Informal care

SUMMARY
The provision of long-term care to older people relies very heavily on the contribution from informal carers. This chapter looks at the provision and costs of informal care, and factors such as changing demographics which will influence the future availability of informal care.

- It is estimated that in 2000 there were around 5.8 million carers in England, of whom between 3.4 million and 4 million were providing care to those aged 65 and over. More than one-fifth of carers who are living with the care recipient provide care for 100 or more hours a week.
- Informal carers provide personal care and monitor medication, but they generally devote most time to practical care tasks, such as shopping and laundry. Large numbers of carers also see a key role as providing company and 'keeping an eye' on the older person, particularly if the care recipient is cognitively impaired.
- The older generation supplies a disproportionate amount of care. In 2000, 16 per cent of people over the age of 65 were providing some form of care, and this age group made up 28 per cent of carers providing 20 hours or more care each week.
- Women tend to have heavier care commitments, although the gender division with regard to caring has become less stark.
- Other factors impacting on the propensity to provide care include economic status, level of education, location and ethnicity.
- Carer support and information services do exist but are currently received by only a minority of carers.
- Estimating the true gross financial cost of informal care to either society or individuals is difficult. An accurate figure would need to take account of reduced earnings from employment, the consequent loss to the Exchequer, the long-term impact of reduced pension contributions and the cost of carer support services. There are also indirect or non-financial costs of caring, such as social exclusion, erosion of personal relationships and adverse effects on health (which then presents a cost to the NHS).
- Availability of informal care may well not keep pace with increases in care needs in the future. Assuming current patterns of care, the PSSRU model suggests that from 2003 to 2026 the 'demand' for informal care will increase by around 45 per cent.
- Various trends affect availability of informal care. There has been a significant decline in co-residence between adults and elderly parents, and an increase in one-person households, both of which point to lower availability of informal care. Second, people who might currently be prepared to care for those in need in certain circumstances may not be so willing in future.
1 Introduction

In this Review, the term ‘informal care’ includes support (looking after or other ‘special help’) provided to the sick, disabled or elderly in a non-professional capacity. It excludes instances where only financial support is given to the recipient.

‘Informal care’ is a misleading term for the magnitude of the task it describes and the dedication of the individuals who perform it. There is debate over the correct term to use for carers who provide support in these circumstances, with all proposed definitions presenting issues. The Review Team considers the term 'informal care' to be the least problematic regarding clarity, but recognises the issues around its usage.

Many of the issues summarised in this chapter are discussed in more detail in Background Paper 6 (‘Informal care’) in the Appendix.

2 Current position

Carer inputs

In recent years, there has been a small (but not steady) increase in the prevalence of caring in Great Britain. Households with carers and carers in the population have stayed between 16–21 per cent and 11–16 per cent respectively between 1985 and 2000 (Maher and Green 2002). The situation of people being cared for is changing, however. There has, for example, been a consistent increase in the number of one-person households in Great Britain. Taken together, these trends have significant implications for the amount of care needed in the future.

As is the case in formal care, the data varies according to the source that is used and the definitions and inclusions within this. According to Carers 2000 (Maher and Green 2002), in 2000 there were approximately 6.7 million carers in Great Britain; 86 per cent of them in England (5.8 million). Seventy per cent of the care recipients were over 65. So, in 2000, England had a caring population for the over 65s of around 4 million people. Analysis of the 2001 Census, however, gives a figure of 4.9 million people providing some care in England, which would imply around 3.4 million people caring for those over 65. This chapter uses data from Carers 2000.¹

The time devoted to caring varies. Some people spend more than 100 hours per week providing care, although 70 per cent of carers provide care for less than 20 hours per week. Hours vary significantly with factors such as whether the carer lives in the same or another household. While those living in another household are very unlikely to care for 50 or more hours per week, more than 20 per cent of carers living in the same household are caring for 100 or more hours per week (see Table 34 opposite).
Nature of care
The tasks performed by informal carers reflect those performed by formal carers, but vary in the proportions devoted to different types of support. Tasks such as personal care and medication make up the majority of formal carers’ work but are provided by smaller proportions of informal carers (Maher and Green 2002), especially where the carer does not reside with the care recipient (Hirst 2001). Informal carers devote most time to practical care tasks, such as shopping and laundry. Large numbers of carers also see a key role in providing company and ‘keeping an eye’ on the person generally (what some describe as ‘supervision’). This task is particularly important when the cared-for person is cognitively impaired.

