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**Assessing Needs of Care in European Nations**

## **THE LONG-TERM CARE SYSTEM FOR THE ELDERLY IN ENGLAND**

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**ADELINA COMAS-HERRERA, LINDA PICKARD,  
RAPHAEL WITTENBERG, JULIETTE MALLEY  
AND DEREK KING**

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# The Long-term Care System for the Elderly in England

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Adelina Comas-Herrera, Linda Pickard, Raphael Wittenberg,  
Juliette Malley and Derek King\*

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## 1. The long-term care system of England

### 1.1 Overview of the system

The long-term care (LTC) system in England can be characterised as a ‘safety-net’ type of system that only supports those with very severe needs who are unable to meet the costs of their care (Fernandez et al., 2009). The system has evolved incrementally from earlier systems of welfare for the poor by developing specific services to meet the long-term care needs of older persons and a limited relaxation of the means tests (Ikegami and Campbell, 2002). Partly as a result of its origins, it is a complex system that most people do not understand. A recent review of eligibility criteria for social care in England by the former Commission for Social Care Inspection (CSCI) concluded that there is “a lack of clarity and transparency in practice, particularly relating to the complexity of the framework, so neither professionals nor those using services are confident of their understanding” (CSCI, 2008, p. 4).

The philosophy of the current English LTC system places the primary responsibility for the non-health care components of long-term care with individuals and their families. Only individuals with income and assets below the means-tested level receive publicly funded social care and the system also directs services towards those who live alone and do not receive informal care (see, for example, Pickard 2001). There are plans for a major reform of the long-term care system in England, as outlined in the government’s Green Paper published in 2009 (see section 4.2).

The current labour government followed up its election pledge to reform the LTC system with the establishment of a Royal Commission that reviewed in depth the system and made a series of recommendations to the government (see section 4.2). Since the Royal Commission’s report there has been an intense period of activity and debate on the LTC system, with a great number of government documents that have attempted to address some of the problems that had been identified by the Commission. The system of LTC funding in England, however, has remained almost unchanged, except for nursing care being made free to all those who need it and some small changes to the means tests. In 2006 the King’s Fund (an independent UK think tank)

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\* Adelina Comas-Herrera ([a.comas@lse.ac.uk](mailto:a.comas@lse.ac.uk)) is a research fellow at the Personal Social Services Research Unit, LSE Health and Social Care, London School of Economics. Linda Pickard ([l.m.pickard@lse.ac.uk](mailto:l.m.pickard@lse.ac.uk)) is a research fellow at the Personal Social Services Research Unit, LSE Health and Social Care, London School of Economics. Raphael Wittenberg ([r.wittenberg@lse.ac.uk](mailto:r.wittenberg@lse.ac.uk)) leads the Personal Social Services Research Unit’s programme of research on the financing of long-term care for older people. He is also an Economic Adviser at the Department of Health for England and has also worked at the Department for Work and Pensions on the economics of pensions and long-term care. Juliette Malley’s ([j.n.malley@lse.ac.uk](mailto:j.n.malley@lse.ac.uk)) main areas of interest include the financing of LTC, the performance and quality of social services provision and the measurement of user experience. Derek King ([d.king@lse.ac.uk](mailto:d.king@lse.ac.uk)) is a research fellow at the Personal Social Services Research Unit, LSE Health and Social Care, London School of Economics.

For more information on the Personal Social Services Research Unit (PSSRU) at the London School of Economics, see the penultimate page of this study.

reviewed once more the system and its financing and suggested a new financing and service provision model (Wanless et al., 2006). In July 2009 the government launched a consultation process outlining the creation of a National Care Service and is considering completely new (to the UK) ways of financing long-term care, including compulsory insurance (HM Government, 2009).

Long-term care in the UK is usually taken to mean help with domestic tasks (such as shopping and preparing meals), assistance with personal care tasks (such as dressing and bathing) and nursing care. An increasing number of older persons are now receiving cash instead of services in the form of direct payments or individual budgets. Most long-term care for older persons living at home is provided by informal carers (Pickard et al., 2000). Formal services are provided by a range of agencies including local authority social services, community health services and independent (for- and non-profit) sector residential care homes, nursing homes, home care and day-care services. Long-term care services are financed by the National Health Service (NHS), local authorities, charities and by older persons themselves. While health care services are free at the point of use and access is based on needs, most formal long-term care is considered social care and is strictly means-tested. There is also a non-means-tested benefit for older disabled persons with personal care needs and a benefit for carers.

## 1.2 Assessment of needs

Access to publicly funded social-care services is mainly through an assessment of care needs coordinated by the local authority's social services department. Assessment and care management aim at matching individuals' needs to the services available, with an emphasis on targeting services at those with greater disabilities. The process involves an assessment of care needs and arrangement of a package of care required to meet those needs and varies locally. A care manager may be involved in coordinating the assessment and organisation of care. The care manager may have a devolved budget with which to purchase services. Those assessed as eligible for a package of care can instead opt for a direct payment that they can use to buy equipment or services themselves. There is no national definition of the need for care, but individuals are classified according to their needs using the eligibility bands of the Fair Access to Care initiative, a national framework for eligibility criteria introduced to address inconsistencies across the country (Department of Health, 2002). The aim of the framework was to ensure that individuals with similar needs would be able to achieve similar outcomes. It does not require those with similar needs to be given similar services. The eligibility framework provides four severity bands (low, moderate, substantial and critical – see Box 1) to which individuals are allocated.

In 2006-07, 460,000 older persons not already in receipt of services had a completed assessment of their needs (Department of Health, 2008b). Allowing for population change, there had been a gradual reduction in the rates of completed new assessments in the years to 2006-07.

With regards to the source of the referrals for assessments (for all ages), in 2006-07 29% were self-referrals, 23% were from secondary health services, 14% from a family, friend or neighbour and 13% from primary or community health. After first contact, 62% of older persons had their completed assessment within two weeks and 94% within three months (Department of Health, 2008b).

Following an assessment, a person may be provided with a new service, may not be offered a service, may themselves decline any service or may have some other outcome. Some may be referred to the NHS or housing agencies or to voluntary sector services. Among older persons receiving services, 79% received all their services within two weeks after the assessment, 10% after two to four weeks and 11% after more than four weeks. In 2006-07 councils reviewed 71% of adults receiving a service in the year.

Those who have been assessed as eligible for services are then subject to a means test to establish whether their services will be funded wholly or partly by the local authority (see section 2).

Access to publicly funded, long-term care health services (mostly home nursing) is through referral from a general practitioner (GP) or as a result of a care package arranged following hospital discharge. As there is a universal entitlement to health care, there are no meanstests for these services.

*Box. 1. Fair Access to Care eligibility bands*

**Critical – when**

- Life is or will be threatened.
- Significant health problems have developed or will develop.
- There is or will be little or no choice and control over vital aspects of the immediate environment.
- Serious abuse or neglect has occurred or will occur.
- There is or will be an inability to carry out vital personal care or domestic routines.
- Vital involvement in work, education or learning cannot or will not be sustained.
- Vital social support systems and relationships cannot or will not be sustained.
- Vital family and other social roles and responsibilities cannot or will not be undertaken.

**Substantial – when**

- There is or will be only partial choice and control over the immediate environment.
- Abuse or neglect has occurred or will occur.
- There is or will be an inability to carry out the majority of personal care or domestic routines.
- Involvement in many aspects of work, education or learning cannot or will not be sustained.
- The majority of social support systems and relationships cannot or will not be sustained.
- The majority of family and other social roles and responsibilities cannot or will not be undertaken.

**Moderate – when**

- There is or will be an inability to carry out several personal care or domestic routines.
- Involvement in several aspects of work, education or learning cannot or will not be sustained.
- Several social support systems and relationships cannot or will not be sustained.
- Several family and other social roles and responsibilities cannot or will not be undertaken.

**Low – when**

- There is or will be an inability to carry out one or two personal care or domestic routines.
- Involvement in one or two aspects of work, education or learning cannot or will not be sustained.
- One or two social support systems and relationships cannot or will not be sustained.
- One or two family and other social roles and responsibilities cannot or will not be undertaken.

