorities of the Joint Futures Project to underpin the 'Achieving Change' section of the current strategy. The 2004-2007 strategy aims to:

- Ensure more carers are identified by statutory health and social care providers, benefit agencies and employers.
- Challenge cultures within organisations to make sure that all staff recognise carers as partners in the planning of care for the person they support and in their ability to contribute to strategic and operational planning processes.

- Ensure Carers Assessments are more accessible, informative and useful, resulting in increased take-up of carers services.
- Develop innovative flexible services that meet carers' needs, in reference to Best Value frameworks, particularly targeting carers of people with mental ill health.

The legislative context in Scotland has meant that unlike in England, NHS and community health providers have been key partners with the local authority. They provide direct funding to develop carers' services, and their staff proactively engage carers in their participation activities, alongside patients. In East Ayrshire, almost half of all referrals to the Carers Centre come from health sources. To pioneer new ways of reaching 'hidden' carers (those who do not recognise themselves as having that role), the centre has been funded by a local GP practice to provide advice and information sessions in the surgery setting²⁰.

In recognition that only 46% of its members are of working age (compared with 78% of carers nationally) the Carers Centre has developed services to target employed carers through collaboration with Carers Scotland and the Action for Carers and Employment National Partnership. It has undertaken a one year pilot to develop a 'person-centered' approach to Carers Assessments, in which discussions about work and employment aspirations can be raised. Through the *Carers in Employment Initiative*, the centre has made links to local employers, providing information and advice to ensure that their employees can better manage their job alongside a caring role²¹.

Policy developments in Falkirk

The Falkirk Carers Strategy Action Plan (2006-2007) relates to the Council's focus on the need to:

Take into account the growth of carers' rights [through national legislation] and the need to acknowledge the central role they play in the community as providers of health and social work services²².

This strategy has been developed by the Housing and Social Work Services Department, in consultation with a number of different sources

Table 6 Home care provision and Direct Payments: Scotland and selected areas

Source:

* Home Care Scotland, 2006, Statistical Release, Scottish Executive National Statistics publication.

** Distribution of Home Care Hours Received, by local authority, 2006.

*** Direct Payments Scotland 2006, Statistical Release, Scottish Executive National Statistics publication.

| | East Ayrshire | Falkirk | Highland | SCOTLAND |
|--|---------------|--------------|--------------|-----------------|
| Home care* | | | | |
| Hours of service provided or purchased by the LA | 22,593 | 19,364 | 15,875 | 604,081 |
| Change since 2005 | +19% | +34% | -1.4% | +3% |
| Number of clients receiving home care (in the week beginning 31st March 2006)** | 1,859 | 2,325 | 2,633 | 70,657 |
| Change since 2005 | +6% | +7% | -5% | -0.6% |
| Number of clients receiving 10+ hours of homecare per week (in the survey week) ** (%) | 749 (40%) | 535 (23%) | 435 (17%) | 18,324 (26%) |
| Number of clients receiving Direct Payments*** | 36 | 58 | 194 | 1,829 |

including: carers attending the Annual Falkirk Carers Conference and other local events; the Carers Consultative Forum – a network of carers coordinated by the health services; carers support organisations, and other Council Services and Forth Valley NHS.

Although local feedback from the Council's community care teams suggests that carers' views are taken into account in the process of Single Shared Assessment, the number of independent Carers Assessments remains relatively low. The Action Plan prioritises this work as a main area of service development, along with actions to identify more 'hidden' carers.

The Council's provision of respite care and breaks since 2001 has aimed to deliver positive outcomes for both users and their carers, by being flexible in design and availability. The Short Breaks Bureau is a well established service offering a range of successful options: holiday-type breaks which include the cared for person and their family are popular, as well as respite at home, which uses Direct Payments. To improve this service further, in 2008 an Independent Living Service will be created, which will encompass the Short Breaks Bureau, the Direct Payments Scheme and access to the

Independent Living Fund²³. Combined, these areas of service provision will offer more opportunities and flexibility for carers, something that is crucial if they are to maintain a 'normal' life without adverse effects on their health, personal interests or employment.

Changing Lives, the report of the 21st Century Social Work Review (2006) highlights the importance of carers in community social care interventions and the expectation that carers and service users will have an active role in determining the design and delivery of services which are personalised and flexible, as mentioned above. The Falkirk Carers Strategy (2007-2008) aims to involve carers as stakeholders in their own right in service planning processes. A Carers Consultative Forum was set up several years ago for this purpose. It has been regularly attended by representatives from the Carers Centre, representatives from Falkirk Council and health services and representatives from local carers' voluntary sector organisations. Attendance by carers has been less consistent. To boost their involvement, the Carers Centre is set to take over the running of the Forum from statutory health services in 2007. Carers' participation has been highest in local educational and support groups run

by the Carers Centre, Falkirk District Association for Mental Health and Alzheimer's Scotland and at the Annual Carers Conference run by the Carers Centre.