Factors affecting the provision of informal care
Categorising the provision of informal care is important, not least because disaggregating allows us to be more accurate when attempting to predict future numbers. Many personal and circumstantial factors impact on the likelihood of a person providing care, as follows.

HOUSEHOLD STATUS
The residence of the carer in relation to the care recipient has a significant impact on the time spent caring; those who live in the same place tend to care for a much higher number of hours. That also has an impact on the likelihood of being a main or subsidiary carer, with those who live in the same household being twice as likely to be the main carer as those looking after someone who lived elsewhere (Maher and Green 2002).

Table 35 overleaf shows the numbers of carers for older people in England according to their relationship with the care recipient. These have been derived from figures from Carers 2000 applied to the carer population for England (Maher and Green 2000). It is important to note that the number of carers tends to be higher than the number of care recipients. In particular, many older people have more than one child providing care.

Of carers in total, the highest numbers are children (and children-in-law) of the care recipient (filial carers). Married or cohabiting adults appear to be more likely to be carers

### TABLE 34: CARERS OF PEOPLE AGED 65+, HOURS PER WEEK SPENT CARING, 2000

<table>
<thead>
<tr>
<th>Number of hours per week spent caring for main person cared for</th>
<th>Percentage of carers of people aged 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Person cared for in carer’s household</td>
</tr>
<tr>
<td>0–19</td>
<td>33.4</td>
</tr>
<tr>
<td>20–34</td>
<td>14.3</td>
</tr>
<tr>
<td>35–49</td>
<td>9.8</td>
</tr>
<tr>
<td>50–99</td>
<td>11.8</td>
</tr>
<tr>
<td>100 or more</td>
<td>20.7</td>
</tr>
<tr>
<td>Varies, 20 or less</td>
<td>2.2</td>
</tr>
<tr>
<td>Varies, 20 or more</td>
<td>6.4</td>
</tr>
<tr>
<td>Other</td>
<td>1.4</td>
</tr>
</tbody>
</table>


8 INFORMAL CARE

139
than those who are single or previously married (19 per cent compared with 10 per cent and 12 per cent) (Maher and Green 2002). This is also significantly linked to gender, age and household status trends.

AGE AND GENDER
The likelihood of being a carer also varies with age and gender. The burden of care is shouldered disproportionately by the older generation, both in the proportion caring and in hours of care. The probability of becoming a carer increases with age, with probability notably higher for co-residential care the older one becomes (Hirst 2002). In 2000, 16 per cent of people over the age of 65 were providing some form of care, equating to 28 per cent of carers providing 20 hours or more care each week. Some 37 per cent of those carers over the age of 65 were caring for 50 hours or more per week for a care recipient they lived with against an average of 31 per cent for 30- to 64-year-olds co-residing with the recipient.

The role of caring has traditionally been performed by females. In recent years, the gender division with regard to care provision has become less stark, but care tends still to be administered by more women than men; similar to older people, women disproportionately shoulder caring responsibility. Key points regarding this are:

- a greater proportion of women are carers than men (Office for National Statistics (ONS) 2004b)
- women tend to have the heavier commitments, with 11 per cent of women compared with 7 per cent of men being main carers, and 5 per cent of women compared with 3 per cent of men spending 20 hours a week or more on caring tasks (Maher and Green 2002)
- in both spousal and filial relationships, women generally perform the caring role more than the man; nonetheless, in their later years (70+) a high proportion of male spouses are carers.

ECONOMIC STATUS/INCOME
There is disagreement over whether the wealth and economic status of the person has an impact on the levels of informal care. Some claim those from less advantaged backgrounds are more likely to provide intensive care, especially to a spouse (Young et al 2005a), (possible reasons for this including higher levels of poor health and disability in manual groups). Opposing this view, however, is the assertion that wealth is not a deciding factor in provision of informal care; additional income does not reduce the

### TABLE 35: NUMBERS OF CARERS BY RELATIONSHIP WITH CARE RECIPIENT, 2000

<table>
<thead>
<tr>
<th>Relationship of carer to care recipient</th>
<th>Great Britain(^1) (%(^2))</th>
<th>Great Britain (millions(^3))</th>
<th>England(^4) (millions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>18</td>
<td>1.2</td>
<td>1.0</td>
</tr>
<tr>
<td>Child/child-in-law</td>
<td>52</td>
<td>3.5</td>
<td>3.0</td>
</tr>
<tr>
<td>Friend/neighbour</td>
<td>21</td>
<td>1.4</td>
<td>1.2</td>
</tr>
<tr>
<td>Other</td>
<td>30</td>
<td>2.0</td>
<td>1.7</td>
</tr>
<tr>
<td>Total</td>
<td>8.1</td>
<td>7.0</td>
<td></td>
</tr>
</tbody>
</table>

\(^1\) Based on figures in Maher and Green 2002.
\(^2\) Percentages add to more than 100 because some carers were looking after more than one person and are therefore counted more than once in these figures.
\(^3\) Estimate, Wanless Review.
\(^4\) 86 per cent of total for Great Britain.
probability of individuals providing informal care, if other factors are constant (Leontaridi and Bell 2005).