## 1.3 Available LTC services

### 1.3.1 Which services?

Formal services are provided by a range of agencies, including local authority social services, community health services and independent (for- and non-profit) sector residential care homes,

nursing homes, home care and day-care services. People are also able to buy their own services using direct payments and individual budgets, or using their own private funds.

In 2006-07, 1,231,000 older persons were receiving services (or direct payments) that had been arranged by the local authorities, following assessments (Department of Health, 2008b).

The main long-term care services available in the UK for individuals living in their own home are home care or home help services, private home help, community nursing services, day care in day hospitals or centres, meals on wheels or in lunch clubs, chiropody, therapy services and private domestic help. The main institutional services are residential homes and nursing homes. There are a few persons in long-stay hospitals and the government has recently invested in the development of extra-care housing (also known as very sheltered housing).

### 1.3.2 Who is eligible?

#### *Eligibility for services (or cashbenefits in lieu of services)*

People considered eligible by the local authority and who pass the means test are eligible for local authority-funded services (or direct payments). Eligibility criteria, arrangements for assessments and budgetary arrangements are determined locally and there is variability among local authorities. As discussed in section 1.2, there is a national framework for eligibility criteria, introduced with the aim that individuals with similar needs would be able to achieve similar outcomes. It does not require individuals with similar needs to be given similar services. The eligibility framework provides four severity bands (low, moderate, substantial and critical – see Box 1) to which individuals are allocated. Councils can choose where to set their eligibility criteria within those bands and can create sub-bands. Most councils only consider eligible those in the substantial band and some only those in the critical band. There are concerns that the needs of those in the more moderate bands are not being met.

A report of the Audit Commission (2008) on the effects of the Fair Access to Care bands on expenditure and service provision found that there were wide variations in spending on care for older persons, according to how restrictive the use of thresholds was. A recent report by the former social care regulator found that despite the implementation of the eligibility framework, there are still wide variations among the councils (CSCI, 2008). It also raised concerns that the needs of those with less severe levels of disability are not being met.

#### *Eligibility for the Attendance Allowance (non-means-tested benefit)*

To be eligible for the Attendance Allowance, a claimant must normally have needed help for six months before the allowance is paid. There are two ways to qualify as needing help during the day, based on the need for

- frequent attention during the day in connection with bodily functions. This is interpreted as covering activities such as eating, toilet use, washing and dressing, communicating with other people and walking. The allowance is not paid if the only help that is needed is with domestic chores; or
- supervision during the day to avoid substantial danger to oneself or others.

There are two ways to qualify as needing help during the night, based on the need for

- repeated attention in connection with bodily functions; or
- another person to be awake for the purpose of supervision to avoid substantial danger to oneself or others.<sup>1</sup>

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<sup>1</sup> Source: Disability alliance (<http://www.disabilityalliance.org>).

People receiving either care or a mobility component under the Disability Living Allowance scheme before the age of 65 continue to receive it after age 65 (instead of the Attendance Allowance). There is also a benefit for carers, called the Carer's Allowance. (See section 3.2 for details.)

#### **1.4 Management and organisation (role of the different actors/stakeholders)**

The central government is responsible for overall policy on health and social services. As health and social services are a devolved function within the UK, however, this central government role in the three countries other than England is devolved to the Scottish Executive, the National Assembly for Wales and the Northern Ireland Assembly. This means that policies may differ among the four constituent countries of the UK.

Health services under the NHS are funded by the central government, mainly from general taxation but partly from national insurance contributions. Resources are distributed by the central government to local primary care trusts, which are responsible for commissioning a range of health services for their populations.

Social services are funded by local authorities. Local authority resources are derived from local taxes and user charges for services but mainly from central government grants. This means that social services are also funded primarily by general taxation. Local authorities are responsible for assessing the care needs of individuals living in their area, arranging care services and providing financial support to those who have been assessed as eligible and meet their financial criteria. Local authorities are not responsible for care provision and capacity planning, but they need to ensure the needs of their local populations are being met.

Local authorities have an important degree of autonomy in their purchasing and funding roles. They receive a grant from the central government and also raise their own funding through setting their own local taxes. The central government grant they receive is mostly not 'ear-marked' for particular services, so local authorities can decide how to allocate their overall budget to the different services for which they are responsible, such as education, social services, planning, etc. On the other hand, local authorities are accountable for the funds they receive by means of a National Indicator Set of indicators for local government, several of which relate to adult social care. These include indicators for living alone independently, user choice, rehabilitation, timeliness of assessments, timeliness of care packages and support for carers. The central government can also reward local authorities with greater autonomy (i.e. with less ring-fencing of grants) for good performance but can step in with more control when there are problems.

Local authorities, sometimes in partnership with other organisations, assess the care needs of their resident population and arrange for care. Local authorities purchase care both from public sector providers and from voluntary and private providers. Fees are negotiated between the local authorities and the providers. They can formulate their own charging policies for non-residential care (although the Department of Health has recently introduced guidelines). The charging system for residential care services (residential care homes and nursing homes) is determined by the central government.

Local authorities are now required to offer cash equivalents of care packages for clients to use to pay for home care. This means that the care user has become the 'purchaser' and, as take up of cash benefits increases, this is likely to result in changes in the balance of care. This has also created new job roles in the long-term care area, such as personal assistants and the development of brokerage services to help individuals in their new roles as employers.

Care is also partly funded by individual service users, through direct private purchase of services and through user charges for local authority services. Private long-term care insurance is minimal.

The regulator for long-term care services is the Care Quality Commission. This was set up in 2008 and was formed through the merger of the CSCI, which only covered social care services, and the Healthcare Commission, which covered health care services. Its role is to regulate, monitor and improve the quality of health and social care. It is responsible for the registration and inspection of specified services (those providing health or personal care). National Minimum Standards (NMS) for care were introduced in the early 2000s as a tool to improve the standard of care services. They have been updated recently to focus the standards on outcomes for people. The NMS form the basis for the inspection of services and the performance assessment of commissioning departments, and more recently provider organisations. Performance assessments are based on diverse information, including interviews with staff and service users, information given to the CSCI by the care service, surveys filled in by service users, their relatives and other professionals involved in their care, a key inspection visit by CSCI inspectors (normally unannounced) and information the CSCI holds about the history of the service. The resulting assessment for providers (but not commissioning departments as of 2008) is summarised as a quality (star) rating. In May 2008 the CSCI rated as good or excellent 80% of services in the voluntary sector, 79% of council-run and 66% of services in the private sector. Of care homes for older persons, 67% were rated as good or excellent, 28% as adequate and 4% as poor. Among home care agencies, 73% were rated as good or excellent (CSCI, 2008). Notably, 22% of those moving permanently into homes for older persons arranged for them by the council did so to a home that was rated as 'poor' or 'adequate' (CSCI, 2008).

With regard to the NMS, services run by voluntary organisations perform better in relation to NMS than services run by other types of organisations. Care homes for older persons were meeting 82% of the standards in 2008, compared with 59% in 2003. Home care agencies were also meeting 82% of the standards in 2008. Nursing agencies met 87% of the standards.

## **1.5 Integration of LTC**

### *1.5.1 Integration within the LTC system*

In the UK the LTC system involves mostly social care services (or their cash equivalent), run by local authorities and overseen by the Department of Health, health care services (also run by the Department of Health), cash payments (the Attendance Allowance) by the Department of Work and Pensions, and housing, which is also a local authority responsibility and depends on the Department of Communities and Local Government. At present there is little integration among the different areas of responsibility. There have been many policy initiatives to address integration between health and social care (see the next section), and some initiatives – such as Supporting People, Extra Care Housing and Individual Budgets – to seek better integration in other areas, particularly housing and care. The 2009 Green Paper is consulting on integration of the Attendance Allowance and social care.

