



Health systems and long-term care for older people in Europe  
Modelling the interfaces and links between  
prevention, rehabilitation, quality of services and informal care

## **Prevention and rehabilitation in the long-term care system**

### **National Report England**

**Kerry Allen | Jon Glasby**

Birmingham | September 2009

European Centre for Social Welfare Policy and Research (AT) • Ecole d'études sociales et pédagogiques (CH) • University of Southern Denmark (DK) • National Institute for Health and Welfare – THL (FI) • Institut de Recherche et Documentation en Economie de la Santé – IRDES (FR) • Institut für Soziale Infrastruktur (DE) • Wissenschaftszentrum Berlin für Sozialforschung – WZB (DE) • CMT Prooptiki ltd. (EL) • University of Valencia – ERI Polibienestar (ES) • Studio Come S.r.l. (IT) • Stichting Vilans (NL) • Institute for Labour and Family Research (SK) • Institute of Public Health (SI) • Forum for Knowledge and Common Development (SE) • University of Kent – CHSS (UK) • University of Birmingham – HSMC (UK)



Funded by the European Commission  
under the Seventh Framework Programme  
Grant agreement no. 223037

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# 1 Introduction and background

The UK health system incorporates four separate National Health Systems for England, Wales, Scotland and Northern Ireland. Each system operates independently, and is politically accountable to the relevant devolved government of Scotland ([Scottish Government](#)), Wales ([Welsh Assembly Government](#)) and Northern Ireland ([Northern Ireland Executive](#)), and to the [UK government](#) for England. This report will concentrate on policy and services in England, although some of the underlying issues will also be relevant for other parts of the UK. While the main body of the report focuses primarily on issues of rehabilitation and prevention, some later sections concentrate on more generic features of the English system in order to provide an overview for other EU countries working on the Interlinks project.

## 1.1 Demographic starting point

Reflecting the overall European trend, the UK population aged 65 and over is increasing. In 2006 there were 9,696,655 people aged 65 and over in the UK (16% of the overall population), as compared with 10 years before when this population was 9,221,204 (an increase of 475,451 people). Within this time frame the life expectancy of people living in the UK has also risen significantly; from 79.5 years to 81.7 years for women and from 74.3 years to 77.3 years for men. However, within the UK there is evidence that although older populations are growing they are also staying healthier for longer. For women, average healthy life years have risen from 61.8 years in 1996 to 65 years in 2005 and for men they have risen from 60.8 years to 63.2 years within the same period<sup>1</sup>. Of particular relevance to long term care (LTC) is that the population over 85 years is forecast to rise 12% between 2006 and 2012 and 45% by 2022.

## 1.2 Organisation and delivery

In English health and social care, there is growing recognition of the need to more fully embed prevention and rehabilitation in services for older people. Historically, many current services were established following the Second World War with a particular focus on providing a basic safety net for those in severe need. In the words of William Beveridge, one of the key architects of the post-war welfare state, the aim of services was to tackle “five giants” (or serious social problems). As Table 1 suggests, his language would not be used today, but the concepts and responses which Beveridge outlined remain as relevant now as they were then. From the beginning, therefore, the health care system in particular was focused on meeting the needs of people with an *immediate crisis* in their health. While the English NHS has often been criticised for being a ‘sickness service’ rather than a more positive and proactive ‘health service’, its origins in the 1940s desire to tackle the ‘giant’ of ‘disease’ make this more understandable.

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<sup>1</sup> All data Eurostat: ‘Proportion of population aged 65 and over’; ‘Total population, by age’; ‘Healthy life years and life expectancy at birth, by gender’. Data extracted 30 June 2009.

**Table 1** The origins of English welfare services

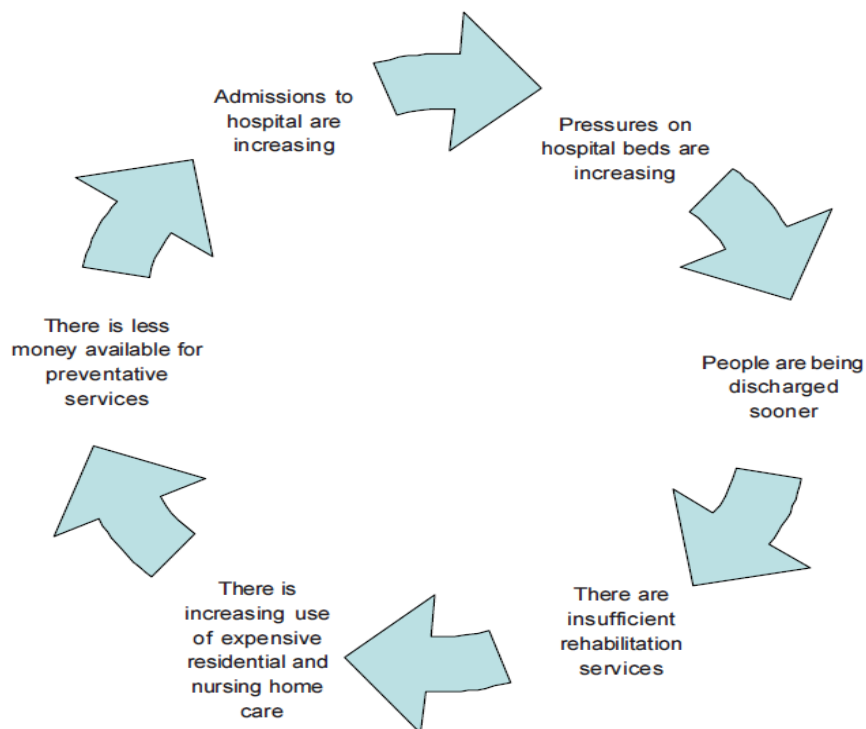
<i>Beveridge's 'five giants'</i>	<i>2009 concepts</i>	<i>Government response/departments</i>
'Want'	Poverty/social exclusion	Social security
'Disease'	Health and well-being	NHS
'Ignorance'	Commitment to education and life-long learning	Education
'Squalor'	Neighbourhood renewal	Housing and regeneration
'Idleness'	Meaningful employment and recreation	Employment and leisure

Source: Glasby, 2008.

Building on this legacy, UK welfare services have tended to have something of a crisis focus, targeting resources on those in greatest need. Because of their historical origins, moreover, many current health and social services have developed from an institutional background, with the main focus of the system on large, resource-intensive services such as hospitals and care homes. While a series of more community-based services began to develop from the 1960s onwards, the emphasis has still primarily been on meeting the needs of people in crisis.