The correlation between working status and caring is more certain. Caring rates are higher (21 per cent) among the economically inactive (that is, not specifically seeking work due to retirement, long-term illness, etc) compared with full-time workers (13 per cent), part-time workers (17 per cent) and the unemployed (15 per cent) (Maher and Green 2002). Economic status can be influenced by the need to provide care, however, with the reduced income, pensions and reduced likelihood of employment frequently negatively impacting on finances.

EDUCATION

Level of education has some impact on the propensity to care. Higher levels of education appear to reduce the probability of caring (for those living outside the household of the care recipient) (Machin and McShane 2001).

LOCATION

The provision of informal care across the UK varies considerably with region and local authority. General trends seem to include:

- very rural areas generally have a higher proportion of adults providing care (ONS 2004a)
- some degree of clustering of higher propensity to provide informal care in the heavily industrialised areas, such as the West Midlands
- lower levels of caring in the more affluent areas, such as London and the South East and South-Central England.

It has also been suggested that there may be some correlation between levels of informal caring and levels of deprivation and poor health (Young et al 2005a), although the evidence is not conclusive.

In addition to the location of the carer and care recipient, the proximity of the carer to the care recipient can have an impact on the likelihood of caring. This is particularly the case where a child is the carer. Unsurprisingly, the further a child lives from the parent, the less likely they are to administer care on a regular basis.

ETNICITY

Research in the UK on the correlation between informal care and ethnicity has been limited but suggests that ethnicity does have an impact on propensity to care, with prevalence being highest among Bangladeshi, Pakistani and Indian groups (Young et al 2005a). Reasons suggested for this include socio-economic and cultural factors.

Carer support services currently provided

At present there is a range of services available to support carers, including respite care of various types, information and training of carers, social work and counselling. The government collects information on total numbers of carers that receive council assessments and services (NHS Health and Social Care Information Centre 2005). Table 36 overleaf gives details. To put these numbers in context, the lowest estimates of carers for older people is 3.4 million people (derived from the Census). If it is assumed that only those people providing more than 20 hours a week would benefit from carer support (not necessarily a valid assumption) then only about 20 per cent of 3.4 million might apply, that
is 680,000 carers. The figures in Table 36 suggest around 10 per cent of the 680,000 receive support services.

The apparent low level of provision of information is particularly concerning. As to the type of services received by carers, information is not routinely collected, but a picture can be put together from various sources (Keeley and Clarke 2002) (see Annex, p 152).

3 The current cost of caring

Costs of caring are not simple to define or establish. The evidence base is poorly developed.

**Individual costs**

The reasons why people provide informal care are complex. That people are motivated to do so is self-evident from the large numbers of people who do devote time and effort in this way (see also Evandrou and Glaser 2003, Young et al 2005a). Whether because of some sense of commitment, duty or emotional attachment, people provide care despite the potentially significant costs.

People suffer a loss of income if they forgo employment opportunities. In practice, while there are many who successfully combine work and a caring responsibility, this is difficult for carers to manage (Arksey et al 2005b, Machin and McShane 2001) found from an analysis of the Family Resources Survey that 75 per cent of carers living elsewhere from the cared-for person and 19 per cent of co-habiting carers were economically active. (The latter low figure reflects the high number of spousal carers who will have retired.) The loss of income can also have a detrimental effect on pensions, particularly for women in pre-retirement years (Thomas Coram Research Unit 2002, Hirst 2002).

It has been argued that the regulations around receipt of carers’ benefits are overly restrictive, creating a disincentive to work (Arksey et al 2005). Those caring for older people are particularly affected, despite reforms such as removing the upper age limit for Carers Allowance (CA) in 2002 (Department for Work and Pensions 2005, Evandrou and Glaser 2003). People also incur care-related costs such as travel, food, accommodation costs etc (Pickard 2004).