### *1.5.2 Integration with health and social services*

In the UK, the health and social care interface is between the NHS and local authority social services. This interface is also an interface between services that are free at the point of delivery and services that are means-tested. Since the 1980s, there has been a shift from services that are free at the point of delivery to services that are means-tested, as long-stay hospital provision has declined and residential care and nursing-home provision has increased.

There has been a long history of policies that aim at improving coordination between health and social care services. Recent policy developments have sought to promote collaboration across the boundary between health and social care, mainly at the local level, with the introduction of primary care trusts, pooled budgets and joint appointments. There is no evidence so far on whether these policy developments have improved coordination in practice.

In 2002 care trusts were introduced to provide better-integrated health and social care. By combining both NHS and local authority health responsibilities, care trusts can increase the continuity of care and simplify administration. At present there are only 5 care trusts in England, compared with 147 standard primary care trusts.

The National Health Service Act 2006 provided an enabling framework so that money can be pooled between health bodies and health-related local authority services, functions can be delegated, and resources and management structures can be integrated. The arrangements, which have been in use since April 2000 as a result of the previous Health Act 1999, allow for the joining-up of commissioning for existing or new services and similarly for the development of provider arrangements. One of the innovations of the NHS Act 2006 is the launch of a pilot programme to test and evaluate new models of integrated care. The programme seeks to empower clinicians, working closely with their partners to lead the testing of new integrated care models crossing boundaries across primary, community, secondary and social care. There are 16 pilots that will run for two years and will be evaluated.

In 2004 a 'single assessment process' was introduced for older persons across health and social care. This assessment includes physical and mental health and should be followed by an individual care plan involving health and social care services as required. These assessments are targeted at persons with complex needs, usually defined as having physical and mental health problems (Department of Health, 2002b). A research project measuring the percentage of multidisciplinary assessments in north-west England before and after the implementation of the single assessment process found that multidisciplinary assessments increased from 36% to 61% following implementation (Sutcliffe et al., 2008, p. 1300); however, they did not find an increase in the targeting towards persons with complex needs. Another study of a sample in Manchester found that the implementation of the single assessment process did result in an improvement in the identification of needs, suggesting that closer cooperation between health and social services has resulted in tangible improvements (Clarkson et al., 2009). The extent to which the single assessment process will lead to better collaboration by itself is under question, as more complex tools may be needed to prompt change, such as the implementation of structures that offer incentives that affect the way professionals operate (Abendstern et al., 2008).

An area where difficulties have arisen is delayed hospital discharge, where older persons are prevented from being discharged from hospitals because there are no alternative long-term care services in place. The government's Community Care (Delayed Discharges) Act 2003 introduced a system of cross-charges for local authorities where hospital discharge is prevented by lack of social services in the community. This is along the lines of the system introduced in Sweden in 1992. This measure was accompanied by grants aimed at supporting improvements in the transfer of care. The number of patients delayed and the number of beds 'blocked' due to delayed discharges have fallen since the introduction of the charging system, but there is a question as to whether this was simply the continuation of a trend predating the introduction of the system (in the context of overall reductions in the length of hospital stays) or whether the charging has had an impact. Research analysing the reasons for delays has shown that the majority of delays are due to the NHS rather than the availability of social services, but also that there was a sharp decline in the number of bed day delays due to social services at the time of the introduction of the charging system (Godden et al., 2009). It has been argued that, because

most hospitals chose to impose charges, those reductions were more likely to be the result of agreements to work cooperatively in using the delayed discharge grant to reduce delays (McCoy et al., 2007).

Another measure expected to improve difficulties in the hospital discharge system is the development of intermediate care services. These services will have a strong emphasis on rehabilitation and are expected to avoid unnecessary hospital admissions, to support early discharge and to reduce or delay the need for long-term residential care (Department of Health, 2001).

A further important development has been the Health and Social Care Act 2008 (Department of Health, 2008c), which brought together existing health and social care regulators into one regulatory body, the new Care Quality Commission, with tough new powers to ensure safe and high-quality services. As a result of the merger, the Care Quality Commission is currently re-developing its approach to inspection and performance review. They have also brought the performance framework together for health and social care into the outcomes and accountability framework and have explored joint health and social care indicators.

The recent Green Paper on care has given much emphasis to more coordinated work among health, housing and social care services and between social care and the disability benefits system. The paper describes a future “joined-up service, such that people will need to have only one assessment of their care needs to gain access to a range of care and support services which will work together smoothly” (HM Government, 2009, p. 9).

## 2. Funding

Health care services provided under the NHS are free at the point of delivery, irrespective of the financial means of users. They are financed almost entirely out of general central taxation. Services arranged by local authorities attract user charges depending on the user’s financial means (except for nursing costs in nursing homes and, in Scotland, nursing and personal care). Local authority expenditure is financed partly out of central taxation and partly out of local taxes. Older persons may also arrange and pay privately for their own residential or home care without involving a local authority. Only a very small number of persons, just under 22,000, had private long-term care insurance in 2008 (Association of British Insurers, 2009).

According to model estimates by the Personal Social Services Research Unit (PSSRU), in the year 2006 total expenditure on long-term care services for older persons in England amounted to just under €20 billion. Of this, 20.6% was funded by the NHS, 39.7% by local authorities (personal social services) and 39.7% by the individuals or their families (of which 10% stemmed from user charges and 29.7% from direct private expenditures) (Wittenberg et al., 2008). These figures do not include expenditure on long-term care by the charitable sector or the contribution of informal carers. They are broadly comparable to the public long-term care estimates used in the latest projections report of the European Commission’s Economic Policy Committee Ageing Working Group and DG Economic and Financial Affairs (2009), which estimates public long-term care expenditure for the UK in 2007 to be 0.8% of GDP. The PSSRU’s estimate for public expenditure on long-term care services in England in 2007 is for it to be 0.86% of GDP.

In recent years, how best to finance long-term care has been the subject of considerable debate in the UK. The reasons for this debate have included past and projected future demographic change, uncertainty about future levels of informal care provided by family and friends, and the community care reforms that took place in the early 1990s (Wistow et al., 1996, p. 161).

The government set up a Royal Commission, a high-level group, to review the financing of long-term care and make recommendations about its future financing. A key recommendation of the Royal Commission (Royal Commission on Long-term Care, 1999) was that the nursing and personal care components of the fees of care homes and home-based personal care should be met by the state, without a means test, and financed out of general taxation. Means-testing would remain for the accommodation and ordinary living costs ('hotel' costs) covered by residential fees and for help with domestic tasks. The UK government accepted many of the Royal Commission's recommendations but only agreed to remove the means test for nursing care in nursing homes in England (Secretary of State for Health, 2000). However, the Scottish Executive decided that it would make both nursing care and personal care free of charge, for residential care and home care. The National Assembly for Wales and the Northern Ireland Assembly have decided to fund only nursing costs free of charge.

The debate on long-term care funding in England continues and consultation is underway for a major reform of the system. The government is currently considering the development of a National Care Service that would give everyone who qualifies for care and support from the state an entitlement to at least some help meeting the cost of care and support needs (HM Government, 2009).

## 2.1 User charges and means tests

The current charging regime for residential and nursing home care in England takes into account the income and assets (in most cases including any housing wealth) of residents. Those with assets over an upper limit, currently set at approximately €27,000 in England, are not eligible for local authority support. Those with assets below this level are required to pay some of the costs of their care, with the amount depending mainly on their income. The NHS makes a non-means-tested contribution towards nursing costs in care homes.

Local authorities have discretion over how they charge for home care services, although there are national guidelines that set out common principles to which local authorities must adhere in determining how much to charge users. They must disregard a sum of income of at least 25% above the level of social security income maintenance benefits. The government funds a part of the nursing home fees that is meant to reflect the nursing input in the care provided.

In Scotland, there is no means test for nursing or personal care, either at home, in residential care or in nursing homes, as these are fully subsidised. The means test in Scotland relates only to 'hotel' costs. Both Wales and Northern Ireland are currently considering reforms to their funding systems.

