In SICKNESS and in HEALTH

Informal care provided by 5.9 million

For the first time, the 2001 Census made visible the work of 5.9 million people providing care and support to others on an informal basis; 1.2 million of these people provide more than 50 hours of care per week. Caring is a phenomenon found all over Britain, and is very strongly related to the need for that care. These findings suggest that people in very different circumstances, rich or poor, young or old, working or not, from deprived or affluent areas, all care for their loved ones in response to those people's needs.

The image above shows British Sign Language for 'access'

Measuring informal care

> "Informal care is a term which hides a rich variety of human relationships between spouses, between children and parents; between kith and kin, friends and neighbours. Most care without giving thought to the financial cost of caring. It somehow demeans them to reduce their dedication to cash amounts."[1]

The 2001 Census was important in that it was the first to ask about self-reported general health (in addition to a question on limiting long-term illness, which was introduced in 1991) and it also asked about an activity directly related to poor health – the provision of informal care. This additional question in 2001 asked:

Do you look after, or give any help or support to, family member, friends, neighbours or others because of:

- **long-term physical or mental ill-health or disability, or**
- **problems related to old age?**

Possible answers were: No; 1-19 hours a week; 20-49 hours a week; 50+ hours a week.

Life in Britain

The latest Census reveals that within the UK people live in very different worlds. For some, resources and amenities abound; for others life is characterised by deprivation and difficulties, especially when their need for support is great.

The 2001 Census marked the bi-centenary of census taking in the UK. It is the most comprehensive social record of life in this country now available. Since 1801 successive governments have asked the population to assist in the taking of a Census.

This report is one of a series of 10 showing key patterns and inequalities in life in the UK revealed by the 2001 Census. These reports focus on geographical inequalities, highlighting where services and opportunities appear not to be available or accessible to those people and places that need them most.

This question thus opens a window on people's private lives, revealing the domestic activities and responsibilities of millions of people.

Even though the 2001 Census was the first to measure caring, people have always cared for each other in the domestic setting of the home. However, the concept of 'informal care' emerged in the 1970s, recognising the continuing role of the provision of unpaid care within the home, in the context of the widening role of the welfare state and the National Health Service (NHS) as providers of formal care in the post-war decades. Britain has what has been described as a "mixed economy of welfare, in which the state, voluntary sector, the family and the market have played different parts at different times"[2]. Support for carers is high on the policy agenda and the current Labour government has a National Strategy for Carers.

For this analysis, as with the other reports in this series, the country is divided into counties, unitary authorities and former metropolitan authorities. For each of these areas, data were obtained based on responses to the health and informal care questions described above. Data from both health questions were used; firstly that which asked whether or not a person has a long-term illness, health problem or disability that limits daily activities or work and secondly the self-reported health question which asked the person to rate their health over the previous 12 months as 'good', 'fairly good' or 'not good'. For this analysis, the group of people *most* in need of healthcare has been classified as those who reported a limiting long-term illness as well as rating their health as 'not good' over the last 12 months. Many, but not all, of these people may well be in need of some informal care.

This report uses 2001 Census data to investigate the extent of informal care provision and some of the characteristics of people who provide informal care. It addresses the question:

Do areas with high proportions of people in poor health also have high proportions of people providing informal care?

Findings

In 2001, 4.5 million people in the UK reported that they had both poor health *and* a limiting long-term illness. This is 7.8% of the population. Around 4 million people provide care for 1-19 hours a week, 0.7 million people provide care for 20-49 hours a week and some 1.2 million people reported that they provide informal care for others for 50+ hours a week. This gives a total of 5.9 million people providing some form of informal care each week, 1 in 10 of the population.

Table 1 gives an indication of who makes up this workforce of informal carers. In terms of those providing the greatest amount of care (50+ hours a week),

- one in a hundred carers is under the age of 18;
- around a third are aged 65+;
- six out of ten are women;
- a fifth are in poor health themselves.