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**TABLE 36: NUMBER OF CARERS RECEIVING CARER ASSESSMENTS AND SERVICES, 2004/5**

<table>
<thead>
<tr>
<th>Carer assessments</th>
<th>Number of carers (thousands)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers assessed or reviewed separately</td>
<td>46</td>
</tr>
<tr>
<td>Carers assessed or reviewed jointly</td>
<td>148</td>
</tr>
<tr>
<td>Carers declining an assessment during the period</td>
<td>30</td>
</tr>
<tr>
<td>Carer services</td>
<td></td>
</tr>
<tr>
<td>Carers receiving ‘carer specific’ services</td>
<td>65</td>
</tr>
<tr>
<td>Carers receiving information only</td>
<td>79</td>
</tr>
</tbody>
</table>

Source: Based on Department of Health Referrals, Assessments and Packages of Care Project data
In addition, there are potentially considerable indirect or non-financial costs of caring, costs such as social exclusion, erosion of personal relationships and adverse effects on health. The Princess Royal Trust for Carers indicated that 85 per cent of carers said that caring had a negative impact on their health (Keeley and Clarke 2002), a factor corroborated by Carers 2000. (The possible effects are summarised in the box above.) Various types of support are available for carers, some of which have been shown to reduce carer stress and other adverse health effects, and produce other positive outcomes. In Chapter 10, below, and in Background Paper 6 (‘Informal care’) in the Appendix, the cost-effectiveness of possible interventions is considered.

**Economy-wide costs**

The costs to the economy of informal caring are twofold: the direct cost of the services provided to carers, and the cost to the economy of the carers not being engaged elsewhere and thus not able to make an alternative contribution to the economy. At present there is little information on either. In Chapter 10, carer support services as they might be deployed in the future and their possible costs are specified. The modelling work by PSSRU on current service patterns detailed in the accompanying paper by Malley and colleagues, Research Paper 1 (‘PSSRU model’), identifies costs of respite care services. These are estimated to cost around £200 million in 2007.

**INDIRECT COSTS**

Costs at an individual level are clearly felt (as described above). Determining the cost of informal care to the economy, however, presents considerable methodological challenges. The initial reaction to the National Institute for Health and Clinical Excellence (NICE) for excluding these costs in its appraisal of new drugs for treatment of Alzheimer’s disease testifies to the strength of concern in this regard (see box below, and Chapter 9).
ALZHEIMER’S DRUGS – NICE APPRAISAL

The high level and cost of informal care for people with dementia has been debated following NICE’s appraisal of various Alzheimer’s drugs. People with dementia and their families argue that assessment of the cost-effectiveness of dementia care should include the hidden costs of informal care.

In its preliminary 2005 recommendation, NICE concluded that the drugs in question should not be used in the NHS, (except memantine as part of certain ongoing clinical studies). It judged that the drugs lay outside the range of cost-effectiveness considered appropriate for the NHS.

The NICE evaluation found that the literature was sparse on the costs associated with Alzheimer’s, but that a significant proportion of these costs fell on patients and caregivers. A review of nine studies on costs for community-based people with Alzheimer’s estimated that the proportion of total costs represented by informal care ranged between 36 per cent and 85 per cent (McDaid 2001). The wide range was in part due to differences in the type of costs included and the methods used to quantify and value caregiver time. A cost study in Ireland found that family care accounted for almost 50 per cent of the overall resource burden for Alzheimer’s (based on an opportunity cost valuation of carer time) (O’Shea and O’Reilly 2000).

There was a fierce reaction to the NICE preliminary recommendations, with families and pressure groups strongly opposed to the suggestion that the drugs should not be prescribed by the NHS. The then Health Secretary indicated that he had brought a number of questions to NICE’s attention:

- Had NICE carried out a cost-effectiveness analysis of this medication compared to non-drug interventions for cognition, behaviour, activity of daily living and carer burden?
- Would NICE consider including carer time when reassessing cost-effectiveness? In its response to NICE, the Department of Health asked: ‘Has NICE considered whether there would be a different answer if the costs of carers as opposed to the benefits were included? Would this make a difference? It is our understanding that NICE generally only considers NHS costs. Is it satisfied that this is sufficiently wide-ranging to cover adequately all the potential benefits of the drugs involved? The care of people with dementia relies heavily on family caregivers. As there is data from randomised controlled trials on reduction in caregiver time as a benefit from these medications, would NICE reconsider re-assessing cost-effectiveness including a factor for carer time in the outcome?’ (Department of Health 2005).