As in East Ayrshire, the health sector is a key partner in the Council's work with carers. The recent introduction of the NHS Forth Valley Carer Information Strategy (October 2006) has widened the net of staff in health services who are able to provide information to carers and facilitate referrals

to appropriate agencies for specialist advice. The Council's own Disability Information Service is an important first point of contact for many carers inquiring about a wide range of issues. The Council is aware that it will only be able to broaden the provision of advice and information (to include education, training and welfare benefits advice) if it links with other local agencies and ensures carers are also part of their agenda.

3. Issues and Challenges

Despite these achievements, reaching working carers, providing them with information and encouraging them to use carers' services is still 'work-in-progress' for East Ayrshire and Falkirk, as for all local authorities. Currently, the level of Carers Assessments, as a gateway to services, is capturing only a small minority of all carers in Britain – and as most of the carers receiving support were not in paid work, very few working carers nationally have had their needs assessed.

In East Ayrshire and Falkirk, as elsewhere, limitations on social services budgets and the associated eligibility criteria used in identifying those who can receive support mean that only carers at the 'heavy' end of caring get support, and local experience suggests that many of those in touch with services were a long way from the labour market. Evidence in the CES study suggests that it is important not to assume that such carers cannot or do not want to work, as carers' experience, up and down the country, indicates that they are rarely asked about their preferences, or if they need support in accessing a paid job. Carers Assessments are one vehicle for identifying ways of improving the support available to working carers – both by identifying direct help for carers (e.g. through respite and breaks) and by delivering services to those they care for in more flexible, sensitive and situation-specific ways.

As already indicated, the authorities we have studied are responding to this challenge. Falkirk's Short Breaks Bureau, mentioned above, has proved

very successful in enabling health and social care practitioners to book appropriate provision for carers with assessed needs, and in helping individuals using Direct Payments to secure the services of their choice.

A second challenge is reaching 'hidden' carers particularly those of working age and those who are employed. It is recognised that promoting the right of carers to a life outside caring by safeguarding their employment and training opportunities is moving forward only slowly. Scottish authorities are increasingly providing more targeted support, including employment-related benefits advice and outreach information services, to carers in work. Their work in this area has nevertheless mainly been delivered through pilots, special projects and short-term initiatives.

East Ayrshire started this work by focusing on its own role as an employer, and in so doing, aims to provide an example which other large local employers can follow. Approaches include a 'payslips campaign', in which basic information supplied by the Carers Centre was sent to every local authority employee on their payslip. A 'Carers Employment Pack' is available to employees requesting further information about their entitlements and rights as a carer. To reach employed carers (beyond those working for the local authority) and to address the barriers to employment faced by working age carers, other agencies must be engaged in delivering this agenda, for example those agencies responsible for

job creation, labour market activation, local strategic development and the supply of skilled labour, as well as local employers – and it is recognised that this is a major challenge.

The additional funding provided by the Scottish Government as part of GAE to local authorities following the National Carers Strategy 1999, has been a very important and effective catalyst for service development, yet these funds represent a ‘drop in the ocean’ in achieving the transformation of services needed by working carers. Some local authorities involved in the CES study were concerned about whether funding of this type would continue and about how to protect such funds, as core budgets were affected by other pressures. Some argued that until a carers’ perspective was adequately embedded in the thinking of all social care and health staff, core funding which supported services for users would not necessarily be allocated in ways which best support carers. As both carers and service providers told us, high quality services to users, funded out of local authorities’ Social Services core budgets, are extremely important in supporting carers.

Recently, the Scottish Government has indicated in its future spending plans that it will increase its commitments to carers, offering local authorities greater scope to develop carers’ services. In November 2007 a concordat between the Scottish Government and local authorities was announced²⁴. Under the terms negotiated, the Government will provide the sums specified in the concordat, together with a number of other components (including streamlining bureaucracy and reporting

requirements, and retention by local authorities of efficiency savings). In return, local government will contribute directly to the delivery of the key commitments, of which carer support is one area: there is a commitment to delivering 10,000 extra respite weeks per annum at home and in care homes; support for an additional 1,000 young carers; and extra resources allocated to carers centres. *The Scottish Budget Spending Review 2007*, outlining the Government’s intentions for the next 3 years, includes carers in its spending priorities under the Health and Wellbeing Portfolio. It makes a commitment to:

*Improving outcomes for frail older people and family carers, by investing in care home quality, increasing free personal care payments and significantly extending respite and other carer support.*²⁵

Lord Sutherland²⁶ has been commissioned to undertake an independent review of funding provided to local government to implement the Free Personal and Nursing Care policy, to be delivered in March 2008. The Spending Review foregrounds the results of the Government’s consultation on *Better Health, Better Care* which ended in November 2007, by underlining the priority to develop high quality, person-centred, accessible health and social care services. In this it makes a commitment to carers (as well as users) to expand support for carers, including carer training and local carer centres (2007: £1.0m; 2008: £3.0m; 2009: £5.0m); and to develop a one-stop shop for social care information to improve access by helping people understand their options (2007: £0.5m; 2008: £0.3m; 2009: £0.3m).