### 1.3 Cultural context: attitudes to ageing/older people and their care needs

More recently, a series of social and demographic changes, advances in technology and changing public expectations have led to increased calls for a change in emphasis (see, for example, HM Government, 2007, 2008). With rising numbers of very frail older people both now and in the future, there is growing recognition that the system has too often concentrated *only* on those with the greatest and most complex needs, leaving less and less resource to meet lower-level needs (before a crisis occurs in someone's health and they qualify for formal support). At its worst, this has led to the counter-productive situation where people only requiring a small amount of support to remain independent have been denied access to assistance until a major crisis has occurred and they become eligible for state support. This has been summarised by the government's Audit Commission (1997, 2000) in terms of a 'vicious cycle' (see figure 1). As hospital admissions rise, it is argued, lengths of stay decline, opportunities for rehabilitation are reduced, there is an increased use of expensive residential and nursing home care, and less money for rehabilitation/preventative services - thereby leading to more hospital admissions. To break out of this situation, there is a corresponding need to invest more fully and strategically in both prevention and rehabilitation – helping older people to stay healthier, more independent and more socially included for longer and to recover all these capacities as fully as possible when they do require hospital treatment.

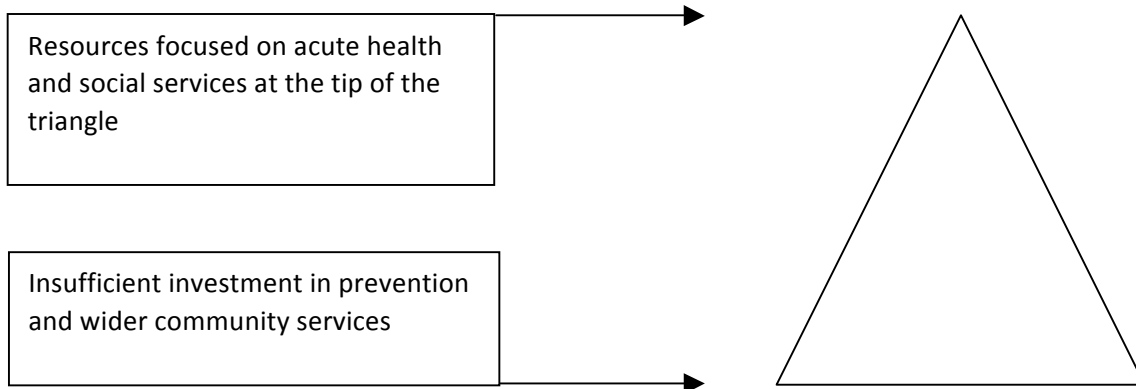
**Figure 1 The vicious circle**

Source: Audit Commission, 1997, 2000

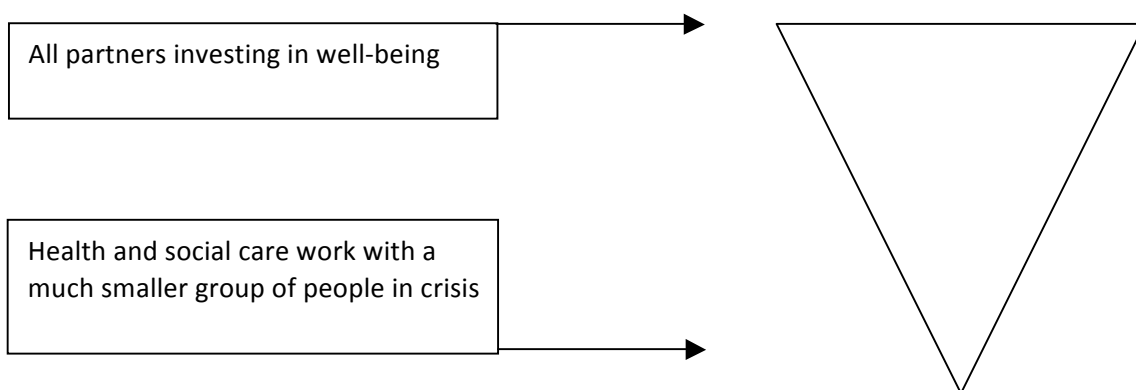
A similar approach has also been suggested by the former Association of Directors of Social Services and the Local Government Association, who emphasise the need to ‘invert the triangle of care’ (see figure 2). At present, it is argued, resources are most focused on a relatively small number of older people in crisis, with insufficient investment in preventative services. By inverting the triangle, it is hoped that services can begin to invest in preventative services for a larger number of older people, thus reducing future crises. A similar model has also been developed in health care, with a growing emphasis on meeting the needs of people with long-term conditions (or chronic diseases) and promoting more effective self-care (see below for further discussion). Attractive though these models are intuitively, they arguably remain largely aspirational, with insufficient evidence to back up some of the claims made and with little sign of the long-term political (and financial) support that might be needed to make such changes (see also Wanless, 2006 for more detailed discussion of future scenarios). Developing a more preventative approach has also been a stated aim of many governments over the years, and it is unclear why we might expect current and future policy to achieve this when previous attempts have arguably had only limited success. Despite this, prevention remains at the forefront of the policy agenda for older peoples’ services. In July 2009, the Department of Health published a ‘Prevention package for older people’ including: information on existing health ‘entitlements’ including sight tests, flu vaccination and cancer screening; best practice on falls prevention and fracture management; measures to improve access to affordable footcare services; updated intermediate care guidance; and summaries of progress on audiology and telecare (Department of Health, 2009).

**Figure 2 Inverting the triangle of care**

Now



Future



Source: ADSS/LGA, 2003.

## 1.4 Developments in English rehabilitation and prevention

In response to a series of social and demographic changes, health and social care for older people have gradually been refocused following a series of linked developments:

- The closure of long-stay hospitals.
- The growth of community-based services and a growing emphasis on 'care in the community' and 'care closer to home'.
- Rising emergency hospital admissions and a reduction in the length of hospital stays.
- Community services beginning to focus on a smaller number of people with more complex needs (with people discharged from hospital 'quicker and sicker').
- Increasing recognition of the interdependence of health and social care.

- The increased refocusing of traditional ‘home help’ services (assisting with housework and meals etc) as ‘home care’ services (focusing on the personal care of people with more complex needs) and as ‘re-ablement’ services (supporting more intensive rehabilitation).
- Increasing recognition of the needs of a growing number of older people with dementia.

Since the election of New Labour in 1997, key policies (explored in more detail below) have included:

- A series of approaches to improve the efficiency of acute care, often focusing on reducing the number of delayed hospital discharges experienced by older people.
- New intermediate care services to prevent admission to hospital, facilitate swift discharge and prevent premature admissions to care homes (including the development of re-ablement services).
- Greater emphasis placed on chronic disease management.
- Growing emphasis on the role of assistive technology.
- Pilots to develop new approaches to cross-cutting issues such as health inequalities and prevention.
- Longer-term (but often very unspecific) aspirations in more recent government documents to develop a more preventative approach.