In January 2006, NICE issued a revised appraisal saying that certain drugs should be available on the NHS but only to those with moderate Alzheimer’s. In the economic modelling, an adjustment was made to cover the quality of life (utility) gains of carers that arose when an Alzheimer’s patient in receipt of one of the drugs did not progress to later and more difficult stages of the disease within 5 years or because of death. However, it was decided that it was not appropriate for carer costs to be included in the economic model. It cited the potential for double counting if the effect on carers was incorporated both as improvements in utilities and some monetary value of the
In acknowledgement of their financial position, some carers are able to claim Carers Allowance. This benefit is estimated to cost at least £19.7 million per week. As of August 2005 there were 441,000 claimants in Great Britain (Department for Work and Pensions 2006b) and the basic benefit rate was £44.35 per week. Carers can also be eligible for income-related benefits and premiums or in-work financial benefits depending on their situation (Arksey et al 2005). Given the complexity and repeated testing for entitlement, uptake can be low. The introduction of Individual Budgets (IBs) will help to streamline the process for claimants.

The level of contribution that individuals would be making to the economy is dependent on whether they would be working (more or at all) were they not in a caring role. As noted above, having caring responsibilities does not automatically result in withdrawal from the labour market, with even those who provide care for longer hours showing a relatively high participation rate (Machin and McShane 2001, Maher and Green 2002). There does, however, appear to be some impact on the decisions and behaviour of carers regarding involvement in the labour market, with correlations existing between both length of time spent caring and the propensity to work, and the level of caring responsibility with the number of hours worked (both inversely proportionate). Furthermore, the likelihood of a person returning to work is affected, as are the wages and position of the employee compared to that prior to the caring break. For those that participate in the workforce throughout caring episodes, employment is frequently compromised by factors such as the need for flexibility, restrictions imposed for benefits and other responsibilities. It is noteworthy, however, that the perceived impact of the caring role on workforce participation is significantly higher than the figures suggest is the case (Machin and McShane 2001). This gives some indication that the caring role may have some impact on optimal employment as well as actual employment rates.

Measuring the economy-wide cost is problematic. There are two broad approaches. These costs can be measured in terms of what it would cost to replace informal care inputs with formal care (market replacement cost), or they can be measured as the income/workings and leisure forgone due to time being devoted to caring. The former is likely to underestimate the full economic cost, but the latter is demanding to calculate and involves assumptions about the value of work and leisure for people. Nonetheless, there have been attempts to estimate these costs. Examples cited in Pickard (2004) include consideration of aspects relating to both the individual and to the economy, such as direct expenditure, forgone waged and non-waged time and forgone career prospects and accommodation income. Estimates by Netten et al (cited in Pickard 2004) were of a cost to the carer of £31.42 per week and to society of £29.98 overall in 1990. Up-rating by inflation (GDP deflator) this is equivalent to a cost per carer in 2006 of £47.13 and £44.97 respectively. If this were to be applied to all those currently caring for those over 65, this would create a figure of £9.4 billion cost to ‘society’. In addition Chapter 10 estimates replacement costs...
of £3.5 billion using the projection model. This difference in figures is consistent with the expectation that full economic costs exceed replacement costs.

4 Future position

In Chapter 10, numbers of older people using informal care in the future are estimated. Assuming current rates hold in the future, the Review model requires an increase of informal care input of just over 50 per cent from 2002 to 2026, in its central projection – details of these assumptions are given in Research Paper 1 (‘PSSRU model’) in the Appendix.

There are two ways in which rates of informal care will change in the future. First, if patterns of informal care remain constant with respect to these personal characteristics, then the changing circumstances of older care recipients will affect the chances that informal care will be available. If, for example, there are more older people living alone then the overall rate of informal care will be lower (because people living alone receive less informal care individually). Second, patterns of informal care may not stay constant. For example, people who might currently be prepared to care for those in need in certain circumstances may not be so willing in future.

It is unlikely that rates of informal care will keep pace with increases in care need in the future.

INCREASING AGE OF CARERS

Whether spousal care will keep pace with the projected increase in demand for care will depend, not least, on the health status of those spouse carers themselves. The age of the caring population as a whole will increase. This has possible implications for the care provided, not only in terms of tasks and hours of care, but also in the nature of the support required for carers themselves.