Table 1: Numbers and characteristics of informal carers in the UK (2001)

	People caring 1-19 hours a week		People caring 20-49 hours a week		People caring 50+ hours a week	
Characteristics of informal carers	**Number**	**% of total**	**Number**	**% of total**	**Number**	**% of total**
Total	**3,952,571**	**100**	**659,071**	**100**	**1,247,294**	**100**
Young people (aged 5-17)	145,853	4	16,113	2	13,029	1
Older people (aged 65+)	542,772	14	113,037	17	381,519	31
Women	2,247,491	57	396,640	60	754,904	61
Carers with poor health themselves	341,594	9	93,460	14	257,038	21

Some people are therefore looking after themselves as well as providing care for others. Evidence from other surveys suggests that a quarter of carers care for more than one person[3].

A total of 1.2 million people provide informal care 50+ hours a week – that is, providing care that is more than the equivalent of a full-time job (the European Working Directive limits most working hours to 48 a week). This is about the same as the number of people working in the formal, paid sector of the NHS.

The Census also allows us to look at whether people combine informal caring and work (see Figure 1). Of those carers aged 16-74 who do 50+ hours of caring a week, 68% are economically inactive and 32% active. One in six (168,000 people) have a full-time job. Full-time in the Census was 30+ hours a week. One in eight (125,000 people) are permanently sick/disabled themselves, compared to one in five of all carers who classify themselves as having poor health.

Figure 1 indicates that while many people combine caring with full-time or part-time work or with studying, those with greater caring commitments are less likely to be economically active. The responsibility of caring is likely to fall on those with the fewest commitments in the formal labour market, and likewise participating in caring will affect any opportunity of taking up paid work or study. As the box '100 years ago' indicates, many people (especially women) have always had to juggle informal care with earning a wage.

Comparing areas

Figure 2 shows that, looking at areas of the UK, there is a very close relationship between caring (taking the most extreme cases of 50+ hours a week) and the need for care (proportion of people with limiting long-term illness and poor self-reported health). Compare this to the findings shown in the companion report to this, *Doctors and nurses* (Report no 1), which shows an 'inverse care law'. This law indicates that those areas with higher proportions of people in need have fewer doctors than those areas with fewer people in need.

If we assume that within these areas informal care is being provided to the people who need it, informal care seems to be responsive to individual needs and circumstances, impervious to the existence of the market. Whereas care in the formal setting of the market is given in exchange (primarily for wages), informal care can be

100 years ago

In 1901 there was no welfare state; those in need of assistance could look only to 'poor relief' supplied by their parish, or the workhouse. For those who had been in a position to pay their membership dues some limited support in times of hardship came from friendly societies and sick clubs. Hospitals were mainly places of death rather than care – the family was the primary source of care for those who could not afford to pay for a private nurse. B.S. Rowntree's survey of poverty in York carried out in 1899 gives some insight into those in need, and their carers, a century ago.

The standard of life: Life in Class A (Income under 18s weekly for a moderate family)

1. No occupation. Married. Age sixty-four. Two rooms. The man "has not had his boots on" for twelve months. He is suffering from dropsy. His wife cleans schools. This house shares one closet with eight other houses, and one water-tap with four others. Rent 2s 6d....

