

# The 'visibility' of unpaid care in England

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## Abstract

- *Summary:* Social work practice is increasingly concerned with support not just for service users but also for unpaid carers. A key aspect of practice is the assessment of carers' needs. The Government has recently passed legislation that will widen eligibility for carers' assessments and remove the requirement that carers must be providing a substantial amount of care on a regular basis. This article examines which carers are currently 'visible' or known to councils and which are not, and uses the results to examine the likely effects of the new legislation. In order to identify the characteristics of carers known to councils, the article uses large-scale surveys, comparing the 2009/10 Personal Social Services Survey of Adult Carers in England and the 2009/10 Survey of Carers in Households in England.
- *Findings:* Carers who are known to councils provide extremely long hours of care. Among carers providing substantial care who are known to councils, the majority care for 100 or more hours a week. The focus of councils on carers providing long hours of care is associated with a number of other carer characteristics, such as poor health.
- *Applications:* Councils' emphasis on the most intense carers is unlikely to be attributable solely to the current legislation. Therefore, dropping the substantial and regular clauses alone will not necessarily broaden access to carers' assessments and, in order to achieve this, considerable new resources may be needed. How far these resources are available will determine the extent to which practitioners can broaden access to carers' assessments.

## Keywords

Social work, adult care, assessment, carers, England, large-scale survey data, social care

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## Introduction

Social work practice with adults in England is increasingly concerned, not just with supporting disabled and older people, but also with supporting people who provide unpaid care to relatives and friends. An increasing number of social care practitioners, including social workers and allied professionals, are involved in developing, coordinating and providing assistance and support for carers (Hussain & Manthorpe, 2012). An important aspect of practice is the identification of carers and assessment of their needs. Social services departments in local authorities (also called councils) in England have certain statutory duties regarding carers' assessments, and adult social care<sup>1</sup> falls within the statutory remit of the 152 Councils with Adult Social Services Responsibilities (CASSRs) (House of Commons Health Committee, 2010). In 2012/13, 411,000 carers were offered an assessment or review in CASSRs in England (Health and Social Care Information Centre [HSCIC], 2013).

The identification of carers is currently a key social policy issue at national level in England. The latest Carers' Strategy, published by the Coalition Government in 2010, has four priority areas, the first of which is 'supporting those with caring responsibilities to identify themselves as carers at an early stage' (Her Majesty's Government [HMG], 2010, p. 6). The White Paper on social care reform, published in 2012, puts an emphasis on ensuring that 'carers are identified earlier' (HMG, 2012a, p. 35) and new legislation, the *Care Act 2014*, which builds on the White Paper proposals, has recently been passed by Parliament, with relevant parts coming into force in April 2015.

For the last 25 years, the identification of carers by local authorities has been embedded in community care law relating to carers' assessments. The Law Commission report on adult social care, published in 2011, identified five pieces of legislation relating to carers' assessments (Law Commission, 2011). The *Carers (Recognition and Services) Act 1995* gave carers the right to request an assessment if the carer provided a substantial amount of care on a regular basis, and if the local authority was carrying out an assessment of that cared-for person under the *NHS and Community Care Act 1990*. This right was subsequently extended by the *Carers and Disabled Children Act 2000*, which introduced a free-standing right to a carer's assessment. These two acts operated alongside each other and both were amended by the *Carers (Equal Opportunities) Act 2004*, which introduced a requirement that any assessment conducted must include consideration of whether the carer worked or wished to work. In addition to these specific statutes on carers' assessments, the *Disabled Persons (Services, Consultation and Representation) Act 1986* required local authorities to take account of a carer's ability to continue to provide care to a disabled person when assessing whether the disabled person's needs call for the provision of services.

The identification of carers by local authorities is particularly important at present because the Law Commission recommended a wholesale reform of community care law, including carers' assessments and, as a result, new legislation has now been passed by Parliament. The Law Commission in 2011 described the existing

legislation for carers' assessments as 'fragmented, overlapping and confusing for local authorities and carers alike' and recommended that the duties to assess a carer should be consolidated into a single duty (Law Commission, 2011, p. 68). In addition, the Law Commission criticised a number of specific aspects of the legislation, in particular, the 'substantial and regular test', which it described as 'unclear, confusing and complex' (Law Commission, 2011, p. 69). It recommended that the 'substantial and regular test' should be removed and that all carers providing care to another person should be entitled to an assessment, where the carer appears to be in need. The Government accepted many of the Law Commission's recommendations on carers' assessments (HMG, 2012b). The *Care Act*, which was passed in May 2014, creates a single duty for local authorities to undertake a carer's assessment. This will replace the existing law, and will remove the requirement that the carer must be providing a substantial amount of care on a regular basis (Care Act 2014). The implication is that the criteria for a carer's assessment will be broadened and more carers will now be able to access an assessment (Law Commission, 2011). Moreover, the *Care Act* will also introduce a new duty on local authorities to provide support to meet carers' needs, and assessments will be a gateway to this new legal right to support for carers.

In the context of the current proposals for legislative reform, including the widening of the definition of eligibility for carers' assessments, it is useful to examine which carers are currently 'visible' to councils and, as a corollary, which are relatively 'invisible' (cf. Evandrou, 1990) and to use the results to examine the likely effects of the new legislation. There is evidence that councils are not currently in touch with many carers. The Information Centre found that only 4% of carers in the *Survey of Carers in Households in England* in 2009/10 had had an assessment (HSCIC, 2010a). It could be argued that it is easier to identify carers who provide a 'substantial amount of care on a regular basis' than carers who provide care at a lower intensity or irregularly. It is therefore useful to focus on how far carers providing a substantial amount of care are currently visible to councils. If more carers are to access assessments, it is arguably those carers who are currently relatively invisible that councils will increasingly need to reach, with clear resource implications.