#### **1.4.1 Hospital discharge**

Since 2000, a key aim of government policy has been to improve the efficiency and throughput of the acute sector and, in particular, to reduce the number of delayed transfers of care. Although a more detailed overview of government policy is provided by Glasby (2003) and Henwood (2004), this has long been a difficult area of policy and practice, often characterised by:

- Poor communication between hospital and community.
- Lack of assessment and planning for discharge.
- Inadequate notice of discharge.
- Inadequate consultation with patients and their carers.
- Over-reliance on informal support and lack of (or slow) statutory service provision.
- Inattention to the needs of specific groups such as people with dementia or people from minority ethnic communities.
- The risk of premature discharge, with some patients and health/social care practitioners feeling that individual patients have sometimes been discharged from hospital too quickly in order to make room for new patients.

More recently, a raft of government policies have begun to improve practice. Measures to date have included the publication of good practice guides, the creation of a national Change Agent Team to support improvements in front-line services and the provision of additional government funding to develop new services at the interfaces of community support and hospital admission and discharge. However, the most controversial policy was the introduction of ‘reimbursement’ (modelled on the Swedish approach, social services can be ‘fined’ by local hospitals if people are delayed in hospital for social care-related reasons). From the beginning, this has been a contested area of policy and practice – while some felt that this would help to concentrate the mind of local managers and provide appropriate incentives for swift discharge, others felt that it would undermine existing joint working and penalise one partner for a whole system issue.

Certainly, the number of delayed hospital discharges has reduced. In the second quarter of 2001-2002, there were an estimated 7,065 people whose discharge from acute hospital was delayed, representing six per cent of all acute beds (House of Commons Health Committee, 2002). Although it is difficult to calculate precise figures, it seems that the cost of such delays may have been in the region of £720 million per year. Since the full implementation of reimbursement in January 2004, a press release from the Health Secretary announced a “dramatic fall” in the number of delayed discharges (Department of Health, 2004, p.1). Between September 2001 and March 2004, the number of delays fell from 7,065 to 2,895 (a reduction of 59%). In the press release, this is described as saving the NHS the equivalent of eight hospitals. However, these figures tend to gloss over the fact that the biggest falls in the number of delayed discharges predated the reimbursement policy and may be linked more to extra funding provided in 2001 than the launch of reimbursement in early 2004. More recent research has also suggested that:

- It is problematic to ascertain which initiatives and aspects of the Community Care Act have contributed to the decline in delays in England because of the impact of other prior and concurrent measures, such as intermediate care and admission avoidance initiatives. Delays have also reduced in Scotland (which has not introduced reimbursement).
- Perceptions of the positive impact of the reimbursement initiative are dependent on the professional’s location within the system. While hospital managers and clinicians may welcome reimbursement, others are concerned about the potential to shift delays to other parts of the system and about inequities in access to follow-on services for groups such as older people with mental health problems.
- Despite dramatic falls in delayed hospital discharge since 2002, there are still some very lengthy delays, especially in complex cases. This suggests the need to move beyond incentivising rapid throughput towards greater investment in rehabilitation and ongoing care and support.
- Key operational differences made by reimbursement appear to be in clarifying processes for assessment and discharge and creating auditable systems to facilitate these. However, many professionals feel that there are disadvantages to this, as it has created a large amount of bureaucracy (Godfrey et al., 2008).
- Premature/inadequately supported discharge has been seen to lead to fluctuating increases in numbers re-admitted as an emergency within 28 days.

### 1.4.2 Intermediate care

From 2000-1, a key element of England’s approach to prevention and rehabilitation has been the development of intermediate care services – with an additional £900 million pledged by government (Department of Health, 2000a, 2001a). Although some of the specific services now badged as ‘intermediate care’ were often smaller pilot projects which pre-dated this announcement, almost all health and social care communities have been working to bring these together into a more coherent and explicit intermediate care system. Although details were initially scarce, intermediate care was essentially designed to prevent unnecessary hospital admissions, facilitate swift and timely hospital discharges and prevent premature admissions to permanent residential and nursing care. While the term ‘intermediate care’ is a broad one that is used to refer to a wide range of diverse services (including rapid response, Hospital at Home, step-up and step-down care home places, supported discharge, and residential/day rehabilitation), the essential characteristics shared by such services were subsequently set out in a government circular (Department of Health, 2001b – see also Department of Health, 2009), with intermediate care



described as services that met all the criteria in figure 3. Although intermediate care is a relatively new concept and area of service provision, there is now a growing evidence base to help begin to understand some of the many issues that this new way of working raises (see, for example, Martin et al., 2007; Regen et al., 2008; Kaambwa et al., 2008; Godfrey et al., 2005; Green et al., 2005). These include:

- Conceptualising a working model of intermediate care. Overall, one of the defining aspects of intermediate care may be that it is a 'bridging' service - between locations (home/hospital and vice versa), between individual states (illness to recovery or management of chronic illness) and between sectors (acute, primary, social care and housing).
- There is a need to move beyond 'services' alone when developing intermediate care to concentrate on the intermediate care 'system' (including issues such as eligibility criteria/referral processes, accessibility and workforce development).
- Within intermediate care, provision has tended to concentrate on supported discharge (rehabilitation in residential settings), with fewer services addressing admission avoidance (preventative in non-residential settings).
- Based on evidence from randomised controlled trials, rehabilitative care in community hospital locations is associated with greater independence for older people than care in district general hospital settings.

Updated guidelines for intermediate care published in July 2009 highlight new areas of interest within intermediate care. These include:

- Particular attention to users with dementia or mental health needs. Intermediate care teams should include or have easy access to mental health specialists. Flexibility on the six-week maximum time frame may be needed to accommodate the complexity of need and slower recovery times for this user group.
- Integration within mainstream health and social care. Intermediate care should function within the context of existing local health and social care services. Intermediate care teams should be continuously aware of developments and working closely with both mainstream health and social care services.
- The importance of ensuring that an appropriate governance framework is in place for intermediate care. Specific goals should be set such as acute admissions reductions as well as monitoring user experiences to ensure a high quality and user-centred service.

Overall, however, the jury is still out as to whether intermediate care, although a welcome concept, will be sufficient to rebalance the current health and social care system for older people (with a danger that it becomes something of an 'add on' to existing services, rather than a lever for transforming the system as a whole).

**Figure 3 Intermediate care – in principle**

**Intermediate care services:**

- Are targeted at people who would otherwise face unnecessarily prolonged hospital stays or inappropriate admission to acute inpatient care, long-term residential care, or continuing NHS inpatient care.
- Are provided on the basis of a comprehensive assessment, resulting in a structured individual care plan that involves active therapy, treatment or opportunity for recovery.
- Have a planned outcome of maximising independence and typically enabling patients/users to resume living at home.
- Are time-limited, normally no longer than six weeks and frequently as little as 1-2 weeks or less.
- Involve cross-professional working, with a single assessment framework, single professional records and shared protocols.