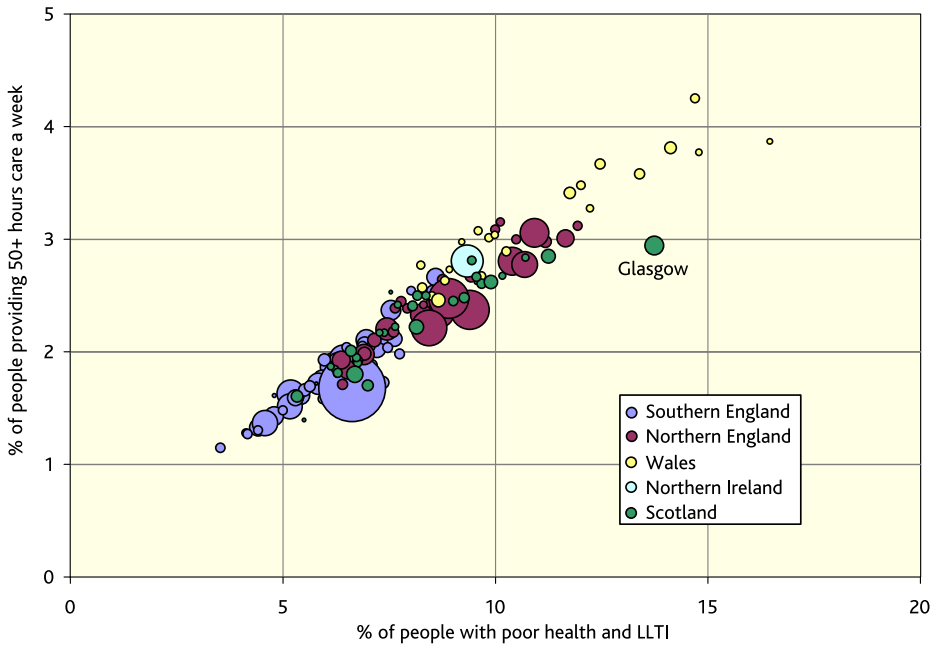
23. Blind. Age sixty-three. Married. Two rooms. Parish relief. Husband been blind twenty years. Sober. Wife delicate, but earns a few shillings by needle-work and sitting up at night with sick people. This house shares closet with another house. Rent 2s 3½d.

For more information see Rowntree, B.S. (1901) *Poverty: A study of town life*, reprinted by The Policy Press, Bristol, for the Joseph Rowntree Foundation, in 2000.

Figure 1: Percentage of all people providing informal care for different amounts of time in different economic activity categories

Note: The graph only includes people between the ages of 16 and 74, as Census data on economic activity is limited to this age group. It shows that, for example, about 30% of people caring 1-19 hours a week are economically inactive, while nearly 70% of those caring for 50+ hours a week are economically inactive.

Figure 2: The association between the percentage of the population with poor health and limiting long-term illness (LLTI) (X-axis) in each area and the percentage providing informal care for 50+ hours a week (Y-axis)[TR]



Note: Each circle is a county, unitary or former metropolitan authority, drawn with the area in proportion to the total population in 2001 (the largest circle represents London, with a population of just over 7 million). Areas in northern England are those that lie west or north of the counties of Gloucestershire, Warwickshire, Leicestershire and Lincolnshire (the Severn-Humber divide).

provided through a sense of duty, as an unconditional gift for a loved one, or as part of a complex system of reciprocity between kith and kin which may stretch across generations (caring for an elderly parent because they in turn cared for your spouse as a child; helping a friend who may return the favour in the future). The increased prevalence of divorce and step-families increases the complexity of these family structures and caring relationships. It should also be borne in mind that the standard of care in the formal sector is monitored and regulated, whereas the Census tells us nothing about the type or standard of informal care.

The largest 'outlier' on Figure 2 is Glasgow. Given the percentage of people with limiting long-term illness and poor health here, we would expect just under 4% of the population to be providing 50+ hours of care a week if the pattern was the same as for the rest of the UK. However, the proportion of people providing 50+ hours of care is actually just under 3%. This relative deficit of informal carers may be explained by greater provision of social services in that area, by disproportionate out-migration from Glasgow of a well-educated, young and able subset of the population, or by some other factor.

Table 2 lists the five areas with the highest percentage of people with poor health and limiting long-term illness. Four of these are old mining, iron or steel community areas of South Wales, and the other is Glasgow.