The present article uses recent large-scale survey data on unpaid care to examine the visibility of carers to councils in England. The article draws on two surveys conducted in 2009/10, the *Personal Social Services Survey of Adult Carers in England* and the *Survey of Carers in Households in England*. The first survey was administered through Councils with Adult Social Services Responsibilities (CASSRs) and was designed for adult carers in contact, either directly or via the person they care for, with social services (HSCIC, 2010b). From 2012, the *Personal Social Services Survey of Adult Carers in England* is being conducted every two years and is compulsory for CASSRs but, in 2009/10, participation in the survey was voluntary and 90 CASSRs participated. The 2009/10 *Personal Social Services Survey of Adult Carers in England* was the first national user experience survey of carers in England and included questions on the characteristics of carers known to

councils and their experiences of support and services, health and employment. The second survey, the 2009/10 *Survey of Carers in Households*, was a survey of carers in the general population (HSCIC, 2010a). This survey captured information about people providing unpaid care in a nationally representative sample of households in England. The *Survey of Carers in Households* also included questions on the characteristics of carers and their experiences of support and services, health and employment, but for a national sample of carers, whether or not they were in contact with councils.

The main aim of this article is to compare the two surveys collected in 2009/10 and thereby identify the characteristics of carers known, or visible, to councils. A subsidiary aim is to use these results as the basis for discussing the likely effects of the new legislation regarding carers' assessments.

## Methods

The eligible population in the *Personal Social Services Survey of Adult Carers in England* was defined as carers aged 18 and over who had been assessed or reviewed by social services during the previous year and, in some CASSRs, carers identified from the records of service users (known as 'carers by association'). In this survey (which will be referred to here as 'the survey of carers known to councils'), an eligible population of 175,600 carers was identified and, of these, 87,800 were sent a postal questionnaire and 35,165 carers then responded, giving a response rate of approximately 40% (HSCIC, 2010b). The 2009/10 *Survey of Carers in Households* (which will be referred to here as 'the household survey of carers') was carried out through face-to-face interviews in a representative sample of randomly selected households in England. Carers were identified through a short screening questionnaire, which was completed by over 25,000 individuals aged 16 and over. Subsequently, 2,400 carers were interviewed to obtain detailed information on their provision of care. The unadjusted response rate for the household screening was 72% and at the individual level was 76% (HSCIC, 2010a).

The present study builds on a preliminary comparison of the survey of carers known to councils and the household survey of carers, which was carried out by the Information Centre (HSCIC, 2010c). The Information Centre's comparison suggested that carers known to councils have different characteristics from carers in households more generally. Carers known to councils appear more likely to be caring for long hours; to be aged 65 and over; and to be caring for a spouse or partner. The Information Centre acknowledged, however, that its initial results may have been affected by differences in methodologies between the surveys. The present analysis takes forward the work of the Information Centre by, first, controlling for methodological differences between the surveys and, second, controlling for current eligibility criteria for assessments. In addition, the analysis examines a wider range of characteristics of carers, cared-for people and caring, as well as using standard statistical techniques to identify differences between the surveys.

### *Controlling for methodological differences between the surveys*

The present analysis controls for a number of methodological differences between the surveys. First, the survey of carers known to councils includes people aged 18 and over caring for others aged 18 and over, whereas the household survey of carers includes people aged 16 and over caring for others of all ages. The dataset for the latter survey only records the age of respondents and the people they care for in broad age-bands, beginning with those aged 16 to 25. It was therefore not possible to confine the analysis to people aged 18 and over caring for others aged 18 and over, and the analysis here relates to carers aged 25 and over caring for others aged 25 and over in both surveys.

In addition, the survey of carers known to councils asks about care provided to the *main* person cared for, whereas the household survey of carers asks separately about care provided for up to six cared-for people. The latter survey also asks the respondent to identify the main person cared for and the analysis here is therefore confined to care provided to the main person cared for in both surveys. The definition of the main cared-for person is similar in both surveys. He or she is defined as the person that the carer spends the most time helping. If carers spend an equal time caring for two or more people, they are asked to answer in relation to the person who lives with them.

Table 1 shows the sample sizes of respondents aged 25 and over providing unpaid care to a main cared-for person aged 25 and over. Controlling for methodological differences, the sample size of the survey of carers known to councils is 31,558, while the sample size of the household survey of carers is 1,962. Given the large difference in sample sizes, the comparisons between the two surveys utilise 95% confidence intervals around the results. Results for the two surveys are significantly different where the confidence intervals do not overlap. All analyses are performed using the Stata 12.1 software package (StataCorp, 2011).

There are issues of representativeness in relation to both surveys, but these limitations can be addressed. In the survey of carers known to councils, only 90 out of the 152 CASSRs in England are included. However, the Information Centre regards the survey as representative of CASSRs in England (HSCIC, 2010c, p. 8). The household survey of carers tends to under-represent lower intensity carers compared with other surveys (HSCIC, 2010a). However, it is with more intense carers that the present analysis is concerned (as explained below).

### *Controlling for current eligibility criteria for assessments*

It is important to confine the analysis of both surveys to carers likely to be eligible for an assessment in 2009/10, that is, those providing substantial care on a regular basis. This is important because, otherwise, differences between the surveys are likely to be due to comparing eligible and non-eligible carers, whereas the purpose of the comparison is look at which of the eligible carers are visible to councils. However, the current eligibility criteria are not defined in legislation (Law Commission, 2010).

**Table 1.** Sample numbers of carers in *Personal Social Services Survey of Adult Carers in England* and *Survey of Carers in Households in England*, controlling for methodological differences and intensity of care, 2009/10.

	<i>Personal Social Services Survey of Adult Carers (Carers known to councils)</i>	<i>Survey of Carers in Households in England<sup>a</sup></i>
Total	35,165	2,400
Aged 25 and over	33,621	2,207
Aged 25 and over and main cared-for person is aged 25 and over	31,558	1,962
Aged 25 and over, care is provided to main cared-for person aged 25 and information on hours of care is available <sup>b</sup>	27,272	1,833
Aged 25 and over and care is provided to main cared-for person aged 25 and over for 20 or more hours a week	21,526	778
Percentage of carers aged 25 and over who provide care for 20 or more hours a week to main cared-for person aged 25 and over	78.9%	42.4%

<sup>a</sup>The *Survey of Carers in Households* data is weighted using weights supplied with the dataset by the UK Data Archive.