## 2.2 Mechanisms for negotiating fees

In the UK the local authorities negotiate the fees that are paid to the providers of publicly subsidised residential care and home care services. As local authorities are in many areas the main purchaser of care from local providers, they have considerable market power to negotiate fees at relatively low levels. These fee levels seem to be a key reason for the recent decline in the numbers of residential care and nursing home places (Netten et al., 2002). As well as low fees, the reimbursement and contract arrangements (which consist of a lot of spot contracts) have also become a problem for providers (Knapp et al., 2001). Private residential care and nursing home providers often charge higher fees to individuals who fund their own care. This means that, effectively, privately funded residents are subsidising the care of publicly funded residents (Netten et al., 1998).

People who receive direct payments or individual budgets (or their representatives) negotiate the fees directly with the providers. Brokerage services are often used to help with this process.

### 3. Demand and supply of LTC

#### 3.1 The need for LTC (including demographic characteristics)

The most crucial determinant of the need for long-term care is disability, which is at the root of the need for help and support. As the probability of being disabled increases sharply with age, the number of older persons is often used as a proxy indicator of the need for long-term care.

In 2006 there were over 8 million persons aged 65 or older in England (representing 16% of the total population), of whom 2.3 million (4%) were aged 80 or older (Table 1).

*Table 1. Number of older persons (65 or older) in England (2006)*

Number of older persons by age and gender			
Age	Men	Women	Total
65-69	1,075,000	1,156,000	2,231,000
70-74	906,000	1,035,000	1,941,000
75-79	714,000	924,000	1,638,000
80-84	476,000	746,000	1,222,000
85+	324,000	731,000	1,055,000

*Source:* Government Actuary's Department (2007).

The PSSRU macro model (Wittenberg et al., 2008), is a cell-based simulation model that makes projections of future demand for long-term care services and associated expenditure, combining information from a number of surveys covering older persons in households and institutions. According to estimates from that model, in 2006 over 550,000 older persons were estimated to have a severe disability,<sup>2</sup> among whom just over 400,000 were women (Table 2). Overall, 1.8 million older persons were estimated to have moderate levels of disability.<sup>3</sup>

*Table 2. Estimated number of disabled older persons (percentages), England (2006)*

Men	No disability	Moderate disability	Severe disability
65-69	923,000 (85.9)	122,000 (11.3)	30,000 (2.8)
70-74	745,000 (82.2)	141,000 (15.5)	20,000 (2.2)
75-79	528,000 (73.9)	161,000 (22.6)	25,000 (3.5)
80-84	330,000 (69.4)	115,000 (24.2)	31,000 (6.5)
85+	136,000 (41.9)	148,000 (45.7)	40,000 (12.4)
All men	2,662,000 (76.2)	687,000 (19.7)	146,000 (4.2)

<sup>2</sup> Defined as needing help with two or more activities of daily living.

<sup>3</sup> Defined as having difficulties with instrumental or basic activities of daily living, or needing help with one activity of daily living.

Table 2. *cont'd*

<b>Women</b>	<b>No disability</b>	<b>Moderate disability</b>	<b>Severe disability</b>
65-69	958,000 (82.9)	169,000 (14.6)	29,000 (2.5)
70-74	778,000 (75.2)	220,000 (21.2)	37,000 (3.6)
75-79	615,000 (66.6)	257,000 (27.8)	52,000 (5.6)
80-84	412,000 (55.2)	254,000 (34.0)	80,000 (10.8)
85+	256,000 (35.0)	263,000 (35.9)	212,000 (29.0)
All women	3,019,000 (65.8)	1,163,000 (25.3)	410,000 (8.9)
All older persons	5,681,000 (70.3)	1,850,000 (22.9)	555,000 (6.9)

Sources: PSSRU model estimates (Wittenberg et al., 2008), based on data from the 2001/2 General Household Survey (GHS), the 2005 PSSRU survey of older care-home admissions, and Department of Health March 2006 data on residential care.

### 3.2 The role of informal and formal care in the LTC system (including the role of cash benefits)

#### 3.2.1 The role of informal and formal care in the LTC system

The long-term care system in England relies heavily on informal or unpaid care provided by family, friends or neighbours (Pickard et al., 2007). Approximately 85% of all older individuals with a functional disability<sup>4</sup> living in private households in England receive some informal care (Table 3). Of the 2 million disabled older persons living in private households in England, approximately 1.8 million receive some informal care.

Table 3. *Persons with a functional disability in private households aged 65 and older, by receipt of informal care, England (2006) (estimated numbers in thousands and column percentages)*

<b>Receipt of informal care</b>	<b>Number of disabled older persons</b>	<b>Percentage of disabled older persons</b>
Without informal care	295,000	14
With informal care	1,775,000	86
All disabled in households	2,068,000	100

Notes: Numbers are rounded to the nearest 5,000. Informal care is defined as help with domestic tasks.

Sources: PSSRU model estimates, based on data from the 2001/2 GHS and 2006 official population data.

<sup>4</sup> Defined as having either a moderate or severe disability (see previous two footnotes).

Receipt of informal care is closely associated with marital status and household type, because marital status and household type are important structural correlates of the availability of informal care (Pickard et al., 2000). Single persons living alone are less likely to receive informal care than those living as a couple or with others. The majority of disabled older persons in private households in England live with others, with approximately 60% living with others and 40% living alone (Table 4). Of those who live alone, approximately one in four do not receive informal care, compared with fewer than one in ten of those who live with others (Table 4). The majority of disabled older persons without informal care in private households live alone. Of the approximately 300,000 disabled older persons who do not receive informal care, approximately 200,000 live alone (Tables 3 and 4).

*Table 4. Persons with a functional disability in private households aged 65 and older, by marital status, household type and receipt of informal care, England (2006) (estimated numbers in thousands and column percentages)*

<b>Marital status, household type and receipt of informal care</b>	<b>Number</b>	<b>Column (%)</b>
Single, living alone, no informal care	205,000	10
Single, living alone, receives informal care	670,000	32
Single, living with child, receives informal care	160,000	8
Single, living with others, receives informal care	55,000	3
Couple, no informal care	75,000	4
Couple, receives informal care from spouse	695,000	34
Couple, receives informal care from child	100,000	5
Couple, living with others, receives informal care	110,000	5
All disabled in households	2,068,000	100

*Notes:* Numbers are rounded to the nearest 5,000. ‘Single’ refers to widowed, divorced, separated and never married persons who are not cohabiting; ‘couple’ refers to those living in legal or de facto partnerships.

*Sources:* PSSRU model estimates, based on data from the 2001/2 GHS and 2006 official population data.

Receipt of formal community care services is strongly associated with receipt of informal care and household type in England (Arber et al., 1988; McNamee et al., 1999; Evandrou, 2005). In general, older persons who live alone are more likely to receive formal services than those living with others (Evandrou, 2005). Logistic regression analysis using the 2001/2 General Household Survey (GHS) shows that, among disabled older persons, informal care and household type are significantly associated with receipt of formal community care services, including home care and private domestic help (Wittenberg et al., 2006; King et al., forthcoming). As illustrated further in section 3.4, the probability of receiving formal services in England is considerably lower when disabled older persons receive informal care than when they do not.

In effect, then, in England community care services are primarily directed at disabled older persons who do not receive informal care (see also section 3.4). The availability of informal care is taken into account in determining eligibility for service allocation, so that older persons with similar levels of disability do not receive the same amounts of formal service support. Therefore, unlike a number of other long-term care systems in Western Europe, the long-term care system in England is not ‘carer-blind’ (Pickard, 2001; Fernandez et al., 2009).

There has been increasing emphasis on support for informal carers in government policy in England over the last two decades (Beesley, 2006). Current policies are embodied in a new

national strategy for carers (HM Government, 2008). The policy emphasis is on provision of 'carer-support services' to enable informal carers to continue providing care. Since the mid-1990s, caregivers providing substantial and regular care in England have had the right to a local authority assessment of their needs for services and, since 2001, they have been entitled to receive services in their own right (Beesley, 2006). However, only a minority of 'heavy duty' carers receive assessments and only around one in ten receive carer-support services (Beesley, 2006). Indeed, viewed from an international perspective (Lundsgaard, 2005), the most important type of support offered to informal carers in England may not be the carer-specific services, on which policy has focused over the past 20 years, but a longer-established cash benefit for carers, described in the next section.