The maps in Figure 3 show in which areas informal carers are more and less prevalent, depicting all people providing informal care for 20+ hours (combining the 20-49 and 50+ hours groups). The lowest rates of informal care provision are found in London, the Home Counties, and other parts of central southern England. The proportion of people providing care, and the proportion of people with limiting long-term illness and poor health increases to the west and north, with the highest rates of both in the Valleys of South Wales, parts of Scotland, and the areas around Tyneside and Merseyside. Both provision of informal care and the prevalence of ill health reflect the classic UK geographical health divide. As Figure 4 illustrates, these patterns are not simply reflecting the distribution of the older population of the UK.

Table 2: Informal carer figures for the five areas with the highest percentage of people with poor health and limiting long-term illness (LLTI) in the UK (2001)

	% of population providing informal care			
Area	% of people with poor health and LLTI	1-19 hours a week	20-49 hours a week	50+ hours a week
Merthyr Tydfill	16.5	6.8	2.0	3.9
Blaenau Gwent	14.8	6.8	1.9	3.8
Neath Port Talbot	14.7	8.0	2.0	4.2
Rhondda, Cynon, Taff	14.1	7.1	1.7	3.8
Glasgow City	13.7	5.5	1.5	2.9
UK average	**7.8**	**6.8**	**1.1**	**2.2**

Figure 3: The geographical variation in the percentage of the population providing informal care for 20+ hours a week