**1.4.3 Re-ablement**

Re-ablement is an emerging concept in the UK, with many local authorities increasingly refocusing their traditional home care services in order to achieve more preventative and rehabilitative ends. Above all, the re-ablement approach aims to maximise independence and quality of life in older age, whilst at the same time reducing costs by aiming for the lowest appropriate level of care for individuals (see Table 2).

**Table 2 The concept of re-ablement**

<i>Prevention</i>	<i>Rehabilitation</i>	<i>Re-ablement</i>
Services for people with poor physical or mental health to help them avoid unplanned or unnecessary admissions to hospital or residential settings. Can include short-term emergency interventions as well as longer term low-level support.	Services for people with poor physical or mental health to help them get better.	Services for people with poor physical or mental health to help them accommodate their illness by learning or re-learning the skills necessary for daily living.

Source: Care Services Improvement Partnership, 2007.

Local councils have demonstrated a variety of approaches to delivering re-ablement through home and day care. The features which remain constant throughout the different approaches have been:

- Encouraging individuals ‘to do’ rather than ‘doing it for’ them
- Focusing on real practical outcomes within a specified timeframe
- Continuous rather than one-off assessment to decide on individual’s care needs

To date, re-ablement approaches seem to offer a series of positives. From national monitoring and development work (as well as some independent research), it seems as though there may be over 120 local authorities, out of 150 councils nationally, either with or in the process of setting up/extending a re-ablement scheme (Pilkington, 2009). Re-ablement services have been created from restructured/retrained in-house home help services. Although in many early sites they were prompted by the need to extend hospital discharge/intermediate care initiatives, they are increasingly extending their

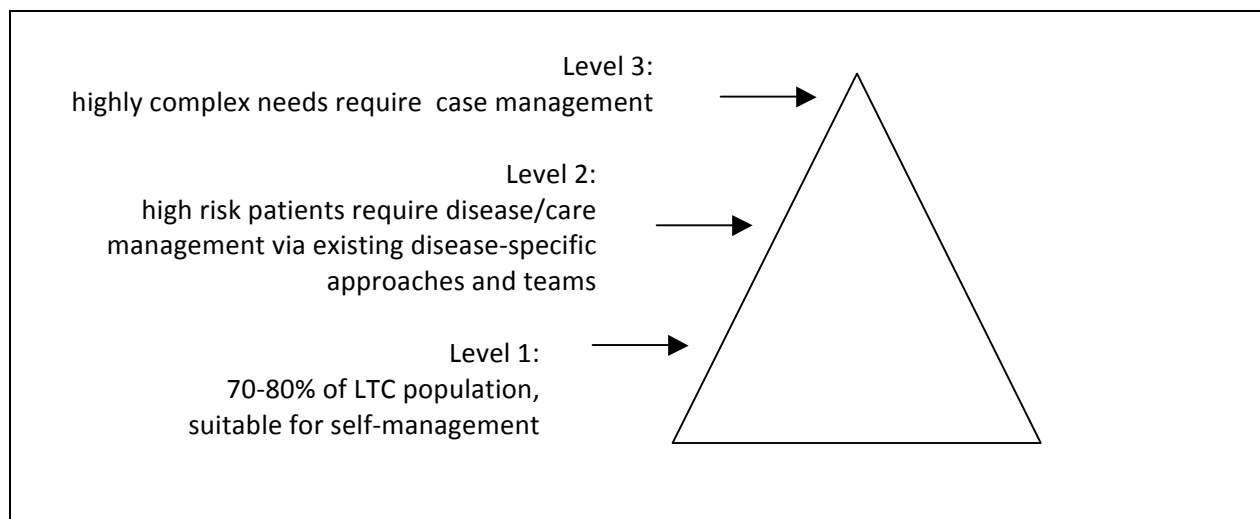
scope to take on all referrals for home care, whether from hospital or community. Only people with advance dementia or requiring end-of-life care are usually excluded.

One retrospective longitudinal study has also suggested that an average of 60 per cent of people leaving homecare re-ablement did not require a homecare package and, 24 months later, had still never required a homecare package. A local independent evaluation of one such scheme also found that 5 per cent of people without re-ablement required no homecare package and 70 per cent had their homecare unchanged at their first six week review. With re-ablement, 58 per cent did not require homecare with only 17 per cent having a package unchanged at the six week review (Pilkington, 2008). While further research is underway to understand the implications of this model in more detail, national trends suggest that such approaches have not yet succeeded in transforming the nature of the system as a whole. There are also some underlying concerns that some current policy may underestimate the social dimension of re-ablement, which can also aim to build confidence, promote abilities to carry out activities of daily living and provide relatively low-tech equipment as well as engage in more formal admission avoidance/rehabilitation work.

#### 1.4.4 Chronic disease management

Since 2004, English health policy has tended to emphasise the importance of chronic disease management, with a combination of prevention, self-management, disease management and case management for more complex needs. This is often portrayed in terms of a triangle of need (see figure 4), with different responses appropriate at different degrees of need.

**Figure 4 The long-term conditions triangle of care**



Source: adapted from Department of Health, 2005: 10.

To date, the results of this process have been difficult to untangle, and it remains very much early days for case management. Despite competing claims about both the impact of and the evidence base for case management (see, for example, Boaden et al., 2006; Hutt et al., 2004; UnitedHealth Europe, 2005), it remains to be seen whether current models and approaches are sufficient to rebalance the whole

health and social care system, and whether new case managers can link sufficiently with mainstream health and social care services to begin to deliver the high hopes which have been placed on them.

At the same time, the focus to date on 'community matrons' and 'chronic disease' has given the long-term conditions agenda a strong NHS flavour, and there is much less certainty about the role of social care. As a classic example, there is currently little clarity about how the government's long-term conditions model (figure 4) fits those developed in social care around the preventative agenda (see figure 2). There is also little recognition that this NHS policy draws heavily on previous case management pilots in social care (see, for example, Challis et al., 1995, 2002), which in many ways were the inspiration for the reform of social care in 1990. Indeed, the system of 'care management' introduced for adult social care at this time was initially to be called 'case management' until patients complained that they were not cases to be managed by professionals and the name was changed.

To date, a key element of the English approach to chronic disease management has been the promotion of greater self-care through the Expert Patients Programme (EPP). The EPP was launched by the government in 2001 with the overall aim of establishing patient-led self-management (of chronic illness) programmes within the NHS. The key activity of the EPP is a six-week self-care skills training course facilitated by people with personal experience of living with long-term conditions. The national evaluation of the EPP (NPCRDC, 2007) concluded that EPPs are useful additions to the current range of long-term conditions management services. Users expressed a high level of satisfaction with the course and improvements in quality of life were evident in the evaluation results. For EPP users there were moderate gains in self-efficacy and small gains in energy levels and psychological well-being. The course was also seen to be cost-effective, with some reductions in costs of hospital use.