<sup>b</sup>Information on hours of care is missing if respondents did not answer the question on hours of care or answered 'other'.

Nevertheless, there is no doubt that current eligibility criteria place a great deal of 'emphasis on the amount of time spent in a caring role' (Law Commission, 2011, p. 69). In a review of the information provided by local authorities, the Law Commission found that some local authorities define substantial and regular care in terms of hours per week, ranging from 10 to 20 hours per week in different local authorities (Law Commission, 2010).

The upper threshold of 20 or more hours a week is used in this article to define carers likely to be eligible for an assessment for two reasons. First, previous research shows that, in practice, local authorities give little priority to those providing care for less than 20 hours a week (Arksey, 2002). Moreover, several local authorities currently state on their websites that, to qualify for a carers' assessment, carers are required to care for 20 or more hours a week (Newcastle Borough Council, 2014; Staffordshire County Council, 2014). Second, the wider literature on unpaid care in this country tends to use hours of care, or intensity, as a measure of substantial care, and the most frequently used measure of intensity is care for 20 or more hours a week (Hirst, 2001). This is based on associations between long hours of care and other characteristics of caring, including help with personal care tasks and co-residence (Parker & Lawton, 1994), as well as negative effects of

**Table 2.** Assessments of carers<sup>a</sup> providing care for 20 or more hours a week, *Personal Social Services Survey of Adult Carers in England* and *Survey of Carers in Households in England*, 2009/10.

		<i>Personal Social Services Survey of Adult Carers in England</i> (Carers known to councils)		<i>Survey of Carers in Households in England</i>	
		Sample numbers	% of sample (95 % CI)	Sample numbers	% of sample (95% CI)
Receipt of carer's assessment	Any assessment/review	16,327	82.7 (82.1, 83.2)	56	7.3 (5.5, 9.2)
	No assessment/review	3,427	17.3 (16.8, 17.9)	706	92.7 (90.6, 94.3)
	Total <sup>b</sup>	19,754	100.0	762	100.0
Type of assessment <sup>c</sup>	Joint assessment with cared-for person	8,625	43.7 (43.0, 44.4)	–	–
	Separate assessment	7,702	39.0 (38.3, 39.7)	–	–

<sup>a</sup>Includes carers aged 25 and over, looking after main cared for person aged 25 and over.

<sup>b</sup>The numbers of carers are lower than in Table 1 because of missing data on assessments (2,204 in *Personal Social Services Survey of Adult Carers in England* and 71 in *Survey of Carers in Households*).

<sup>c</sup>Type of assessment not available in *Survey of Carers in Households*.

caring on employment and health (Heitmueller, 2007; Young, Grundy, & Kalogirou, 2007).

Table 1 shows that 78.9% of carers in the survey of carers known to councils are providing care for 20 or more hours a week. Not all these carers are assessed, but the overwhelming majority (82.7%) are assessed (Table 2). (The minority of carers who are not assessed are those who are 'known by association' with the cared-for person.) In terms of the analysis in this article, this suggests that defining eligibility for a carer's assessment in terms of care for 20 or more hours a week captures the overwhelming majority of carers in contact with councils.

In contrast, using a 20-hour a week threshold includes only a minority of carers in the household survey of carers. Only 42.4% of carers in households provide care for 20 or more hours a week (Table 1). Moreover, even among those caring for 20 or more hours a week, only a tiny minority (7.3%) report that they have been assessed (Table 2). Therefore, even controlling for the provision of 'substantial' care, the comparison between the surveys is essentially a comparison between carers who are by and large assessed, in the survey of carers known to councils, and carers who are by and large not assessed, in the household survey of carers.

## Findings

### *Characteristics of carers providing care for 20 or more hours a week*

Compared with carers in the household survey, carers providing care for 20 or more hours a week who are known to councils are more likely to be older; to be

women; to be from a non-White ethnic background; to have an illness or disability; and not to be in paid employment (Table 3). The most striking differences between the surveys are in age, health and employment. In the survey of carers known to councils, carers are more likely to be aged 70 and over compared with carers in the household survey. In particular, 27.6% of carers known to councils are aged 75 and

**Table 3.** Characteristics of carers<sup>a</sup> providing care for 20 or more hours a week in *Personal Social Services Survey of Adult Carers in England* and *Survey of Carers in Households in England*, 2009/10.

		<i>Personal Social Services Survey of Adult Carers in England (Carers known to councils)</i>		<i>Survey of Carers in Households in England</i>	
		Sample numbers <sup>b</sup>	% of sample (95% CI)	Sample numbers <sup>b</sup>	% of sample (95 % CI)
Age	25–34	269	1.3 (1.1, 1.4)	50	6.5 (4.9, 8.4)
	35–44	1,082	5.0 (4.8, 5.3)	91	11.8 (9.7, 14.2)
	45–54	3,080	14.3 (13.9, 14.8)	152	19.6 (17.0, 22.5)
	55–64	5,831	27.1 (26.5, 27.7)	172	22.2 (19.4, 25.2)
	65–69	2,680	12.5 (12.0, 12.9)	84	10.8 (8.8, 13.2)
	70–74	2,643	12.3 (11.9, 12.7)	71	9.1 (7.3, 11.4)
	75+	5,941	27.6 (27.0, 28.2)	156	20.1 (17.4, 23.1)
	Total	21,526	100.0	776	100.0
Gender	Women	13,809	64.4 (63.7, 65.0)	466	59.9 (56.4, 63.3)
	Men	7,640	35.6 (35.0, 36.3)	312	40.1 (36.7, 43.6)
	Total	21,449	100.0	778	100.0
Ethnicity	White	18,312	89.3 (88.9, 89.7)	712	92.0 (89.9, 93.7)
	Mixed	107	0.5 (0.4, 0.6)	1	0.1 (0.0, 0.1)
	Asian/Asian British	975	4.8 (4.5, 5.1)	52	6.7 (5.2, 8.7)
	Black/Black British	410	2.0 (1.8, 2.2)	9	1.2 (0.6, 2.2)
	Chinese	232	1.1 (1.0, 1.3)	0	0.0
	Other/not stated	471	2.3(2.1, 2.5)	0	0.0
	Total	20,507	100.0	774	100.0
	Health	Has illness/disability	11,784	56.3 (55.7, 57.0)	387
No illness/disability		9,136	43.7 (43.0, 44.3)	375	49.2 (45.7, 52.8)
Total		20,920	100.0	762	100.0
Employment <sup>c</sup>	In paid employment	2,262	33.0 (31.9, 34.1)	213	49.3 (44.6, 54.0)
	Not in paid employment	4,602	67.0 (65.9, 68.2)	219	50.7 (46.0, 55.4)
	Total	6,864	100.0	432	100.0