### 3.2.2 *The role of cash benefits in the LTC system in England*

#### *Cash benefits for disabled/older persons in lieu of service*

Direct payments are cash payments made in lieu of social service provision to individuals who have been assessed as needing services and are eligible for publicly funded support. They were made available to older persons in 2000. The level of a direct payment is calculated according to the amount of personal support needed by the individual and it is estimated with reference to the costs of equivalent services in kind. Direct payments are commonly used by recipients to employ a personal assistant or helper to provide the support they need. The employment of close relatives living in the same household is not allowed, except in exceptional circumstances. The purchase of services from the local authority is not allowed either. Numerous barriers to the take-up of direct payments have been identified, including the restrictions on the use of the payments.

In 2005 a new system of individual budgets (IBs) was introduced that would bring together, for any individual, the resources from a number of different services or funding streams to which he or she is entitled. These resources include local authority funding for social care, community equipment and housing adaptations and other disability-related benefits (but not the Attendance Allowance or NHS funding). An IB would pool these resources for any one person and the total amount would be made transparent to the individual. The budget can be used to secure a flexible range of goods and services, from a wider variety of providers than is possible with direct payments. For example, the IB can be used to pay informal carers living in the same household, or to purchase goods or services from local authorities. The Department of Health set up IB pilots in 13 English local authorities for different client groups and commissioned a national evaluation. IB resources were typically used to pay for personal care, domestic help and social, leisure and educational activities. Most people chose to purchase conventional forms of support. The evaluation found that those receiving an IB were significantly more likely to report feeling in control of their daily lives, welcoming the support obtained and how it was delivered, compared with those receiving conventional social care services. Overall, holding an IB was associated with better social care outcomes but older persons reported lower psychological well-being with IBs, perhaps because they felt the processes of planning and managing their own support were burdens (Glendinning et al., 2008).

#### *Other cash benefits for disabled/older persons (independent of receipt of services)*

The Attendance Allowance (and the Disability Living Allowance for those who continue to receive this benefit after the age of 65) is the main source of non-means-tested funding for older persons with disabilities. In 2006-07 these benefits paid out £5.3 billion. The Attendance Allowance is paid at two rates, depending on whether the older person needs assistance during the day (2006-07 £43.15 a week) and/or night (£64.50), and is not means-tested. In 2006, 1.2 million persons were receiving the Attendance Allowance in England. Eligibility for the Attendance Allowance is governed by the need for help or supervision, but the

claimant does not actually have to be in receipt of such support. It is a compensation for disability rather than a payment to cover the costs of services. There is concern that substantial numbers of disabled individuals are not claiming the benefits they are due, but an estimation of the take-up rate is hampered by the lack of information available on the size of the eligible population (Kasparova et al., 2007).

Analysis of data from the English Longitudinal Study of Ageing showed that only a minority (27%) of Attendance Allowance claimants used either state- or privately funded social care. Some 29% were receiving neither formal nor informal care (Wanless et al., 2006, p. 94).

#### *Cash benefits for informal carers: Carer's Allowance*

The long-term care system in the UK has been characterised as one in which there is “limited or average provision of formal home care but extensive financial support for informal care” (Lundsgaard, 2005). Financial support for informal care in this country takes the form of the Carer's Allowance, a cash benefit paid to carers providing long hours of informal care. The allowance, which amounts to £53.10 (approximately €62) a week, is paid to informal carers who provide at least 35 hours informal care per week, earn less than £95 (approximately €110) per week, are not in full-time education and look after someone who receives any of the qualifying disability benefits (such as the Attendance Allowance). The Carer's Allowance is based on a social security model of payments for care (Glendinning and McLaughlin, 1993) and is regarded by the Department for Work and Pensions as a compensation for loss of earnings, not as a wage for caring. There were approximately 365,000 recipients of the Carer's Allowance in England in 2005 and UK expenditure on the allowance was approximately £1.3 (€1.5) billion in 2007-08 (NAO, 2009). The Carer's Allowance (and its predecessor, the Invalid Care Allowance) has long been the subject of criticism in this country, primarily because of its low level, its poor coverage of heavily committed carers, its complexity and its failure to facilitate employment and caring (Pickard, 1999; NAO, 2009).

### **3.3 Demand and supply of informal care**

Both the demand for and supply of informal care are structured by the relationships between care-receivers and care-providers (Pickard et al., 2007).

The most important sources of informal care for individuals aged 65 and older with a functional disability in England at present are adult children and spouses. Of the 1.8 million disabled older persons living in private households who receive informal care in England, over 80% receive care either from a child or a spouse or both (Table 5). Of those receiving care from either a child or a spouse, just over half receive care from a child and just under half from a spouse. Slightly more disabled older persons in England therefore receive help from their children than from their spouses, although the difference is not great.

A central factor affecting sources of informal care for individuals aged 65 and older is their marital status (Pickard et al., 2007). The most important source of informal care for *single* older persons with a disability in England is their children, whereas the most important source of care for *married* disabled older persons is their spouse or partner (Pickard et al., 2007). However, there are more single than married older persons with a disability at present (Table 4), and this helps to explain the present balance between care by children and care by spouses. Another important factor affecting sources of informal care for older persons is their age. Reliance on help from children is much greater than reliance on help from spouses among the oldest old (those aged 85 and older) (Pickard et al., 2007). This is primarily because those aged 85 and older are much more likely to be single than married.

*Table 5. Persons with a functional disability in private households aged 65 and older, by sources of informal care, England (2006) (numbers in thousands and column percentages)*

<b>Receipt of informal care by source</b>	<b>Number of disabled older persons receiving informal care</b>	<b>Proportion of disabled older persons receiving informal care</b>
No informal care	295,000	14
Care from adult child	680,000	33
Care from spouse	675,000	33
Care from child + spouse	95,000	5
Care from others	320,000	16
All with informal care	1,775,000	86
All disabled in households	2,068,000	100

*Sources:* PSSRU model estimates, based on data from the 2001/2 GHS and 2006 official population data.

Future demand for informal care is likely to vary by source of care (Pickard et al., 2007, Wittenberg et al., 2008). The PSSRU's long-term care projections model suggests that the number of disabled older persons in private households receiving informal care will approximately double between 2005 and 2041, from around 1.75 million in 2005 to over 3.5 million in 2041 (Wittenberg et al., 2008). The number of disabled older persons receiving care from a spouse or partner is projected to increase faster than the number receiving care from an adult child, under base case assumptions. Yet care by children will still need to increase by roughly 90% over the next 35 years, if the proportion of disabled older persons (by age, gender and marital status) receiving care from their children is to remain the same as it is today (Wittenberg et al., 2008).

A key factor underlying the projected increase in demand for care by spouses is the projected increase in the number of older persons who are married or cohabiting in future years, which is itself due to the narrowing of gender differentials in life expectancy (Pickard et al., 2001, 2007). A key reason for the projected increase in demand for care by children relates to the very rapid increase in the oldest old population. Since the majority of the oldest old will continue to be single in 2031, and because single persons rely on their children more than on any other source of informal care, the implication of the very rapid increase in the oldest old population is that demand for care by children will also rise rapidly (Pickard et al., 2007).

On the supply side, there are currently approximately 5.8 million persons providing informal care in Britain, of whom around 4 million are caring for older persons (Maher and Green, 2002; Wanless et al., 2006 p.138). The form of care that is most relevant to disabled older persons is likely to be 'intense care', provided for 20 hours a week or more (Pickard et al., 2007). Currently, approximately 4% of the adult population provide care for 20 hours a week or more (Pickard et al., 2007), constituting around 1.5 million persons in England, although not all of these provide care to older persons.