Alongside the concept of 'expert patients', English adult social care has recently pledged to roll out a national system of personal budgets and to further promote the existing concept of direct payments. The Community Care (Direct Payments) Act 1996, which came into force on 1 April 1997, has often been seen as a defining moment in the struggle by the disabled people's movement for greater civil rights. After longstanding pressure from a range of user groups, the Act empowered social services departments to make cash payments to service users aged between 18 and 65 in lieu of direct service provision (see Glasby et al., 2009 for an overview). Although progress was initially slow, the number of direct payments has continued to increase and the original Act has been extended to include older people, younger people aged 16 and 17, carers, the parents of disabled children and people lacking capacity to consent to receiving a direct payment. Initially discretionary, direct payments quickly became a national performance indicator and became compulsory for all local authorities to offer to those who met the criteria and wanted to receive a payment.

From 2003, the concept of a direct payment was supplemented by the notion of a personal budget. Under this approach, the local authority gives the person an immediate indication of how much money is available to spend on meeting their needs, and then allows them to choose how this money is spent and how much direct control they have over the money itself. To date, options range from having a social worker manage the personal budget on your behalf right the way through to taking the full amount as a direct payment (with several other options in between). In this way, self-directed support seems likely to offer more of a spectrum of options which differs significantly from the more 'all or nothing' nature of direct payments. Although it is still early days, the evidence from both direct payments

and personal budgets is that service users and their families can achieve better outcomes from either the same (or potentially less) money, with these ways of working enabling people to be creative in meeting their own needs and producing more imaginative and effective support (see Glasby et al., 2009; see also [www.in-control.org.uk](http://www.in-control.org.uk)).

### 1.4.5 Assistive technology

Assistive Technology (AT) is an umbrella term for any device, system or product that enables a task to be performed or increases the ease and safety of this process. As well as basic practical applications, ATs can also be viewed in line with broader social model objectives to be devices which enable autonomy and independence for disabled and older people. For instance, this includes technologies which not only simply allow people to remain in their own homes (e.g. telecare and gas/fire/fall detectors and monitors), but also more general technologies (e.g. access to and accessible format of internet content) which reduce social isolation and enable greater independence.

Growing acute care costs, linked to the growing population of older people, have led governments to recognise the importance of preventative approaches and the role of AT within this. In recent years, key developments include additional funding (for example, a total of £80 million (€93 million) was allocated to local authorities and organisations between 2006 and 2008 using the Preventative Technologies Grant). Although further research is needed, existing research evidence and user feedback suggest several beneficial impacts of AT:

- Increased choice, autonomy, control and independence
- Improved quality of life
- Maintenance of ability to remain at home
- Reduction of burden placed on carers
- Improved support for people with long-term health conditions
- Reduced accidents and falls in the home (Beech et al., 2008)

### 1.4.6 Pilot project initiatives: HAZs, HCC, POPPs and LinkAge Plus

The Health Action Zone (HAZ) initiative was established by the New Labour government shortly after they were elected in 1997. The initiative's main aim was to tackle health inequalities by working across organisational boundaries. Twenty-six HAZs were set up as seven year pilot projects (with priority given to bids from areas of pronounced deprivation and poor health). It was thought that the good practice learnt would be mainstreamed into NHS services after this seven year period. The specific strategic objectives of the HAZs were to:

- Identify and address the public health needs of the local area
- Increase the effectiveness, efficiency and responsiveness of services
- Develop partnerships for improving people's health, adding value through creating synergy between the work of different agencies (Barnes et al., 2005).

Evaluators of the work carried out under the HAZ initiative found that the general impact was limited and outcomes were not easily measurable in terms of reductions in health inequalities. In the three or four years that HAZs were active there were thousands of projects undertaken with diverse activities

and beneficiaries. It was this plurality in addition to the short-term nature of the programme which made the measurement of impact problematic. However, it was seen that at a local level the work had clear benefits for improving working practice and impacting the health of target group users. These included:

- Greater recognition of health inequalities and understandings of the determinants of health within local agendas
- Raising the profile of 'hidden' health-disadvantaged groups, including older people
- Developing partnership structures and collaborative working
- Developing of more systematic planning processes
- Improving mainstream services, especially in disadvantaged areas (Health Development Agency, 2004)

Healthy Community Collaborations (HCC) are a programme led by the Improvement Foundation, a UK company for quality improvement in public services. Similarly to HAZ projects, HCC involve partnerships of professionals - but importantly also include and are led by community members. The initiative started with just three project sites and there are currently over 50 in the UK. The topics are often specifically targeted towards prevention of illness in older people. These topics have covered fall prevention and promotion of early detection of cancer and cardiovascular disease. The broader key objectives of HCC are stated as:

- Addressing health inequalities in areas of socio-economic disadvantage
- Acting as a catalyst enabling communities to work together for common goals
- Harnessing the skills and knowledge in communities to reduce inequalities (Slater et al., 2008)

The 'Partnerships for Older People Projects' (POPPs) programme began in 2006. Between 2006 and 2008 around 470 projects were undertaken by local authorities and their partners focused on older people, providing person-centred integrated care and developing preventative approaches that promote health, well-being and independence. A key aim of the programme was to develop approaches which shift resources and culture away from institutional and acute settings towards earlier health interventions within home/community settings. This preventative approach has a wider objective of preventing and delaying the need for high intensity or institutional care. To date, evaluators have found that there are several improved outcomes for older people associated with the work of POPPs:

- Improved accessibility of services to older people including older people being more readily referred to specialist services
- Provision of a wider range of services for older people
- Increased awareness by older people of the services available
- Increased involvement of older people in service delivery
- Cost reductions and efficiency of services were suggested to be significantly improved in comparison with non-POPPs sites. There are also indications that POPP pilot sites have an effect on emergency hospital bed-days use. The results show that for every £1 (£1.16) spent on POPPs, an average of £0.73 (£0.84) will be saved on the per month cost of emergency hospital bed-days.

Many of the benefits of the POPPs programme relate specifically to improved working structures and practices of the service provider organisations:

- More systematic, evidence-based and 'joined-up' systems for making commissioning decisions
- Making more effective use of a wide range of resources, services and skills available in the voluntary sector, resulting in a more mixed economy of service provision to support local older people
- New systems for referral and sharing of information have been established through POPPs, which have improved the way in which different services work together

POPPs has reinvigorated locality working with local older people to identify needs and inform commissioning processes not only for health and social care services, but also for wider well-being services (Windle et al., 2008).

However, as extremely time-limited and localised pilot exercises, the impact of the POPPs programme is to some extent limited. Although measures were built into the programme in an attempt to ensure the sustainability of positive outcomes, evaluators identified several factors which may impede the mainstreaming process, including financial constraints; inability to attribute positive gains to particular interventions; and changes in government policy. Even where reductions in hospital admissions could be clearly demonstrated, hospitals were sometimes seen as a barrier to the progression of POPPs work by staff involved, with difficulties in extracting money.