<sup>a</sup>Includes carers aged 25 and over, looking after main cared for person aged 25 and over, except where indicated (see note c).

<sup>b</sup>Total sample numbers vary due to missing data.

<sup>c</sup>Employment data confined to 'working age' carers aged 25 to 64.



over, compared with 20.1% of carers in the household survey, a statistically significant difference. This result is consistent with the Information Centre analysis (HSCIC, 2010c). Thus, controlling for methodological differences between the surveys does not alter the finding that carers known to councils tend to be older than those in the household survey.

The Information Centre analysis did not include health or employment, but the differences between the surveys are very marked with respect to these characteristics (Table 3). The majority (56.3%) of carers providing care for 20 or more hours a week in the survey of carers known to councils have an illness or disability themselves, compared with around half of those in households more generally. With respect to employment, only a third of carers of 'working age' known to councils are in employment, whereas nearly half of those in the household survey are in employment, a statistically significant difference.

### *Characteristics of cared-for people*

People providing substantial care in the survey of carers known to councils are less likely to care for a parent or parent-in-law than similar carers in the household survey (Table 4). However, there is little difference between the two surveys in the proportion of carers looking after a spouse or partner. This latter result differs from that found by the Information Centre, which found that carers known to councils were more likely to be caring for a spouse/partner. The difference in the results shown here is likely to be due to the fact that the present analysis is concerned with people caring for 20 or more hours a week, who are more likely to care for a spouse/partner than carers providing less intense care (HSCIC, 2010b, 2010c).

Carers known to councils are, however, more likely to care for an 'older old' person than carers in the household survey (Table 4). In the survey of carers known to councils, 54.3% look after someone aged 75 and over, compared with 47.4% in the household survey, a difference that is statistically significant. Consistent with the older age of the cared-for person, carers in the survey of carers known to councils are more likely to care for someone with dementia and with a sight or hearing loss. Carers known to councils are also more likely to care for someone with mental health problems or a learning disability, but less likely to care for someone with a physical disability or long-standing illness.

### *Characteristics of care provided*

People providing substantial unpaid care in the survey of carers known to councils are more likely to provide care for very long hours than carers in the household survey (Table 5). This result is consistent with the Information Centre analysis, which also found that carers known to councils tend to 'have more intensive caring duties' (HSCIC, 2010c, p. 4). However, the results in the present article focus only on carers providing care for 20 or more hours a week and it is striking that, even among these intense carers, carers known to councils provide care for very

**Table 4.** Characteristics of people cared for by carers<sup>a</sup> providing care for 20 or more hours a week in Personal Social Services Survey of Adult Carers in England and Survey of Carers in Households in England, 2009/10.

	Personal Social Services Survey of Adult Carers in England (Carers known to councils)		Survey of Carers in Households in England	
	Sample numbers <sup>b</sup>	% of sample (95 % CI)	Sample numbers <sup>b</sup>	% of sample (95% CI)
Relationship of cared-for person to carer				
Parent/parent-in-law	5,689	26.5 (25.9, 27.1)	247	31.7 (28.6, 35.2)
Spouse/partner	12,023	56.1 (55.4, 56.7)	419	53.9 (50.4, 57.4)
Other	3,739	17.4 (16.9, 17.9)	112	14.4 (11.9, 16.9)
Total	21,451	100.0	778	100.0
Age of cared-for person				
25–34	1,220	5.7 (5.4, 6.0)	37	4.8 (3.5, 6.5)
35–44	1,360	6.3 (6.0, 6.7)	54	6.9 (5.4, 9.0)
45–54	1,567	7.3 (6.9, 7.6)	72	9.3 (7.4, 11.5)
55–64	2,152	10.0 (9.6, 10.3)	99	12.7 (10.6, 15.3)
65–69	1,496	7.0 (6.6, 7.3)	70	9.0 (7.2, 11.2)
70–74	2,043	9.5 (9.1, 9.9)	77	9.9 (8.0, 12.2)
75+	11,688	54.3 (53.6, 55.0)	368	47.4 (43.9, 50.9)
Total	21,526	100.0	777	100.0
Health condition of cared-for person <sup>c</sup>				
Dementia	5,797	27.2 (26.6, 27.8)	75	9.7 (7.8, 11.9)
Physical disability	11,940	56.0 (55.3, 56.7)	499	64.2 (60.8, 67.5)
Sight/hearing loss	5,827	27.3 (26.7, 27.9)	154	19.8 (17.2, 22.8)
Mental health problems	3,396	15.9 (15.4, 16.4)	96	12.4 (10.2, 14.9)
Learning disability/difficulty	2,967	13.9 (13.5, 14.4)	57	7.4 (5.7, 9.4)

(continued)

**Table 4.** Continued.

	Personal Social Services Survey of Adult Carers in England (Carers known to councils)		Survey of Carers in Households in England	
	Sample numbers <sup>b</sup>	% of sample (95 % CI)	Sample numbers <sup>b</sup>	% of sample (95% CI)
Long-standing illness	8,148	38.2 (37.6, 38.9)	348	44.8 (41.3, 48.3)
Terminal illness	1,111	5.2 (4.9, 5.5)	39	5.1 (2.1, 5.5)
Alcohol/drug dependency	246	1.2 (1.0, 1.3)	5	0.7 (0.3, 1.5)
Total	21,317	–	777	–

<sup>a</sup>Includes carers aged 25 and over, looking after main cared for person aged 25 and over.