DECLINE IN FILIAL CO-RESIDENCE

The number of caring hours is much higher among those that co-reside with the care recipient. Most of those caring for people living in another household care for less than 20 hours per week (89 per cent) and there has been a significant decline in co-residence between adults and elderly parents (Grundy 1999). The implication of a trend towards care being provided by carers living in a different household is that the number of hours spent caring will decrease, specifically for the tasks that are largely currently administered by those that live within the household, such as personal care. Furthermore, there is a decline in more intensive and demanding care where the carer lives apart from the carer recipient, and increases in the intensity of care within households, particularly for elderly spouses (Hirst 2001).

EXPECTATIONS AND ATTITUDES

Expectations about quality of life and levels of independence have risen, and will continue to rise, amongst recipients and carers. Care recipients have growing expectations of support that will enable them to have increased freedom and independence. Carers’ expectations reflect the increasingly atomistic perspective of society, with individuals wanting more freedom to determine their own life and fewer restrictions (which would arguably include those effectively imposed by caring responsibilities). This is in line with a school of thought that suggests the filial responsibility assumed by many in the UK and
other countries is eroding, and the ‘fixed obligations’ no longer compel to the extent seen previously (Finch 1995).

Reconciling such conflicting views would require increasing expectation on the role of formal care and the rights it should support for the individual, including, for example, the right to personal independence. With regard to caring there seems to have been a move towards the assumption that when a person forgoes their individual rights, such as through sacrificing their time by caring for someone else, they should be compensated by the rest of society, that is, by the public purse (such as in the case of Stephenson vs Stockton on Tees Borough Council 2005).

In addition to the numbers of people requiring care rising at a rate faster than that of informal care supply, the nature of the care provided will change, for example, with an increase in care provided from outside the household. This shift would mean less hours per carer and less provision of the more intimate forms of care, such as personal care. Meanwhile, care recipients will arguably expect increasing levels of independence, thus possibly requiring greater input. This combination of developments seems likely to create a widening gap between the available supply and the required care inputs. Projections of the extent are developed in Chapter 10 onwards.

5 New strategies on informal care

At present, there is a high reliance on informal care, with significant costs falling on carers and potential carers. In the future, the indications are that informal caring rates can be expected to reduce.

A number of strategies can be adopted in response to this. These include:
- improving support for carers
- giving potential carers further incentives to supply informal care
- increasing the provision of formal care services.

Supporting carers

SUPPORT SERVICES

The current provision of services to support carers in their role varies significantly with location and personal circumstances (such as residential status), and is argued to be inadequate (Keeley and Clarke 2002, Maher and Green 2002). There have been steps to improve the situation, for example, by articulating more clearly the rights of carers and the obligations of local councils through the 1995 Carers Recognition and Services Act, and Subsequent Acts in 2000 and 2004. The recent White Paper (Department of Health 2006) also focuses on carers to some degree.

There is evidence that support for carers can be effective (Pickard 2004). The impact of services on carer outcomes can be judged in (at least) two ways. First, in the way that services delay the need for people to go into care homes (because it delays a breakdown of the caring situation at home). Second, in the way that services directly impact on measures of carer stress. Davies and Fernández (2000 in Pickard 2004) find that social care services and especially day care and respite care are effective in both ways. Social work can also be highly effective at tackling carer stress.
Improving the situation of carers also has consequences for their employment opportunities (and so broader economic performance considerations). In principle, reductions in carer stress ought to go hand-in-hand with improvements in the working situation of carers (even where work cannot be continued, opportunities to develop human capital during a caring episode would help maintain employability and keep skill levels at a preferred level). Similarly, reductions in these ‘costs’ of informal care to potential carers are likely to improve supply. It might also be an effective strategy to cover some of the financial costs of caring, as discussed above. However, there is no evidence to confirm any of these later conjectures directly.

Improvements and increases in carer support should also directly impact on the quality of care provided. A less stressed, overworked, unhealthy or tired carer will have an increased ability to care, and there is likely to be a generally improved atmosphere. In addition, training support should mean care of a higher quality.

It is recommended that evidence on the cost-effectiveness of services regarding delays in institutionalisation and carer outcomes is developed, and used, together with that which is currently available, to justify further development of carer services.

**INCENTIVES**

Payment for informal caring potentially improves carer supply as well as providing compensation to carers for some of the costs of caring. The benefits system already provides payments via provision of Carer Allowance and other benefits with carer-enhanced rates. Many other countries have similar benefits or allow direct payment or care budget equivalents to compensate informal carers (see Lundsgaard 2005).

Paying carers has a range of consequences.