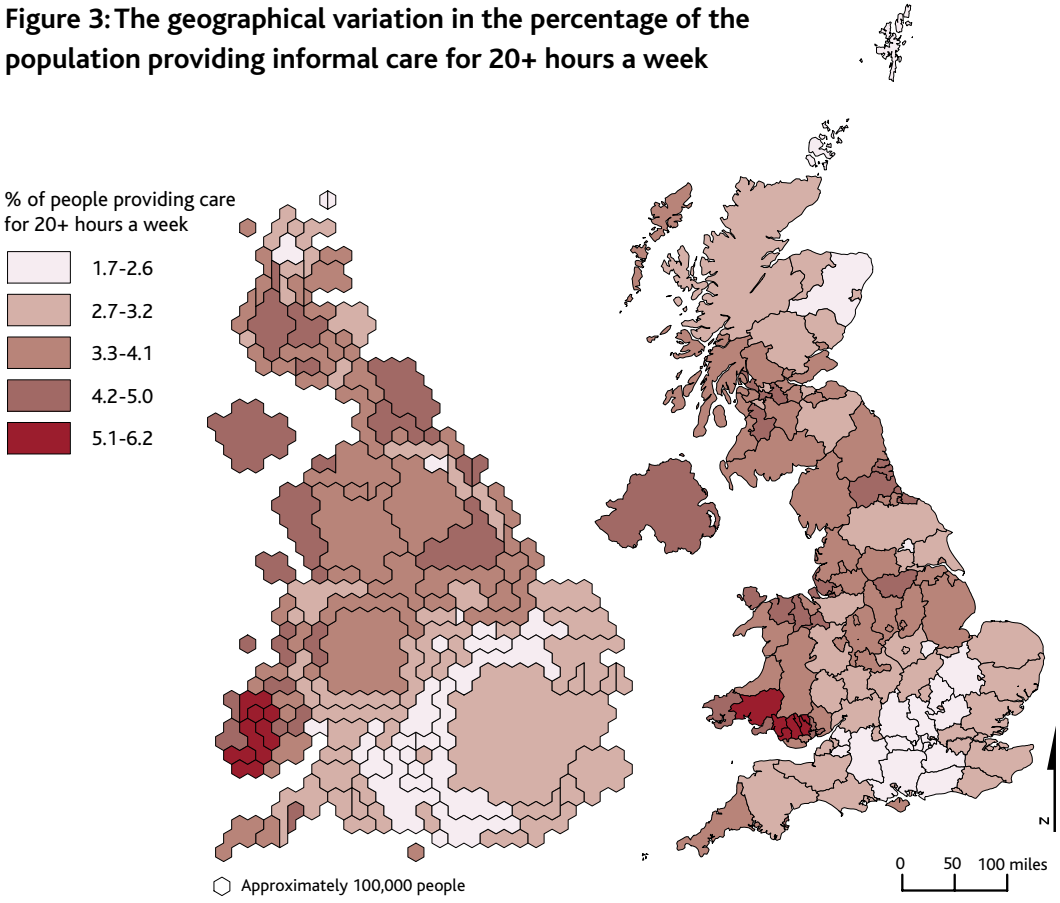
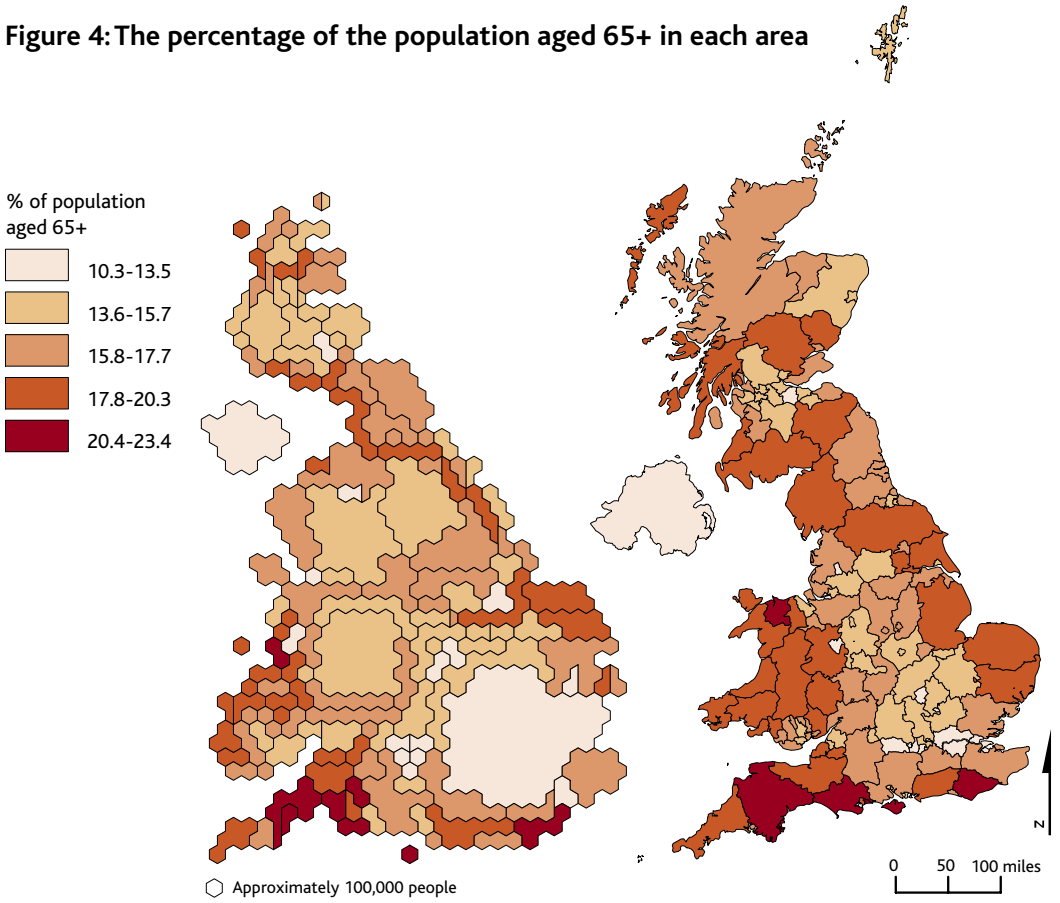


Figure 4: The percentage of the population aged 65+ in each area



Note: Both maps in each figure represent the same places, shaded identically. The map on the left is a cartogram – each area is shown in proportion to the size of its population in 2001. The largest area is London, since it has the highest population of any of the places[TR]. The map on the right shows the actual boundaries of the areas.