<sup>b</sup>Total sample numbers vary due to missing data.

<sup>c</sup>The question on the health condition of the cared-for person is optional in the survey of carers known to councils and there are differences in question wording between surveys. Cared-for people could have more than one health condition, so sample numbers do not add up to totals.

**Table 5.** Characteristics of care provided by carers<sup>a</sup> providing care for 20 or more hours a week in *Personal Social Services Survey of Adult Carers in England* and *Survey of Carers in Households in England, 2009/10*.

		<i>Personal Social Services Survey of Adult Carers in England (Carers known to councils)</i>		<i>Survey of Carers in Households in England</i>	
		Sample numbers <sup>b</sup>	% of sample (95 % CI)	Sample numbers <sup>b</sup>	% of sample (95% CI)
Intensity of care	20–34 hours a week	2,432	12.7 (12.2, 13.1)	225	32.1 (28.7, 35.6)
	35–49 hours a week	2,391	12.4 (12.0, 12.9)	126	17.9 (15.3, 20.9)
	50–99 hours a week	3,589	18.7 (18.1, 19.2)	134	19.1 (16.3, 22.1)
	100 or more hours a week	10,810	56.2 (55.5, 56.9)	217	30.9 (27.6, 34.4)
	Total	19,222	100.0	702	100.0
Locus of care	35 or more hours a week	16,790	87.3 (86.9, 87.8)	478	68.1 (64.6, 71.4)
	50 or more hours a week	14,399	74.9 (74.3, 75.5)	352	50.1 (46.4, 53.8)
	Total	21,015	100.0	777	100.0
	Co-resident care	17,666	84.1 (83.6, 84.6)	587	75.6 (72.4, 78.4)
	Extra-resident care	3,349	15.9 (15.5, 16.4)	190	24.5 (21.6, 27.6)
	Total	21,015	100.0	777	100.0

<sup>a</sup>Includes carers aged 25 and over, looking after main cared for person aged 25 and over.

<sup>b</sup>Total sample numbers vary due to missing data.

long hours. Of those caring for 20 or more hours a week, 87.3% of those known to councils provide care for 35 or more hours a week, compared with 67.9% of intense carers in the household survey, a statistically significant difference. In other words, among intense carers, councils tend to focus almost exclusively on those providing full-time care. As a corollary, carers who provide intense care, but do not do so full-time, are less likely to be known to councils. Indeed, over half of the substantial carers known to councils are providing care for 100 or more hours a week, compared with less than a third of those in households more generally.

Carers known to councils are also more likely to be co-resident with the cared-for person than carers in households more generally. Approximately 84% of intense carers in the survey of carers known to councils share a household with the cared-for person, compared with approximately 76% in the household survey, a statistically significant difference. As a corollary, in the survey of carers known to councils, carers are less likely to be 'extra-resident' (that is, living in a separate household from the cared-for person) than carers in the household survey.

### *Association between intensity of care and other characteristics*

One of the key results of the analysis so far is that, even among those caring for 20 or more hours a week, carers in contact with councils provide care for much longer

hours than carers in households more generally. However, as indicated earlier, long hours of care are associated with other characteristics of caring. The intensity of care is, therefore, examined here in greater detail to see if intensity is associated with other differences between carers in the surveys.

Table 6 shows that the greater intensity of caring among carers in contact with councils is associated with a number of their other characteristics: their poorer health, their lower likelihood of caring for a parent; their greater likelihood of caring on a co-resident basis and, to some extent, their lower employment rates. Thus, the percentage of carers in poor health rises with the intensity of care and, because carers in contact with councils are more likely to be caring for very long hours, so they are more likely to be in poor health. As a result, *once the intensity of care is broken down into detailed bands, the differences between the surveys largely disappear*. For example, looking at carers providing care for 100 or more hours a week, 59.5% of carers in the survey of carers known to councils are in poor health, compared with 53.3% of carers in the household survey, a difference that is not likely to be statistically significant (Table 6). Similarly, the percentage of carers providing co-resident care rises with the intensity of care and again, once the intensity of care is broken down, the differences between the surveys largely disappear. At 100 or more hours a week, 96.4% of carers in contact with councils are caring on a co-resident basis, compared with 94.4% of carers in the household survey. The pattern is similar with regard to care for parents, but the relationship between intensity and care for parents is negative, so that, at higher levels of intensity, the likelihood of caring for parents is lower. At 100 or more hours a week, 17.1% of carers in contact with councils are caring for a parent compared with 16.1% of carers in the household survey.

The greater intensity of caring among carers in contact with councils is also associated with their lower employment rates to some extent. Thus, employment rates fall as the intensity of care rises and, at higher levels of intensity, above 50 or more hours a week, the percentages of working age carers in employment are similar in the two surveys (Table 6). However, differences in intensity are not associated with all the differences in employment rates between the surveys. At lower levels of intensity, between 20 and 49 hours a week of caring, carers in contact with councils are less likely to be in employment than carers in households more generally. For example, at 35 to 49 hours a week, just over a third of carers in contact with councils are in employment, compared with over half of those in the household survey.