LinkAge Plus (LAP) was a Department of Work and Pensions pilot programme which ran from 2005 to 2008. Like POPPs, LAP had a specific focus on older people and maximising independence through preventative strategies. As with the other pilot schemes, partnership working between central and local government, the third sector and the beneficiaries themselves were essential aspects of LAP project design. Central to the eight pilot sites was the principle of widening access to a range of services for older people, focussing on local needs and including health and social care alongside broader support services. Services were most commonly delivered through the use of mentors and volunteers, outreach activities and 'drop in' centres, bringing together multiple activities. Examples of preventative initiatives funded by LinkAge Plus are:

- Centres delivering training and information on personal safety such as, falls prevention, trading standards, fire safety, road safety, crime prevention, healthy eating and telecare technologies.
- Various activities building social networks amongst older people, mostly activity-based. This is designed to protect mental health, well-being and quality of life.
- Physical exercise programmes for older people such as tai chi, walking, gentle yoga and chair based classes.

Overall, the lessons from these various pilot schemes may well relate to the difficulty of designing and embedding a preventative agenda in mainstream services. Following a change in Health Secretary, HAZs seemed to become less of a political priority in a government that seemed eager for rapid results. As a result, many projects became dogged by uncertainties about future funding and a loss of political focus – with staff moving to new roles and/or becoming disillusioned for the future. Mainstreaming successful pilots also proved challenging, and there was concern that some of the learning which took place during HAZs may be lost (see Barnes et al., 2005 for an overview). That this might be the case seemed to be concerned when policy makers announced subsequent POPPs pilots – which seemed to learn little from the HAZ experience and were much more time-limited and less ambitious. At the time of writing, there have also been additional government announcements of Integrated Care Pilots to improve the co-ordination of hospital care, community health services and social care (for further information, see

[www. Dh.gov.uk/en/Healthcare/IntegratedCare/DH\\_091112](http://www.Dh.gov.uk/en/Healthcare/IntegratedCare/DH_091112)). As with the other pilots above, however, there remains a concern that this is very much a ‘sticking-plaster’ solution unlikely to resolve the underlying issues at stake. At an expert level it is acknowledged that these are essentially political difficulties, not necessarily automatic/inherent to the work of the pilots. The problems arise because of:

- A continued focus on reducing acute admissions/institutional care (including with POPPs) rather than on broader and more social benefits
- The need to demonstrate impact within a short timescale
- The fact that they are local pilots not national policies/initiatives
- The fact that HAZ, HCC, LinkAge Plus and POPPs were based on short-term project funding

### 1.4.7 More general prevention

Beyond these specific policies, government has often repeated its commitment to developing a more preventative and rehabilitative approach to services for older people. Unfortunately, much of this has been primarily rhetorical to date, and serious questions remain about the extent to which it is possible to rebalance the current system without additional ring-fenced funding, about what works when it comes to prevention and rehabilitation and about how best to change services when the benefits may only be long-term (and indeed may be felt by a different part of the system rather than by the organisation or profession that provides the investment). Examples of general low-level prevention initiatives and approaches are:

- Integrated falls prevention services
- A fund of £33 million (€37.8 million) has been set up to fund handyperson services (including home safety and security) for older, disabled and vulnerable people
- Energy efficiency measures, with financial assistance for several disadvantaged groups including older people to help with insulation and heating costs
- The development of predictive risk models and case-finding initiatives. These models and tools allow patients with high risk of readmission to acute care to be identified so that they can be targeted adequately in preventative and rehabilitative programmes.

## 2 Involvement, equality and diversity

Challenging discrimination is a key element of health and social care and is enshrined in legislation, in government policy and in organisational policies and procedures. However, in practice, the achievements of health and social care in this area have been mixed, and much more remains to be done. In principle, a core and enduring feature of the UK welfare state is its commitment to equality and to treating people on the basis of need rather than of ability to pay. However, the universalism on which the welfare state is founded is problematic in two key areas:

- Treating everybody the same does not recognise the fact that different groups start from unequal positions. Rather than leading to equality, treating everybody equally could actually perpetuate existing inequalities.



- Despite our commitment to treating people on the basis of need, many of our services have been designed from the perspective of dominant groups within society (often white, middle-class, heterosexual men), and (perhaps unwittingly) discriminate against less powerful groups.

Against this background, there is considerable evidence to suggest that various minority groups within UK society can have negative experiences of health and social care, and experiences which perpetuate or even exacerbate the discrimination they face in wider society. While this is a broader issue than can be dealt with here, older people seem to be one of the most marginalised groups (see, for example, All Party Parliamentary Local Government Group, 2008). Thus, while other groups within society are protected by anti-discriminatory legislation (for example, around race or gender), there is no equivalent law around age discrimination (except in employment and the forthcoming Equalities Act which addresses age in light of goods and services). Unit costs for health and social care are also a lot lower than for people of working age – with discriminatory assumptions about older people built into the way that services have traditionally been organised. While health and social care services are tasked with routinely involving service users in decisions about their own care and about services more generally, the evidence suggests that there is much further to go before older people are seen as equal citizens with the same right to choice and control as other members of society.

### 3 Quality assurance

The Care Quality Commission (CQC) is a new independent body which from 1 April 2009 became exclusively responsible for the inspection, monitoring and regulation of health and social care in England, including registration and inspection of residential settings and domiciliary care services. CQC regulate all health and adult social care services in England, regardless of whether they are provided by the NHS, local authorities, private companies or voluntary organisations (see the separate INTERLINKS report on quality assurance in England: Billings/Holdsworth, 2009).

### 4 Supporting carers

According to the 2001 Census, there are some 5.2 million carers in England and Wales, including over one million people providing more than 50 hours of care per week (National Statistics, 2003a-b; see also figure 5). While caring is often perceived as a negative activity (involving a considerable physical and emotional burden on the carer), there is clearly scope for caring to be a rewarding and fulfilling relationship – at its best, being a carer *for* someone implies caring *about* them, and many carers speak passionately about the strength of the relationship they form with the person they care for. Many ‘carers’ also do not conceptualise their role in this way, and simply see themselves as partners, parents, siblings, friends and neighbours rather than as ‘carers’. This may be particularly the case for young carers, older people, people from minority ethnic communities and the carers of people with mental health problems.

However, in spite of many often unrecognised positives, there is also considerable evidence to suggest that being a carer (particularly when feeling unsupported and undervalued by health and social care services) can be a difficult and demanding role (see, for example, Baldwin et al., 1990; Finch et al., 1983; Ungerson, 1987; Henwood, 1998; Department of Health, 2000b). In response, a series of national policy initiatives have been developed to provide more and better support for carers (see figure 6). This emphasis on the needs of carers has also grown as social changes (for example, increased social mobility, greater female participation in the labour market) have meant that more and more people who use services live (potentially a long way) away from family members. Services to support carers are extremely important to a preventative approach, in order to protect the mental health and well being of the high proportion of older carers, but also to avoid institutional care for the person they care for.