Notes

- ¹ The CES Report Series includes 6 titles presenting national level analysis: 1. Stages and Transitions in the Experience of Caring; 2. Managing Caring and Employment; 3. Diversity in Caring: towards equality for carers; 4. Carers, Employment and Services in their Local Context; 5. Action for Carers and Employment: impact of the ACE partnership 2002-7; 6. Carers, Employment and Services: time for a new social contract? Separate reports relating to Scotland and Wales and to the English localities studied are also available.
- ² Details of methods used are given in CES Report 6.
- ³ Highland is included in this report because of the large number of responses received from carers in this part of Scotland. It was not part of the original research design, however, and for this reason the report does not include data about local policy developments and delivery in Highland.

- ⁴ Data on carers' characteristics are from the 2001 Census Standard and Commissioned Tables, Crown Copyright 2003 and the 2004-based Sub-national Population Projections, except where the indicated source is the CES survey 2007.
- ⁵ 2004-based Sub-national Population Projections, ONS, Crown Copyright – GRO Scotland.
- ⁶ 2001 and 1991 SARs, Crown Copyright. The question about general health used in 2001 was not asked in the 1991 Census.
- ⁷ Figure estimated using 2001 Census Standard Tables with data on households with a resident aged 0-15 with a LLTI and the number of carers in the household.
- ⁸ Buckner, L and Yeandle, S (2007) *Valuing Carers: calculating the value of unpaid care* London: Carers UK.
- ⁹ All ethnic groups excluding White Scottish and Other White British.
- ¹⁰ Source: 2001 SAM. The 2001 SAM (Small Area Microdata) is provided through the Cathie Marsh Centre for Census and Survey Research (University of Manchester), with the support of the ESRC and JISC. All tables containing Census data, and the results of analysis, are reproduced with the permission of the Controller of Her Majesty's Stationery Office and the Queen's Printer for Scotland.
- ¹¹ The White Paper *Modernising Social Services* (1998) demanded that care services should meet each individual's specific needs by drawing together statutory services, working in partnership, accessed, provided and financed in a fair way.
- ¹² Scottish Executive *Delivering for Health* November 2005.
- ¹³ Scottish Government (2007) *Scottish Government News 14 June 2007*: <http://www.scotland.gov.uk/News/Releases/2007/06/14101941>.
- ¹⁴ Source: Carers Scotland.
- ¹⁵ This development reflected growing governmental concerns about the future demand for, cost of, and affordability of domiciliary care services, prompted by the findings of the Royal Commission on the Long-Term Care for the Elderly (1999).
- ¹⁶ Health Committee Report, SP Paper 594 <http://www.scottish.parliament.uk/business/committees/health/reports-06/her06-10-vol01-00.htm>
- ¹⁷ PRTC East Ayrshire Carers Centre Annual Review, 2002-2003.
- ¹⁸ East Ayrshire Carers Strategy, Part 1 2004-2007.
- ¹⁹ op. cit.
- ²⁰ op. cit.
- ²¹ East Ayrshire Council, Department of Educational and Social Services Briefing Note to provide information on East Ayrshire Carers Centre (unpublished).
- ²² Falkirk Carers Strategy: Action Plan 2007-2008.
- ²³ A national fund for people aged under 66 years with serious disabilities.
- ²⁴ Concordat between the Scottish Government and COSLA (Convention of Scottish Local Authorities), November 2007: <http://www.scotland.gov.uk/Publications/2007/11/13092240/concordat>.
- ²⁵ Scottish Government (2007) *Scottish Budget Spending Review 2007*, Chapter 11 Health and Wellbeing Edinburgh: The Scottish Government.
- ²⁶ Lord Sutherland chaired the Royal Commission on the Long-term Care of Older People (1999).

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Finding out more

Carers UK improves carers' lives through information provision, research and campaigning. This research was commissioned by Carers UK on behalf of the ACE National partnership, and part-funded under the European Social Fund's EQUAL Community Initiative Programme. To find out more about Carers UK, contact:

Carers UK

20/25 Glasshouse Yard
London EC1A 4JT

Telephone 020 7490 8818
Fax 020 7490 8824
Email info@carersuk.org
Website www.carersuk.org
CarersLine 0808 808 7777
Open Weds and Thurs 10-12 and 2-4pm

Carers Wales

River House
Ynys Bridge Court
Gwaelod y Garth
Cardiff CF15 9SS

Telephone 029 2081 1370
Fax 029 2081 1575
Email info@carerswales.org
Website www.carerswales.org

Carers Scotland

91 Mitchell Street
Glasgow G1 3LN

Telephone 0141 221 9141
Fax 0141 221 9140
Email info@carersscotland.org
Website www.carersscotland.org



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