Differences in intensity of care between the two surveys are not therefore associated with all the differences in characteristics of carers between the surveys. A further difference that is not associated with intensity is the older age of carers in the survey of carers known to councils. Even controlling for a detailed breakdown of intensity, carers known to councils are still more likely to be aged 70 and over than carers in the household survey. For example, at 100 or more hours a week, 46.4% of carers in contact with councils are aged 70 and over, compared with

**Table 6.** Key characteristics of carers<sup>a</sup> providing care for 20 or more hours a week, by intensity (hours a week of care), *Personal Social Services Survey of Adult Carers in England* and *Survey of Carers in Households in England, 2009/10*.

		<i>Personal Social Services Survey of Adult Carers in England</i> (Carers known to councils)		<i>Survey of Carers in Households in England</i>	
		Underlying sample base <sup>b</sup>	% of sample (95% CI)	Underlying sample base <sup>b</sup>	% of sample (95% CI)
Percentage of carers aged 70 and over					
Hours a week	20–34	2,432	25.9 (24.2, 27.6)	225	16.0 (11.2, 20.8)
	35–49	2,391	26.5 (24.7, 28.3)	126	29.4 (21.4, 37.3)
	50–99	3,589	38.2 (36.6, 39.8)	134	38.8 (30.6, 47.1)
	100 or more	10,810	46.4 (45.4, 47.3)	217	34.1 (27.8, 40.4)
Percentage of carers with illness/disability					
Hours a week	20–34	2,363	46.4 (44.4, 48.4)	221	50.7 (44.1, 57.3)
	35–49	2,323	50.6 (48.5, 52.6)	123	42.3 (33.5, 51.0)
	50–99	3,496	57.0 (55.4, 58.7)	133	50.4 (41.9, 58.9)
	100 or more	10,507	59.5 (58.6, 60.4)	214	53.3 (46.6, 60.0)
Percentage of 'working age' <sup>c</sup> carers in employment					
Hours a week	20–34	1,152	52.5 (49.6, 55.4)	172	63.4 (56.2, 70.6)
	35–49	1,135	36.6 (33.8, 39.4)	78	57.7 (46.7, 68.7)
	50–99	1,349	34.7 (32.2, 37.2)	64	40.6 (28.6, 52.7)
	100 or more	3,228	24.0 (22.5, 25.5)	118	28.0 (19.9, 36.1)
Percentage of carers caring for parent/in-law					
Hours a week	20–34	2,423	54.1 (52.2, 56.1)	225	51.6 (45.0, 58.1)
	35–49	2,381	42.3 (40.4, 44.3)	126	31.7 (23.6, 39.9)
	50–99	3,573	23.6 (22.2, 25.0)	134	25.4 (18.0, 32.7)
	100 or more	10,774	17.1 (16.4, 17.8)	217	16.1 (11.2, 21.0)
Percentage of carers caring on co-resident basis					
Hours a week	20–34	2,378	47.1 (45.1, 49.1)	221	46.6 (40.0, 53.2)
	35–49	2,344	65.8 (63.9, 67.7)	123	78.0 (70.7, 85.4)
	50–99	3,496	89.9 (88.9, 90.9)	133	88.7 (83.3, 94.1)
	100 or more	10,551	96.4 (96.1, 96.8)	213	94.4 (91.3, 97.5)

<sup>a</sup>Includes carers aged 25 and over, looking after main cared-for person aged 25 and over, except where indicated (see note c).

<sup>b</sup>Total sample numbers vary due to missing data; sample numbers exclude 'variable' hours.

<sup>c</sup>Employment data confined to 'working age' carers aged 25 to 64.

34.1% of carers in the household survey, a statistically significant difference (Table 6). These results are discussed further below.

## Limitations of the study

Due to data limitations, the study is concerned with adult carers looking after other adults and does not include younger carers (aged under 25) or carers of disabled children. There are also issues of representativeness in relation to both surveys used in the study but, as indicated earlier, these limitations can be overcome. The associations found between long hours of care and other characteristics of caring are not necessarily causal relationships, for which data over more than one time-period would have been needed. They are, however, consistent with the literature on unpaid care, as explained further below.

## Discussion and conclusions

This article has compared the 2009/10 *Personal Social Services Survey of Adult Carers in England* and the 2009/10 *Survey of Carers in Households in England* in order to identify the characteristics of carers known to councils. The article has focused on carers most likely to be eligible for a carer's assessment, defined here as intense carers providing care for 20 or more hours a week. The results suggest that intense carers known to councils are at the very 'sharpest' end of caring (cf. Parker, 1998). Councils appear to be focusing primarily on full-time carers, the majority of whom are caring for 100 or more hours a week and could be described as virtually 'round-the-clock' carers (cf. Vlachantoni, 2010).

The focus of councils on the most intense carers is associated with a number of other characteristics of carers with whom councils are in contact. High levels of intensity are associated with poor health of carers, co-residence with the cared-for person and low employment rates. The extremely long hours of caring undertaken by carers in contact with councils is also associated with the characteristics of carers with whom councils are *not* in much contact: carers providing substantial hours of care but not caring full-time; carers looking after their parents; extra-resident carers; and carers in employment.

As indicated above, the associations reported in this article between long hours of care and other characteristics of caring are not necessarily causal relationships, for which a study carried out over time would have been needed. They are, however, consistent with the literature on unpaid care in this country, which shows a positive association between intensity of care and co-residence with the cared-for person and negative associations between intensity of care and caring for parents, health and employment (Arber & Ginn, 1991; Parker & Lawton, 1994; Vlachantoni, 2010). What the present article has shown are the implications of these well-established associations for the characteristics of the 'sharp' end carers known to councils.

Not all the characteristics of carers in contact with councils are associated with long hours of caring. Councils focus particularly on older carers aged 70 and over, but this is not only associated with the intensity of the care that they provide. It may also derive from the fact that councils have a duty of care to older people in their own right. The focus on older carers may in turn be associated with other characteristics of carers in contact with councils, such as the tendency for carers in contact with councils to be looking after 'older old' people, since older carers are themselves likely to care for other older people (Corden & Hirst, 2011).