Since 2001

It is unlikely that these patterns have changed very much in the few years since the Census. However, the need for care is likely to increase substantially in the near future. The population is ageing: in 2001, 15.9% of the population were aged 65+ and projections suggest that by 2021 this will have risen to 19.1%, and by 2036 to 24.1%[4]. Between 1991 and 2001, the percentage of people stating that they had a limiting long-term illness rose from 13% to 18% – even though the average age of the population did not change.

Discussion

The activity of caring is based on social relations of friendship, support and social obligation and bound up with notions of reciprocity and mutuality. By and large informal care takes place outside the market. Our geographical analysis of the very close relationship between the provision of and need for care suggests that care can be seen as purely and simply a response to a need.

Those carers providing 35+ hours care a week can in some restricted circumstances claim the Carer's Allowance. For most carers, though, their caring work is unpaid (in monetary terms). Providing care may come at a financial cost with benefits to carers falling short of market wages by a long mark, plus the costs of wages foregone and possibly travel and other costs. However, there may also be benefits for the carer – feelings of personal reward, satisfying a sense of duty, forming a social investment – as well as the more obvious benefits to the person cared for.

Caring is either combined with paid work (most often part time) or means that carers are unable to take on the additional tasks of paid work (two thirds of those who do more than 50 hours of caring a week are 'economically inactive'). At some stage it is possible that policies which focus on increasing the proportion of people in paid work might affect the availability of this pool of 5.9 million carers to provide unpaid care. With the longest working hours in Europe it is likely that, for many people, combining roles as worker and carer presents a substantial, often exhausting, challenge. Moreover, with an ageing population, and given the increase in self-reported limiting long-term illness between 1991 and 2001, the need for carers and the demands on them is likely to increase in the future. However, it could also be argued that further investment by the government in formal services could be specifically aimed at reducing dependence on informal care where it is provided out of necessity due to insufficient professional care.

Notes

1 Royal Commission on Long-Term Care (1999) *Note of dissent*, p 133, cited in Land, H. (2002) 'Spheres of care in the UK: separate and unequal', *Critical Social Policy*, vol 22, no 1, pp 13-32.

2 Offer, J. (1999) 'Idealist thought, social policy and the rediscovery of informal care', *British Journal of Sociology*, vol 50, no 3, pp 467-88.

3 Hirst, M. (2001) 'Trends in informal care in Great Britain during the 1990s', *Health and Social Care in the Community*, vol 9, no 6, pp 348-57.

4 Office for National Statistics, Government Actuaries Department[TR].

TR Further information on this point is available in the accompanying technical report.

What do we know?

- The UK has a mixed economy of welfare – people in need of care are provided with a combination of care from the state, the voluntary sector and the private/family sector – with variations and changes according to needs, and with varying levels of market involvement.
- The 2001 Census was the first to enumerate carers and reported 5.9 million providing care, and 1.2 million providing 50+ hours of care a week.

What have we found?

- This study shows how strongly the provision of informal care is related to the need for that care. In areas where need is high, caring is also high. This is not simply explained by the geographic distribution of older age groups of the population.
- Many carers are themselves ill, some combine caring responsibilities with paid work; those with greater caring commitments are less likely to be in paid work.
- While the provision of informal care is by and large external to the market, changes in work patterns combined with an ageing population may have an adverse impact on the availability of carers.

Other reports in the series

The companion report to this, *Doctors and nurses*, describes the relationship between need for health services and availability of practising health professionals, and finds very different results to those shown here.

1. *Doctors and nurses*
2. *In sickness and in health*
3. *Teachers*
4. *Sons and daughters*
5. *Changing rooms*
6. *A place in the sun*
7. *The office*
8. *Open all hours*
9. *Top gear*
10. *Home front*

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Project funder: Joseph Rowntree Foundation

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