Because concerns about the future supply of informal care focus particularly on care by adult children (Allen and Perkins, 1995; Evandrou and Falkingham, 2000), research attention has focused on estimating the number of carers providing intense care to older parents (Pickard, 2002, 2008). Based on analyses of the 2000-01 GHS data on provision of informal care, it has been estimated that there are roughly 400,000 individuals providing care for 20 hours a week or more to older parents in England (Pickard, 2008). Of these, approximately 65% are women, with around a quarter of a million women providing intense intergenerational care, compared with around 135,000 men (Pickard, 2008). Nearly 90% of those providing intense care to parents are

under the age of 65, with around 350,000 men and women aged between 30 and 64 providing this form of care (Pickard, 2008).

The future supply of informal care is likely to vary by source of informal care. The number of spouse-carers is likely to increase in the coming decades and is likely to keep up with increased demand for care (Pickard et al., 2000, 2007). The marked increase in spouse care here does, however, raise some questions about the future supply of care by spouses. PSSRU estimates suggest that, over the next 30 years or so, there is likely to be a four-fold increase in receipt of spouse care by the oldest old in England and there will be nearly a quarter of a million disabled persons aged 85 and older receiving care from a spouse/partner (Pickard et al., 2007). Since the oldest old are likely to have spouses/partners of similar ages as themselves, this raises questions over whether the oldest old will be able to provide care to this extent or whether it is fair to expect this (Pickard et al., 2007).

There are nonetheless greater concerns about the future supply of informal care by the adult children of older persons. The number of carers providing intense care to older parents is projected to increase by 27.5% between 2005 and 2041, with the number rising from around 400,000 in 2005 to around 500,000 in 2041 (Pickard, 2008). This projected increase in the number of people providing intense care to older parents is considerably lower than the projected increase in demand for care from children by disabled older persons. As already observed, the number of disabled older persons in receipt of care from their children under the assumptions of the PSSRU model is projected to increase by around 90% between 2005 and 2041 (Wittenberg et al., 2008). Indeed, the demand for informal care by disabled older persons is projected to exceed supply by 2017, with the 'care gap' widening over the ensuing years (Pickard, 2008). By 2041, the gap between the number of individuals projected to provide informal care and the number needed to provide care if projected demand is to be met amounts to nearly 250,000 care-providers (Pickard, 2008).

A key reason the supply of informal care to older persons by their adult children is unlikely to keep pace with demand the underlying demographic trends (Pickard, 2008). Around 90% of those who provide care to their older parents are themselves under retirement age and it is well known that 'old-age dependency ratios' are due to rise sharply in the next 30 years (Pensions Commission, 2004). If the probability of providing care to older parents remains unchanged, it is very likely that demand for care by older persons will exceed the supply of care by the succeeding generation.

### 3.4 Demand and supply of formal care

The estimated numbers of older individuals receiving care services on a given day in 2006-07 are shown in Table 6.

*Table 6. Estimated number of older persons receiving services on a given day, by service type and age, England (2006-07)*

<b>Service</b>	<b>Number of users</b>	<b>% of older population</b>
Day care	93,000	1.15
Meals	229,000	2.83
Local authority-arranged home care	293,000	3.62
Respite care	24,000	0.30
Private home care	150,000 <sup>a)</sup>	1.86
Community nursing	445,000 <sup>a)</sup>	5.50

Table 6. *cont'd*

Direct payments	18,000 <sup>b)</sup>	0.22
Professional support	101,000	1.25
Equipment and adaptation	136,000	1.68
Independent sector residential care	179,000	2.21
Local authority residential care	22,000	0.27
Nursing care homes	127,000	1.57
Long-stay hospital	9,000	0.11
All in institutions	337,000	4.17

<sup>a)</sup>Estimates from the PSSRU LTC model, based on levels of service receipt reported in the 2001/2 General Household Survey. Note that the private home-care definition solely includes persons who need help with one or more activities of daily living. Using a broader definition (including help with domestic tasks), the total number of users of private home help would be 875,000, or 10.82% of the older population.

<sup>b)</sup> 27,000 in 2007-08

*Note:* There is overlap of home-based services.

*Source:* Department of Health (2008b), p. 6.

### 3.4.1 Institutional care

There are three main types of institutional care, in the UK: residential care homes, nursing homes and long-stay hospital provision (although the formal distinction between residential care and nursing homes was removed from April 2002). Some residential homes are run by local authorities, but most residential care homes and all nursing homes are in the independent sector. Nursing homes provide nursing care and personal care, while residential care homes provide personal care. Long-stay hospital provision is part of the NHS. It has been diminishing and is now at a low level. There is potential for short-stay intermediate care to become a significant element, as the number of places available grows.

In recent years there has been an increase in the number of privately run homes and a drop in the number of places in the voluntary sector (Table 7). There is also evidence of corporate and larger owners becoming more dominant in the market (Philpot, 2008). In 2008, in England there were 10,383 registered care homes for older persons with a total of 361,164 places. Over 40% of persons living in care homes for older persons were identified as having particular needs as a result of dementia (CSCI, 2009). Lately there has been a marked increase in the average severity of disability of those in institutions (Darton et al., 2006). There are concerns that the providers of care homes are facing steep increases in costs owing to, among other factors, the increases in the care needs of residents and the costs of meeting standards. The fees paid by local authorities are not keeping up with the rise in the costs of care homes, raising concerns that homes may have to close.

Table 7. *Ownership of care homes by type of ownership and share (includes services to all adults)*

Type of ownership	Care homes (%)
Private	73.6
Council	6.1
Voluntary	18.0
NHS	0.9
Other	1.4

*Source:* CSCI (2009), p. 58.

In 2003 the government introduced funding for the development of ‘extra care housing’ places (or very sheltered housing) aimed at meeting the housing, care and support needs of older persons, while helping them to maintain independence in their own private accommodation. Most extra-care housing schemes offer a range of services and facilities such as social centres, restaurants, day care and intermediate care. Residents in extra-care housing either rent, own or partly own their homes, enabling people to safeguard their financial assets. Most individuals move there in anticipation of future care needs (Darton et al., 2008).

In 2008 there were just under 41,200 extra-care dwellings in England (Elderly Accommodation Counsel, 2008); the number of residents would be higher than this as many of these dwellings are occupied by couples (Darton et al., 2008). Of these dwellings, 77% were rented (either from a local authority or a social sector landlord) and the rest were owned by the residents (Elderly Accommodation and Counsel, 2008).

Eborall and Griffiths (2008) have estimated that in the year 2006-07, there were 635,000 persons working in institutional care for adults (p. 27).

### 3.4.2 Home care

Most home care is provided by home care agencies, the majority of which (75%) are private. Nearly 14% are run by local authorities and 8% are run by non-profit organisations (CSCI, 2009). In the last ten years there have been some major changes in home care in England. There has been a substantial decrease in local authority direct provision, accompanied by a major expansion of private sector provision (see Table 8). The total number of home care hours arranged by local authorities (for both the old and young) has increased markedly, from just under 2.7 million in 1999 to just over 4 million in 2008. However, the number of recipients of care has decreased, from 415,000 in the year 2000 to 341,000 in 2008, as services have been increasingly targeted at those with the highest levels of need. The average number of contact hours has increased, reflecting the higher levels of need of service recipients (see Table 9).

Table 8. *Estimated number of contact hours of home care provided by sector, all adults (1999 to 2008)*

<b>England, survey week during September rounded numbers</b>	<b>All sectors</b>	<b>Local authorities</b>	<b>Independent</b>
1999	2,684,000	1,324,000	1,360,000
2000	2,791,000	1,241,000	1,550,000
2001	2,882,000	1,162,000	1,720,000
2002	2,983,000	1,079,000	1,905,000
2003	3,175,000	1,044,000	2,131,000
2004	3,359,000	1,022,000	2,337,000
2005	3,577,000	952,000	2,625,000
2006	3,726,000	920,000	2,806,000
2007	3,874,000	843,000	3,031,000
2008	4,083,000	764,000	3,319,000

Source: NHS Information Centre (2009).