Nevertheless, the present article has clearly shown that a key feature of the carers with whom councils are in contact is that they provide very long hours of care. The importance of intensity to the carers identified by councils is likely to derive in part from the wording of the current legislation on carers' assessments and its emphasis on the provision of a substantial amount of care on a regular basis. However, councils' emphasis on the most intense carers is unlikely to be attributable solely to the wording of the legislation. 'Substantial' care is clearly broader than the full-time or virtually 'round-the-clock' caring on which councils currently focus and councils are therefore already targeting *within* carers who provide intense care. The implication is that a change in the legislation and the dropping of the substantial and regular clauses alone will not necessarily broaden access to carers' assessments.

Other reasons why councils focus on the most intense forms of caring may relate to resource constraints (Arksey, 2002; Qureshi, 2004; Seddon et al., 2007). Arksey (2002) describes carers' assessments in the context of resource constraints as a form of 'rationed care' and argues that one mechanism for rationing is for managers and practitioners in local authority social services departments to set priorities. One way of doing this is for priority to be given to the most severe and/or fragile caring situations or, as one senior manager in Arksey's study put it, carers 'at the end of their tether' (Arksey 2002, p. 88). Carers 'at the end of their tether' are likely to include those providing extremely long hours of care, and prioritising carers who are caring virtually 'round the clock' can therefore be seen as a form of 'rationed care'.

The implication is that, if the new legislation is to broaden access to carers' assessments and focus more on prevention and early intervention, there will be a need for more resources. The Government is planning an increase of £25 million a year in England to finance the costs of additional carers' assessments associated with the new legislation (Department of Health, 2012). This is based on the assumption of approximately 250,000 new assessments nationally. However, this increase in the number of assessments seems an underestimate. As already noted, in 2012/13, 411,000 carers were offered an assessment or review in England (HSCIC, 2013) yet there are nearly two million people providing care for 20 hours a week or more in England, according to the 2011 Census (Office for National Statistics [ONS], 2012). Therefore, even if only those caring for 20 or more hours a week are offered an assessment, this implies an increase of over 1.5 million in the number of new assessments required, at a cost of approximately £150 million. Clearly, if the



intention of the new legislation is to extend assessments beyond those providing 'substantial care', even more resources are likely to be needed.

Moreover, as indicated earlier, the *Care Act* will introduce a new duty to provide support to meet carers' needs identified through assessments. It follows that, if the increase in the number of new assessments has been underestimated by the Government, then there may also have been an underestimate of the costs of meeting carers' needs for support identified through these additional assessments. The Government is planning to make available an extra £150 million a year in England to finance the costs of an increase in carer support services arising from the new legislation (Department of Health, 2012). This is based partly on an estimate of increased demand for carer-specific services for 110,000 carers, arising from additional assessments, which uses the 2010/11 ratio of assessments to receipt of services. Using the same method, the additional services for carers arising from an additional 1.5 million new assessments would result in approximately 660,000 additional carers receiving services, at a cost of approximately £665 million a year.

There is evidence from research elsewhere that front-line practitioners in local authority social services departments have been frustrated by the limitations of their work with carers under existing legislation (Seddon et al. 2007, p. 1342). The new *Care Act* potentially offers practitioners the opportunity to give greater support to carers, not just because it would widen eligibility for carers' assessments, but because it would introduce a new duty to provide support to meet carers' assessed needs (Care Act 2014). However, the extent to which the potential of the legislation is realised depends crucially on the availability of resources for carers' assessments and services. The moderate increase in resources for new assessments and support for carers, which has been planned by the Government, coincides with reductions in local authority spending on adult social care, which the Association of Directors of Adult Social Services (ADASS, 2013) estimates at £2.68 billion in England between 2011/12 and 2013/14. If sufficient new resources are not available to implement the *Care Act*, there is a risk that managers and practitioners in social services departments will continue to feel under pressure to 'ration' access to carers' assessments and thereby support for carers. It is therefore important for the Government to ensure that sufficient new resources are committed to implementing the coming changes to carers' assessments and services in England.

## Ethics

The study involved the use of large-scale survey data that had already been collected (secondary data) and did not involve any form of new (primary) data collection. Therefore, the ethical aspects of the study were limited. All individual-level secondary data were supplied in an anonymised form by either the UK Data Archive or the NHS Health and Social Care Information Centre (see acknowledgements below), following formal undertakings to abide by their rules in using the data. These ensure that survey respondents' anonymity is preserved.

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## Note

1. Social care has recently been defined as 'any form of support that assists individuals with certain physical, cognitive or age-related disabilities to sustain involvement in work, education, learning, leisure and other social support systems, such as peer networks and family life' (Atkin & Tozer, 2014, p. 240).

## References

- ADASS. (2013, May 8). Social care funding: A bleak outlook is getting bleaker. Retrieved from <http://www.adass.org.uk/Content/Article.aspx?id=1034>
- Arber, S., & Ginn, J. (1991). *Gender and later life: A sociological analysis of resources and constraints*. London, England: Sage.
- Arksey, H. (2002). Rationed care: Assessing the support needs of informal carers in English social services authorities. *Journal of Social Policy*, 31(1), 81–101. doi:10.1017/S0047279402006529
- Atkin, K., & Tozer, R. (2014). Personalisation, family relationships and autism: Conceptualising the role of adult siblings. *Journal of Social Work*, 14(3), 225–242. doi:10.1177/1468017313476453
- Care Act 2014 (c.23). London, England: The Stationery Office (TSO). Retrieved from <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm>
- Corden, A., & Hirst, M. (2011). Partner care at the end-of-life: Identity, language and characteristics. *Ageing and Society*, 31(2), 217–242. doi:10.1017/S0144686X10000838
- Department of Health. (2012). *Assessment, eligibility and portability for care users and carers* (Impact Assessment No. 7064). London, England: Author. Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/136450/IA-Annex-C-assessment-and-eligibility.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136450/IA-Annex-C-assessment-and-eligibility.pdf)
- Evandrou, M. (1990). *Challenging the invisibility of carers: Mapping informal care nationally*. London, England: London School of Economics and Political Science.
- Heitmueller, A. (2007). The chicken or the egg? Endogeneity in labour market participation of informal carers in England. *Journal of Health Economics*, 26(3), 536–559. doi:10.1016/j.jhealeco.2006.10.005
- Hirst, M. (2001). Trends in informal care in Great Britain during the 1990s. *Health and Social Care in the Community*, 9(6), 348–357. doi:10.1046/j.0966-0410.2001.00313.x