### Figure 5 Carers and the 2001 census

In 2001, the Census included a specific question on caring for the first time. This revealed that:

- There are 6 million carers throughout the UK (10% of the total population and approximately 12% of the adult population).
- Of these, 4.4 million are of working age, over 116,000 are children (aged 5-15) and 1.3 million are over state pension age.
- The number of carers providing support for 20 hours or more every week is increasing, and 1.25 million carers provide over 50 hours per week, with other older people being the most likely carers.
- 58% of carers are women, with the peak age for caring 50-59 (more than 1 in 5 carers or around 1.5 million people).
- The proportion of carers reporting poor health increases as weekly hours of care rise. As older people are the group most likely to care for other older people, this situation is somewhat of a vicious circle to the detriment of older peoples' health.
- Over 3 million people combine work with caring (roughly 1 in 8 of all workers in the UK).

Sources: Buckner et al., n.d., 2005; Carers UK, 2002, 2004, 2005:

### Figure 6 Support for carers

In 1986, the Disabled Person's (Services, Consultation and Representation) Act required social services to "have regard" to carers' ability to provide care. In 1990, much of the policy and practice guidance accompanying the NHS and Community Care Act emphasised the importance of meeting the needs of carers (without necessarily providing any additional direct support or rights). In 1995, the Carers (Recognition and Services) Act (which began as a private member's Bill) required social services to assess the needs of carers (if requested) where they are assessing a potential service user under the NHS and Community Care Act 1990. In 1999, the National Carers Strategy set out a range of government proposals to support carers as part of a new national strategy. In 2000, the Carers and Disabled Children's Act (another private member's Bill) enabled a number of services to be provided to carers, and gave carers a right to an assessment (even where the 'service user' has refused an assessment of their own needs). Local authorities have the power to provide a wide range of services, including vouchers for short-breaks and direct payments. In 2004, the Carers (Equal Opportunities) Act (another private member's Bill) gave carers a right to information on their rights to an assessment, ensured that social services should consider work, life-long learning and leisure when assessing carers, and gave local government new powers to enlist the support of other agencies (including the NHS). The 2006 Work and Families Act gives carers the right to request flexible working.

What is striking about this gradual increase in the rights of carers and the focus placed upon their needs is the fact that:

- There is no single definition of a 'carer' and carers have to rely on a number of different pieces of legislation to claim their rights.

- So much carers' legislation began as private Bills and were not initially introduced as part of central government policy.
- Early legislation in particular focused on a right to an assessment, without conferring any rights to follow-up services or support.
- Entitlement has tended to depend on the carer providing or intending to provide a substantial amount of care on a regular basis (although this is not defined in the relevant Acts and has to rely on associated guidance).
- Increased responsibilities for social services and other services have rarely been matched with new funds to discharge new duties.

Sources: Carers UK, n.d.; Clements, 2005; Mandelstam, 2005.

## 5 Governance and financing

The governance and financing of long-term care in the England is currently controversial, following a longstanding debate about the potential costs of supporting a growing older population and the balance to be struck between individual and state contributions (see HM Government, 2008). Despite the previous work of the 1999 Royal Commission on Long Term Care (which recommended free personal care for older people in care homes) and the 2006 Wanless Review (which proposed a partnership model between the state and the individual), long-term care for older people continues to be paid for by those deemed to have resources to do so. People with savings/property worth more than £22,250 (€26, 265) pay for long-term care, with nursing homes costing an average of £600 (€708) per week. At the time of writing, the current system is recognised as very unfair and unnecessarily complicated – with a recent Green Paper exploring options for future funding (HM Government, 2009). Increasingly, English health and social care is also seeking to separate the commissioning and provision of health care – with Primary Care Trusts tasked with delivering a ‘world class commissioning’ agenda and finding alternative organisational structures for their previous provider services. While the jury remains out on the extent to which this will improve services for older people, this use of choice, competition and strategic commissioning as a potential lever for change is arguably different to approaches being adopted in some other EU countries.

## 6 Conclusions

Although there is now much greater recognition of the need to promote rehabilitation and prevention, at least two key issues remain:

- Despite an increase in funding and support for rehabilitation, many such projects remain something of a ‘bolt on’ to the traditional system, and have yet to rebalance the system as a whole. Although many can demonstrate positive benefits, there is a risk that such provision duplicates or supplements current services rather than reduces future demand.
- In spite of a stated commitment to prevention, there is a lack of clarity about what this means or how to do it in practice. Depending on the definition adopted, ‘prevention’ could refer to preventing disease; keeping people out of hospital; and/or helping people to live fulfilling, chosen lives (and each of these would require a very different set of policies and approaches). Also significant is

the difficulty of establishing an evidence base, and proving that you have prevented something that would otherwise have happened remains challenging (especially when many of the anticipated impacts are long-term in nature and when pilots are funded on a short-term basis with many other similar initiatives underway at the same time). It also seems likely that the timescales required to understand the impact of preventative approaches (and indeed of rehabilitation) may be much longer than the time available to politicians and policy makers to demonstrate more short-term success.

As a result, outstanding issues for older people's services in England include:

- How can we genuinely embed prevention and rehabilitation in the system (so that they reshape current approaches rather than duplicate or act as a 'bolt on')?
- How can prevention and rehabilitation best be organised and focused in order to have the greatest impact?
- In an era of increasing financial constraint, which interventions are likely to be the most effective and should we be investing in now?
- What impact might we expect such investment to have – will this reduce future service use or will it simply keep older people dependent on services for longer (so that they make greater use of services in future)?
- How can we balance the needs of those currently in crisis with longer-term investment in prevention and rehabilitation (in the hope that this will have a longer-term benefit)?

## 7 Appendix A: English National Expert Panel

The research team are very grateful to members of the National Expert panel for their comments on an initial draft of this paper. The NEP includes:

- Prof. Julien Forder, University of Kent
- Prof. Caroline Glendinning, Social Policy Research Unit
- Prof. Jill Manthorpe, King's College London
- Ed Harding, Integrated Care Network
- Luci Beesley, formerly of the Department of Health (DH)
- Deborah Sturdy, DH
- John Young, Consultant Geriatrician
- Amanda Edwards, Social Care Institute for Excellence
- Clive Newton, Age Concern & Help the Aged

## 8 References

All Party Parliamentary Local Government Group (2008) *Never too late for living: inquiry into services for older people*. London, Local Government Information Unit

Association of Directors of Social Services/Local Government Association (2003) *All our tomorrows: inverting the triangle of care*. London, ADSS

Audit Commission (1997) *The coming of age: improving care services for older people*. London, Audit Commission

Audit Commission (2000) *The way to go home: rehabilitation and remedial services for older people*. London, Audit Commission

Baldwin, S. and Twigg, J. (1990) Women and community care: reflections on a debate, in M. Maclean and D. Groves (eds) *Women's issues in social policy*. London, Routledge

Barnes, M., Bauld, L., Benzeval, M. et al (2005) *Health Action Zones: partnerships for health equity*. London, Routledge

Beech, R. and Roberts, D. (2008) *Assistive technology and older people: research briefing*. London, Social Care Institute for Excellence

Billings, J. and L. Holdsworth (2009) *Quality assurance and quality management in long-term care*. INTERLINKS National Report United Kingdom. Canterbury: University of Kent.