Table 9. *Estimated number of service users receiving publicly arranged home help and average number of contact hours per household per week, England (1999 to 2008)*

<b>Year</b>	<b>Estimated number of service users receiving home help</b>	<b>Average number of contact hours per household per week</b>
1999	–	6.3
2000	415,000	7.0
2001	396,000	7.5
2002	382,000	8.1
2003	374,000	8.7
2004	367,000	9.1
2005	368,000	10.1
2006	359,000	10.8
2007	347,000	11.6
2008	341,000	12.4

Source: NHS Information Centre (2009).

#### *Who receives the services?*

Our own analysis of the General Household Survey 2001/2 carried out as part of the development of the PSSRU model provides evidence of the targeting of publicly funded services at individuals with very high levels of need and who lack informal care. It also shows how people are arranging care privately to cover the care gaps left by the public system (King et al., forthcoming).

As an example, Table 10 shows the probability of receiving home help (publicly arranged and publicly funded for those below the means test) and private help by people aged 80 or older. Individuals are categorised by three different levels of disability (being unable to perform one instrumental activity of daily living (IADL), being unable to perform one activity of daily living (ADL) without help and being unable to perform two ADLs without help) and two combinations of household type and receipt of informal care (living alone with no informal help and living as a couple and receiving informal help from a spouse). The probabilities shown are the estimated logit fitted values of analysis of receipt of services by age, disability, household type and receipt of informal care and housing tenure (used as a proxy for economic status). Gender was not found to be significant. Further detail of this analysis is available in King et al. (forthcoming).

Table 10. Probability of receiving home help and private help by persons aged 80 or older, England 2001-02 in three disability categories and two household/receipt of informal care groups

		Probability of receipt of home help	Probability of receipt of private help	
		(Tenure not significant)	Home owner	Tenant
<b>Cannot perform 1 or more IADLs</b>	Living alone with no informal care	14.9	67.9	43.9
	Living as couple and spouse provides informal help*	3.2	15.1	6.2
<b>Cannot perform 1 ADL without help</b>	Living alone with no informal care	36.8	71.9	48.7
	Living as couple and spouse provides informal help*	9.8	17.7	7.4
<b>Cannot perform 2 or more ADLs without help</b>	Living alone with no informal care	68.8	81.8	61.8
	Living as couple and spouse provides informal help*	29.1	26.8	11.9

\* 'Spouse care' illustrates the negative effects of receipt of high levels of informal care on the receipt of formal services in England. Another group with similarly low levels of formal service receipt are those receiving co-resident care from adult children.

Source: Analysis of the General Household Survey, 2001/2.

The table shows how receipt of publicly arranged/funded services is very much concentrated on those with very high levels of need and no informal care support, as the result of a policy of targeting services. Yet it also shows that public services are not meeting the needs of individuals with substantial levels of disability (including those who cannot perform one ADL without help), even when they are not receiving informal care. There is high reliance on private help that increases with the level of disability and especially among those with no informal care who own their own homes, suggesting that those who can afford to are having at least part of their care needs met by purchasing private help. But on the other hand, it is of concern that there are likely to be persons with substantial levels of care needs, no informal care and low economic resources whose care needs will be left unmet. And the figures also suggest that spouse carers (who are likely to be elderly themselves) are getting very little support from the system. These concerns about the system have been raised repeatedly (for example, in Wanless et al., 2006), and the government's new consultation does acknowledge that they need to be addressed (HM Government, 2009).

In 2006-07 there were over 320,000 persons employed in the provision of domiciliary care of adults (Eborall and Griffiths, 2008, p.27). There are no official waiting lists for care homes.

## 4. LTC policy

### 4.1 Policy goals

The government states, in its new Green Paper on social care the aim of achieving a system that is "fair, simple and affordable for everyone, underpinned by national rights and entitlements but personalised to individual needs" (HM Government, 2009, p.9).

In the last few years the government has pursued a policy of 'personalisation' across the whole of public services, putting emphasis on choice and control. In the area of social care this has been reflected in the expansion of direct payments to more user groups and the piloting of individual budgets (Box 2).

*Box. 2. Recent LTC policy changes in England*

## 1990 Caring for People

- The local authorities' role shifted from the direct provision of services to commissioning and procurement.

## 1990 NHS and Community Care Act

- Transferred funding from the benefits system to the councils.

## 1996 Community Care (Direct Payments) Act

- Established the right to receive the cash equivalent.
- Initially applied to younger adults, but it was expanded to older adults in 2003.

## 1998 White Paper on 'Caring for People'

- Stated that the goals of the system are to help people achieve and maintain independence.
- Established fines for councils whose lack of provision of long-term care resulted in people staying in a hospital longer than necessary (delayed discharge).
- Developments took place on the model of intermediate care.

## 1999 Health Act: Removed obstacles to joint health and social care provision by enabling

- pooled budgets,
- lead commissioning, and
- integrated provision.

## 2000 Care Standards Act

- Established the Commission for Social Care Inspection (a single, independent inspectorate for all social care services in England).
- Attributed responsibility for registering local care services.
- Established the General Social Care Council, the social care workforce regulator.

## 2001 Charging

## 2001 National Service Framework for Older People

- Set standards for the care of older persons, with a focus on
  - rooting out age discrimination,
  - providing person-centred care,
  - promoting older persons' health and independence, and
  - fitting services around individuals' needs.

## 2002 Fair Access to Care Services

- Set out a national framework for eligibility criteria to address inconsistencies across the country.
- Aimed at assuring that people with similar needs achieve similar outcomes, irrespective of the services provided to meet eligible needs.

## 2003 Community Care/Delayed Discharges Act

- NHS hospitals can charge councils a daily tariff for patients who continue to occupy a hospital bed after being passed medically for discharge, due to delays in the provision of social services.
- New pilots set up to bring health and social care together.

## 2005 Social Care Green Paper

- Defines outcomes for social care:
  - improved health,
  - improved quality of life,
  - making a positive contribution,
  - exercise of choice and control,
  - freedom from discrimination and harassment,
  - economic well-being, and
  - personal dignity.

## 2007 National Framework for Continuing Health Care

- Attempted to address the long-standing difficulties in defining the boundary between NHS-funded continuing health care and means-tested social care.
- Resulted in an increase in the numbers of persons supported by the NHS from 7,000 to 31,000.

## 2009 Green Paper. Putting People First

### 4.3 Recent reforms and the current policy debate

During 2008, the government ran a six-month engagement process on the care and support system in England. This involved seeking the views of the public, service users and staff. It was followed in July 2009 by the publication of the Green Paper, *Shaping the Future of Care Together* (HM Government, 2009), which sets out the government's proposals for ways to reform the care and support system for adults in England. The Green Paper lists a number of "challenges" within the current system, including the following issues: many people do not get help from the state towards paying for their care and support; state-funded care and support is often provided only when individuals have already developed high levels of need (therefore preventative opportunities are missed); individuals with the same needs receive different levels of care depending on where they live; the different parts of the care and support system do not work together; the care system as a whole is confusing and the system is not tailored to people's needs (HM Government, 2009). These 'challenges' within the social care and support system in England have been described in some detail in the first part of this paper.

The Green Paper states the government's intention to build the first National Care Service in England. The vision is "for a system that is fair, simple and affordable for everyone, underpinned by national rights and entitlements but personalised to individual needs" (HM Government, 2009, p. 9). The proposals extend beyond the financing system, to cover the following aspects:

- prevention services, encompassing free support to stay well and as independent as possible;
- national assessment, which will give individuals the right to have their care needs assessed in the same way wherever they live in England and to have the same proportion of their care and support costs met;
- a 'joined-up' service, such that people will need to have only one assessment of their care needs to gain access to a range of care and support services that will work together smoothly;
- information and advice to help people find their way around the care and support system;
- personalised care and support, with care and support designed around individual needs; and
- fair funding, where everyone who qualifies for care and support from the state will get help meeting the cost of care and support needs.