- House of Commons Health Committee. (2010). *Social care: Third report of session 2009–10. Volume 1* (HC 22-1). London, England: The Stationery Office (TSO). Retrieved from <http://www.publications.parliament.uk/pa/cm200910/cmselect/cmhealth/22/22.pdf>
- HMG. (2010). *Recognised, valued and supported: Next steps for the carers strategy* (Policy paper). London, England: The Stationery Office (TSO). Retrieved from <https://www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-for-the-carers-strategy>
- HMG. (2012a). *Caring for our future: Reform of care and support* (Policy paper, CM 8378). London, England: The Stationery Office (TSO). Retrieved from <https://www.gov.uk/government/publications/caring-for-our-future-reforming-care-and-support>
- HMG. (2012b). *Reforming the law for adult care and support: The government's response to Law Commission report 326 on adult social care* (Policy paper, CM 8379). London, England: The Stationery Office (TSO). Retrieved from <https://www.gov.uk/government/publications/government-response-to-the-law-commission-report-on-adult-social-care>
- HSCIC. (2010a). *Survey of carers in households in England 2009–10*. Leeds, England: Author. Retrieved from <http://www.hscic.gov.uk/pubs/carersurvey0910>
- HSCIC. (2010b). *Personal social services survey of adult carers in England, 2009–10*. Leeds, England: Author. Retrieved from <http://www.hscic.gov.uk/pubs/psscicarerssurvey0910>
- HSCIC. (2010c). *Comparison of results from surveys of carers, 2009–10*. Leeds, England: Author. Retrieved from <http://www.hscic.gov.uk/catalogue/PUB02200/comp-res-surv-care-eng-2009-2010-rep2.pdf>
- HSCIC. (2013). *Community care statistics, social services activity, England, 2012–13*. Leeds, England: Author. Retrieved from <http://www.hscic.gov.uk/catalogue/PUB13148>
- Hussain, S., & Manthorpe, J. (2012). The diversity of staff supporting family carers in England: Findings from an analysis of a national data set. *Diversity and Equality in Health and Care*, 9(2), 101–111. Retrieved from [http://www.academia.edu/2236136/The\\_diversity\\_of\\_staff\\_supporting\\_family\\_carers\\_in\\_England\\_findings\\_from\\_an\\_analysis\\_of\\_a\\_national\\_data\\_set](http://www.academia.edu/2236136/The_diversity_of_staff_supporting_family_carers_in_England_findings_from_an_analysis_of_a_national_data_set)
- Law Commission. (2010). *Adult social care: A consultation paper* (No. 192). London, England: The Law Commission. Retrieved from [http://lawcommission.justice.gov.uk/docs/cp192\\_Adult\\_Social\\_Care\\_consultation.pdf](http://lawcommission.justice.gov.uk/docs/cp192_Adult_Social_Care_consultation.pdf)
- Law Commission. (2011). *Adult social care*. (HC941, No. 326). London, England: The Stationery Office (TSO). Retrieved from [http://lawcommission.justice.gov.uk/docs/lc326\\_adult\\_social\\_care.pdf](http://lawcommission.justice.gov.uk/docs/lc326_adult_social_care.pdf)
- Newcastle Borough Council. (2014). Carers – Regular and substantial amounts of care. Retrieved from [http://www.newcastle-staffs.gov.uk/health\\_content.asp?id= SXAD30-A7808D28&cat=1216](http://www.newcastle-staffs.gov.uk/health_content.asp?id= SXAD30-A7808D28&cat=1216)
- ONS. (2012). Health and provision of unpaid care (2011 census, Table KS301EW). London, England: The Stationery Office (TSO). Retrieved from <https://www.nomisweb.co.uk/census/2011/ks301ew>
- Parker, G. (1998). Trends in caring 1985–1995. In O. Rowlands (Ed.), *Informal carers* (pp. 40–48). London, England: The Stationery Office (TSO).
- Parker, G., & Lawton, D. (1994). *Different types of care, different types of carer*. London, England: HMSO.
- Qureshi, H. (2004). Evidence in policy and practice: What kinds of research designs? *Journal of Social Work*, 4(1), 7–23. doi:10.1177/1468017304042418

- Seddon, D., Robinson, C., Reeves, C., Tommis, Y., Woods, B., & Russell, I. (2007). In their own right: Translating the policy of carer assessment into practice. *British Journal of Social Work, 37*(8), 1335–1352. doi:10.1093/bjsw/bcl015
- Staffordshire County Council. (2014). Carers – What support is available? Retrieved from <http://www.staffordshire.gov.uk/health/carers/home.aspx>
- StataCorp. (2011). Stata Statistical Software (Release 12.1). College Station, TX: StataCorp LP.
- Vlachantoni, A. (2010). The demographic characteristics and economic activity patterns of carers over 50: Evidence from the English Longitudinal Study of Ageing. *Population Trends, 141*, 1–23. Retrieved from <http://www.ons.gov.uk/ons/rel/population-trends-rd/population-trends/no-141-autumn-2010/index.html>
- Young, H., Grundy, E., & Kalogirou, S. (2005). Who cares? Geographic variations in unpaid caregiving in England and Wales: Evidence from the 2001 Census. *Population Trends, 120*, 23–34. Retrieved from <http://www.ons.gov.uk/ons/rel/population-trends-rd/population-trends/no-120-summer-2005/index.html>