Boaden, R., Gravelle, H., Dusheiko, M. et al (2006) Impact of case management (Evercare) on frail elderly patients: controlled before and after analysis of quantitative outcome data , *British Medical Journal*, 334(31), 31-34

Buckner, L. and Yeandle, S. (n.d.) *We care – do you?* London, Carers UK

Buckner, L. and Yeandle, S. (2005) *Older carers in the UK*. London, Carers UK

Carers UK (2002) *Without us...? Calculating the value of carers' support*. London, Carers UK

Carers UK (2004) *Ten facts about caring*. Available online via [www.carersuk.org/Aboutus/CarersLives/Tenfactsaboutcaring](http://www.carersuk.org/Aboutus/CarersLives/Tenfactsaboutcaring) (accessed 29/08/32006)

Carers UK (2005) *Facts about carers*. London, Carers UK

Carers UK (n.d.) *Whose rights are they anyway? Carers and the Human Rights Act*. London, Carers UK

Care Services Improvement Partnership (2007) *Care Services Efficiency Delivery Programme: home reablement workstream discussion documents*. London, Department of Health

Challis, D., Chesterman, R., Lockett, R. et al (2002) *Care management in social and primary health care: the Gateshead Community Care Scheme*, Aldershot, Ashgate

Challis, D., Darton, R., Johnson, L. et al (1995) *Care management and health care of older people: the Darlington Community Care Project*. Aldershot, Ashgate

Clements, L. (2005) *Carers and their rights – the law relating to carers*. London, Carers UK and the Action for Carers Employment National Development Partnership (updated June 2006)

Department of Health (2000a) *The NHS plan: a plan for investment, a plan for reform*. London, The Stationery Office (TSO)

Department of Health (2000b) *Caring about carers: a national strategy for carers* (2<sup>nd</sup> ed. – first published 1999). London, Department of Health

Department of Health (2001a) *National service framework for older people*. London, TSO

Department of Health (2001b) *Intermediate care*, Circular HSC 2001/01, LAC(2001)1, 2001

Department of Health (2004) *Dramatic fall in delayed discharges*. Press release 2004/0196, 17 May

Department of Health (2005) *Supporting people with long term conditions: an NHS and social care model to support local innovation and integration*. London, Department of Health

Department of Health (2009) *Prevention package for older people*. London, Department of Health

Finch, J. and Groves, D. (eds) (1983) *A labour of love: women, work and caring*. London, Routledge

Glasby J. (2003) *Hospital discharge: integrating health and social care*. Abingdon, Radcliffe Medical Press

Glasby, J. (2008) *Understanding health and social care*. Bristol, The Policy Press

Glasby, J. and Littlechild, R. (2009) *Direct payments and personal budgets: putting personalisation into practice* (2nd ed.). Bristol, The Policy Press

Godfrey, M., Keen, J., Townsend, J. et al (2006) *An evaluation of intermediate care for older people: final report*. Leeds, University of Leeds

Godfrey, M., Townsend, J., Cornes, M. et al (2008) *Reimbursement in practice: the last piece of the jigsaw? A comparative study of delayed hospital discharge in England and Scotland*. Leeds, University of Leeds

Green, J., Young, J., Forster, A. et al (2005) Effects of locality based community hospital care on independence in older people needing rehabilitation: randomised controlled trial, *British Medical Journal*, 331, 317-322

Health Development Agency (2004) *Lessons from health action zones (HDA briefing no. 9)*. Available online via [www.hda.nhs.uk](http://www.hda.nhs.uk)

Henwood, M. (2004) Reimbursement and delayed discharges: discussion paper for the Integrated Care Network. Leeds, Integrated Care Network

Henwood, M. (1998) *Ignored and invisible? Carers' experience of the NHS*. London, Carers National Association

HM Government (2007) Putting people first: a shared vision and commitment to the transformation of adult social care. London, HM Government

HM Government (2008) The case for change: why England needs a new care and support system. London, Department of Health

HM Government (2009) Shaping the future of care together. London, TSO

House of Commons Health Committee (2002) *Delayed discharges (third report)*. London, TSO

Hutt, R., Rosen, R. and McCauley, J. (2004) Case managing long-term conditions: what impact does it have in the treatment of long-term conditions? London: Kings Fund.

Kaambwa, B., Bryan, S., Barton, P. et al (2008) Costs and health outcomes of intermediate care: results from five UK case study sites, *Health and Social Care in the Community*, 16(6), 573-581

Mandelstam, M. (2005) *Community care practice and the law* (3rd ed.). London, Jessica Kingsley

Martin, G., Hewitt, G., Faulkner, T. et al (2007) The organisation, form and function of intermediate care services and systems in England: results from a national survey, *Health and Social Care in the Community*, 15(2), 146-154

National Primary Care Research and Development Centre (2007) *National Evaluation of the Expert Patients Programme*. Available online via <http://www.npcrdc.ac.uk/ProjectDetail.cfm?id=117> (accessed 21/09/2009)

National Statistics (2003a) *Census 2001: carers*. Available online via <http://www.statistics.gov.uk/cci/nugget.asp?id=347> (accessed 25/07/2009)

National Statistics (2003b) *Census 2001: informal care* (published 13<sup>th</sup> February). London, Office for National Statistics



Pilkington, G. (2008) *Homecare re-ablement*. London, Department of Health

Pilkington, G. (2009) *Homecare re-ablement: scheme directory*. London, Department of Health

Regen, E., Martin, G., Glasby, J. et al (2008) Challenges, benefits and weaknesses of intermediate care: results from five UK case study sites, *Health and Social Care in the Community*, 16(6), 629-637

Royal Commission on Long Term Care (1999) *With respect to old age: long term care – rights and responsibilities*. London, The Stationery Office

Slater, B., Knowles, J. and Lyon, D. (2008) Improvement science meets community development: approaching health inequalities through community engagement, *Journal of Integrated Care*, 16(6), 26-36

Ungerson, C. (1987) *Policy is personal: sex, gender and informal care*. London, Tavistock

UnitedHealth Group (2005) *Implementing the Evercare programme: interim report*. London, UHG

Wanless, D. (2006) *Securing good care for older people: taking a long-term view*. London, King's Fund

Windle, K., Wagland, R., Knapp, M. et al (2008) *National Evaluation of Partnerships for Older People projects: Interim Report of Progress*. London, Department of Health