- There are potentially deadweight costs in reimbursing carers who would, without payment, maintain levels of caring.
- Some claim that carer payment creates ‘incentive traps’ that attract carers away from the labour market (Lundsgaard 2005).³
- Carer payments help people who choose to care for loved ones even though they bear significant adverse financial and other consequences.
- Even a relatively small payment can induce a significant supply of care as the experience in Germany – where an older person’s cash payment for care can be used to pay carers – testifies (see Background Paper 6 (‘Informal care’) in the Appendix).

If people want to provide care despite the opportunity costs they face, then paying them will improve the outcomes of those carers, but may not induce more people to care. Alternatively, if payment sufficiently offsets the opportunity costs of those who otherwise would not care, then carer supply will increase, but the net effect on the economy is likely to be negative. However, if the opportunity cost is not much greater than the replacement cost of care, and both the carer’s and the care recipient’s outcomes are greater with informal rather than formal care, a case would exist for carer payments. Furthermore, there are strong fairness arguments that where people provide care and their financial and other situations become poor as a result, help should be provided.

Any conclusions to be drawn also depend on the supply of formal services, an issue explored in Chapter 7. If formal care supply is limited, then inducing more informal care would imply a significant improvement in overall care recipients’ outcomes, especially
where needs would otherwise remain unmet. It is not clear that the supply of informal care will meet projected demand for care in future years (Pickard et al., forthcoming). Without some introduction of incentives or support for people, it is difficult to see how the gap could be closed from the informal care side.

Where payments are forthcoming, the situation of carers will be improved. This could be achieved either by reimbursing carers directly (for example through benefits) or allowing them to be paid from a care recipient’s cash payment for care.

The care recipient would benefit from these incentives to carers if their formal care remained unchanged. The potential problem, however, is that formal care might be reduced. Paying carers from a fixed overall budget clearly diverts resources. This problem will be compounded if wider economic performance is also affected by withdrawal of carers from the workforce. Ideally, the care recipient and the carer would be jointly assessed and services deployed, as needed, to address both their outcomes. The Older People’s Utility Scale (OPUS) could be used to develop tools to measure the impact of services on care user outcomes (see Chapter 5). It is recommended that further work is undertaken to extend this scale to account for carers’ outcomes.

**Increased formal care to older people**

Increases in mainstream formal services to older people appear to have little impact on how much informal care is provided. Work done by the Care Development Group for the Scottish Executive (Leontaridi and Bell 2005) suggested that evidence for substantial substitution away from informal care, as a result of the extension of formal provision of care services, is weak. More recently, following increased formal provision under Free Personal Care in Scotland, little evidence could be found of a reduction in informal care (Bell and Bowles 2006). This supports evidence from controlled experiments on substitution in the USA (Leontaridi and Bell 2001). It appears that even when formal care provision is offered, individuals providing care do not easily ‘opt into’ work.

There is some apparently contradictory evidence, however. In Denmark a positive correlation between greater emphasis on formal provision of care and greater workforce participation – particularly for women between 50 and 59 years of age – has been identified (Lundsgaard 2005). However, research suggests that that this change of emphasis needs to be combined with other factors to ensure the net result is increased participation rather than the opposite (as seen in the Netherlands, for example (Lundsgaard 2005)). This would also support the findings of research done for the Department for Work and Pensions (Arksey et al. 2005), which show that decisions about caring and employment status are influenced not only by finances, but by a range of factors, with no single factor dominating the final decision. The possibility of earning more through employment is not necessarily sufficient in itself to entice people to cease or reduce their caring responsibilities.

A greater availability of care services for the older person would improve carers’ outcomes but arguably not as effectively as formal services tailored to supporting carers. This is particularly the case with spousal carers, who are overall less likely to reduce their input than filial carers. With regard to filial carers the situation is less clear-cut, with the level of informal care provided and the likelihood of returning to the labour market being influenced to a greater degree by the support that is received. Where the care recipient’s
children are the primary care givers, the case for care services as well as carer support services is strengthened as part of a strategy to improve carers’ outcomes. Effective support for filial carers could then be provided through a range of options.

While practical support is essential, it is not the only aspect that needs to be addressed. Increases in formal care provision alone will not ease the financial burden on those who do care. Moreover, if formal services do not induce carers to reduce their own inputs much, then the opportunity to earn is not increased to any significant degree.