The Green Paper discusses five possible funding options:

- pay for yourself, under which there would be no support from the state;
- partnership, where everyone who qualified for care and support would be entitled to have a set proportion of their basic care and support costs met by the state, with that proportion inversely related to the person's resources;
- insurance, which would comprise the partnership system plus insurance for those wanting to purchase it;
- comprehensive, where everyone over retirement age who had the resources to do so would be required to pay into a state insurance scheme; and
- tax-funded system, which would provide free care that is funded from increased general taxation.

The Green Paper rules out the first and last of these options and consults on the other three. Because the first option is ruled out, the Green Paper is in essence proposing that "everyone who has high levels of care and support need gets *some* of their care and support paid

for by the state” (HM Government, 2009, p. 19, emphasis added). In this sense, the underlying model advocated in the Green Paper is the partnership approach. As the Green Paper puts it, “[w]e think that the Partnership option should be the foundation of the new system” (HM Government, 2009, p. 19). The questions then are whether, how far and by what financing mechanism, the remaining costs are met (HM Government, 2009, p. 19).

Initial responses to the Green Paper suggest that there is likely to be general approval for a National Care Service, but that consultation related to the Green Paper is also likely to raise a number of issues for debate (Community Care, 2009; Health Service Journal, 2009; Age Concern/Help the Aged, 2009; Scope, 2009). One area is likely to be the proportion of care and support needs to be met by the state in either a partnership- or insurance-based option. The Green Paper suggests that the state might meet, for example, a quarter to a third of basic care and support costs (HM Government, 2009, p. 17). This falls considerably short of the two-thirds of the “benchmark level of care” that Wanless et al. suggested should be met by the state (Wanless et al., 2006). Another area of contention is likely to be the Green Paper’s suggestion that the Attendance Allowance could be integrated into the care and support system (HM Government, 2009, p. 15), a suggestion to which a number of ‘stake-holder’ organisations have already indicated their opposition (Scope, 2009; Age Concern/Help the Aged, 2009). A third area of potential concern is likely to be the ruling out of taxation as a means of funding the proposed National Care Service and the confinement of the funding options to contributions from older persons alone. The leading organisation representing older persons in England has argued instead that “costs must be shared fairly across the generations” (Age Concern/Help the Aged, 2009). Finally, the treatment of informal care in the Green Paper may also lead to debate. Although there is little reference to policy for carers in the Green Paper, its proposals are likely to have consequences for informal care. Because the foundation of the proposals in the Green Paper is a partnership approach (HM Government, 2009, p. 19), and because a partnership approach is not “carer-blind” (Wanless et al., 2006, p. 246), not all the options proposed in the Green Paper would necessarily address concerns, recently expressed, about the dependence of the care and support system on the availability of informal care (Himmelweit and Land, 2008; Glendinning and Bell, 2008).

#### **4.4 Critical appraisal of the LTC system**

The existing system is not considered sustainable because of the impact of changing demographics and expectations. The system is also widely considered to be unfair, both because some people receive no formal help at all (due to either the means tests or their receipt of unpaid care) and because there is a great deal of local variation.

The recent Green Paper lists a number of “challenges” of the current system (HM Government, 2009):

- Many individuals do not get help from the state towards paying for their care and support.
- State-funded care and support is often provided only when people have already developed high levels of need (therefore preventative opportunities are missed).
- People with the same needs receive different levels of care depending on where they live.
- The different parts of the care and support system do not work together.
- The care system as a whole is confusing.
- The system is not tailored to people’s needs.

There also concerns that the current economic recession will have an impact on the supply of care home places as independent providers close their businesses as a result of economic pressures (Carvel, 2009).

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## **About the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science**

The PSSRU conducts research and policy analysis aimed at the improvement of equity and efficiency of community-based health and social care services. The PSSRU was established at the University of Kent at Canterbury in October 1974, and in 1996 became a multi-site unit with additional branches at the London School of Economics (LSE) and at the University of Manchester. The director at LSE is Professor Martin Knapp. The branch at the LSE joined the distinguished Department of Social Policy. The School has a unique reputation for depth and breadth in British Social Science, with a long history of policy impact.

The PSSRU carries out policy analysis, research and consultancy in the UK and abroad. Contributions of various kinds are also made to teaching at LSE and elsewhere. The programme of research focuses on needs, resources and outcomes in social and health care, with particular interest at the LSE in economic aspects of community care, residential and nursing home provision, social care markets, long-term care finance, commissioning and mental health policy and practice. Much of the PSSRU research, consultancy and policy analysis is focused on community health and social care, but the Unit also works on other areas such as in-patient health care, housing and criminal justice services.

With the core research activities, there is a long-established programme of work on long-term care finance. The Long-term Care Finance programme is concerned with arrangements for funding long-term care for older people in England. It has produced a simulation model to make projections to 2041 of numbers of disabled older people, long-term care services, and public and private expenditure on long-term care. The research team have in the last three years produced reports with long-term care projections for the UK Department of Health, National Assembly for Wales, Disability Rights Commission, Joseph Rowntree Foundation, Wanless Social Care Review, Alzheimer's Research Trust, Nuffield Foundation and a number of individual local authorities. It has also provided advice to the European Commission (DG ECFIN) on methods of producing projections for EU Member States. The Long-Term Care Finance team is currently developing and expanding the range of scenarios that it investigates in terms of trends in disability rates, patterns of informal (unpaid) care, and workforce implications, as part of its work for the Department of Health.

The PSSRU publishes an annual PSSRU Bulletin and a number of papers, monographs and books.

# ANCIEN

## Assessing Needs of Care in European Nations



*FP7 HEALTH-2007-3.2-2*

**L** launched in January 2009, ANCIEN is a research project financed under the 7th EU Research Framework Programme. It runs for a 44-month period and involves 20 partners from EU member states. The project principally concerns the future of long-term care (LTC) for the elderly in Europe and addresses two questions in particular:

- 1) How will need, demand, supply and use of LTC develop?
- 2) How do different systems of LTC perform?

The project proceeds in consecutive steps of collecting and analysing information and projecting future scenarios on long term care needs, use, quality assurance and system performance. State-of-the-art demographic, epidemiologic and econometric modelling is used to interpret and project needs, supply and use of long-term care over future time periods for different LTC systems.

The project started with collecting information and data to portray long-term care in Europe (WP 1). After establishing a framework for individual country reports, including data templates, information was collected and typologies of LTC systems were created. The collected data will form the basis of estimates of actual and future long term care needs in selected countries (WP 2). WP 3 builds on the estimates of needs to characterise the response: the provision and determinants of formal and informal care across European long-term care systems. Special emphasis is put on identifying the impact of regulation on the choice of care and the supply of caregivers. WP 6 integrates the results of WPs 1, 2 and 3 using econometric micro and macro-modelling, translating the projected needs derived from WP2 into projected use by using the behavioral models developed in WP3, taking into account the availability and regulation of formal and informal care and the potential use of technological developments.

On the backbone of projected needs, provisions and use in European LTC systems, WP 4 addresses developing technology as a factor in the process of change occurring in long-term care. This project will work out general principles for coping with the role of evolving technology, considering the cultural, economic, regulatory and organisational conditions. WP 5 addresses quality assurance. Together with WP 1, WP 5 reviews the policies on LTC quality assurance and the quality indicators in the EU member states, and assesses strengths, weaknesses, opportunities and threats of the various quality assurance policies. Finally WP 7 analyses systems performance, identifying best practices and studying trade-offs between quality, accessibility and affordability.

The final result of all work packages is a comprehensive overview of the long term care systems of EU nations, a description and projection of needs, provision and use for selected countries combined with a description of systems, and of quality assurance and an analysis of systems performance. CEPS is responsible for administrative coordination and dissemination of the general results (WP 8 and 9). The Belgian Federal Planning Bureau (FPB) and the Netherlands Bureau for Economic Policy Analysis (CPB) are responsible for scientific coordination.

*For more information, please visit the ANCIEN website (<http://www.ancien-longtermcare.eu>).*