It is recommended that to improve outcomes for spousal carers, developing carer support services should be the main focus rather than care services for cared-for people. For filial carers, it is recommended that a range of options are considered and additional work is undertaken to ascertain the most preferable approach. In line with this latter recommendation, the modelling work in this Review (see Chapter 10) examines the implications of social care being ‘carer-blind’ to children carers.

**Alternative and development options**

Potentially more wide-ranging options regarding informal care could include:

- further engagement and support of local community and voluntary networks. The use of *Time Banks* for example is embryonic in this country, but experience from the US in particular, is promising
- further development of new types of carer support services such as adult day care and home sharing
- promoting support for carers from employers regarding both flexible working practices for working carers and also support for retired employee carers. Examples of good practice do exist in some organisations, but the onus is currently on employers. This needs to be developed.

It is recommended that these possible initiatives are investigated further.

**6 Other issues to consider**

Specific policy on carers now and in the future is also affected by other considerations.

- There is a need for increased clarity in overall policy on the role and the responsibilities of the state, family and individuals (which affect the perceptions of potential carers).
- There is a need for regular assessment and review of carers’ needs. This would help to improve the quality of the informal care they provide and ensure the support and information they receive is appropriate and effective. Some have concerns, in principle, about the quality of care that is provided by unpaid carers, but there is limited evidence (Lundsgaard 2005). There are legitimate questions to ask about the potential for risk and abuse. However, any response needs also to consider the wider regulatory burden that would be imposed. More work is required to weigh the benefits in terms of better quality and safety against the costs, and the conclusions need to be acted upon in future policy.

Extending choice to care recipients is high on the policy agenda. Allowing Direct Payments or similar to pay for informal care from co-habiting relatives is a relevant issue. As noted above, payment of informal care (especially close relatives) has a range of pros and cons,
which will need to be resolved. Sufficient evidence does not yet exist to form a view on which direction should be followed. It is recommended that additional research is done on this question, and the results are used to direct future policy.

7 Conclusion

Informal (and unpaid) care plays a vital role in the support of older people. Very large numbers of people provide at least some level of care, with some providing a very substantial input. Key questions are: Should we continue to rely on informal care? If so what are the consequences? Are the resultant situation and outcomes for carers reasonable? And is the supply of informal care going to keep pace with likely increased demand for care?

Given demand and also the willingness of many to care for others, it is inevitable that informal care will continue to provide a significant input. Many decide to care with little regard for 'substitution potential' of formal care and are motivated by many factors other than the provision of formal care or lack of it. Moreover, as detailed in Chapter 10, the costs of increasing formal care to address unmet need arising from a reduction of informal care would be prohibitively high, even if the trained workforce could be created (see Chapter 7).

Based on current patterns, it is expected that informal care rates will fall short of increases in demand. Furthermore, at present, outcomes for some carers deteriorate to unacceptable levels. This can be expected to continue into the future if current arrangements persist. There are solutions ranging from support services to carers and payment for carers, through to broader attempts to foster better societal attitudes to caring.

The evidence base is not as developed as it should be, but the case for further carer support services looks strong. The cost and outcomes implications of this are modelled in Part 2 of this report. For spousal carers, the best form of support seems to be services that address carers’ outcomes directly, relieving some of the pressures of care. For filial carers, this argument also holds, but the case for possible substitution of informal care by formal services for the care recipient is stronger. The implications of a ‘children carer blind scenario’ are examined in Chapter 10.

There are also strong fairness arguments, particularly around supporting those people committed to caring whose financial and other situation is reduced to low levels as a result. This argument can support a case for extending financial support for all carers. It is reasonable to expect that those individuals fulfilling the perceived obligation of caring for the vulnerable are not actively disadvantaged, both financially and personally, and are not driven to poor health through an excessive workload.

These arguments concern not only the implications for the cared-for person, but also the carer themselves. Policy development in this area should not undervalue improvements in carer outcomes, even if this creates tensions with improving service user outcomes.
Notes

1 Although 2001 Census data is more recent, it is much less detailed and thus offers less scope for analysis. Data from Carers 2000 excludes from its figures: those caring as a volunteer or for other organisations and those caring for individuals receiving care in an institution or with a temporary illness or disability (as defined by the respondent).

2 If there are 6.7 million carers in Great Britain, then those that care for more than 35 hours per week would number around 1 million. On this basis, with 441 thousand claimants, take-up looks low, perhaps only 50 per cent.

3 These arguments are somewhat contradictory in that these traps only apply to people would be unwilling to provide care without payment (people who would provide with payment would not be trapped)