# Health and social care for older people in the UK: a snapshot view

Working paper 607

## Kenneth Howse,

Oxford Institute of Ageing

November 2007 Oxford Institute of Ageing Working Papers Editor: Kenneth Howse www.ageing.oc.ac.uk

### Health and social care for older people in the UK: a snapshot view

#### Contents

#### Introduction

#### Older people as users of health and social care

-Health care

-Long-term care

#### The travails of the NHS

-An under-performing and underfunded health service?

-A step change in resources and the reform imperative

-Delayed discharges, bed-blocking and intermediate care

#### The travails of long-term care

-The importance of informal care

- -The entitlement to publicly subsidised care
- -A mixed economy of care

#### Users' views and users' choices: quality assurance, consumerism, and empowerment

-Age and user satisfaction-The regulatory framework for health and social care-Choice and empowerment

#### **Conclusion: challenges for the future**

- pressures for reform

#### Acknowledgements

The work for this paper was commissioned as part of a multi-national collaborative study of migration and elder care funded by the Nuffield Foundation.

#### Introduction

Major healthcare reforms were common throughout the OECD in the 1980s and 1990s, and the National Health Service, the main provider of health care in the UK since its establishment in 1948, has certainly had its fair share of reforms over the last two decades. Despite repeated waves of major structural reorganization, however – beginning in the early 1990s with the introduction of a functional split between the provision of care and the purchasing (now commissioning) of care, and the attempt to introduce an 'internal market' for providers – two centrally important features of the NHS have been left intact. Publicly subsidised health care remains 'free at the point of delivery' for all UK residents<sup>1</sup>, and it is funded almost entirely out of general taxation (including 'National Insurance'). That access to care should be determined by clinical need, and not the ability to pay, is generally regarded as *the* core principle of the NHS.

Successive reforms have, furthermore, left *most* of the 'infrastructure' for the delivery of care under public control. The OECD (2003) may be right in suggesting that, for several years now, the NHS appears to have been hovering indecisively between a *public-integrated* model of provision and a *public-contract* model, but UK citizens are still served by a national network of publicly-owned hospitals staffed by professionals who are public employees. Recent efforts to finance the development of this network though private capital (PFIs) and to enlist 'bed capacity' from the private sector ('private treatment and diagnostic centres') have angered some commentators (e.g. Pollock 2004) as evidence of the 'the creeping privatisation of the NHS', but the scale of private sector involvement remains small (by the standards of OECD countries with public-contract models of provision). And for all its structural complexity it still makes sense (mainly because of the nature of the budgetary controls exercised by central government) to speak of the NHS as a single organization with operational responsibility for planning, managing and delivering health care for everyone in the UK – though it might be more accurate to refer to the four 'national health services' that co-exist in the four nations that make up the United Kingdom.

The situation is quite otherwise with the provision of what are usually called long-term care services for people who need help with essential activities of daily living. Not only is there no

<sup>&</sup>lt;sup>1</sup> This includes the 11.5% of the population who purchase some form of private health insurance – usually with the intention of widening their choice of providers or cutting waiting times for specialist treatment (NAO 2003a). Only 5% of people aged 65+ have private health insurance, and policy holders are concentrated in London and the south-east of England (ONS 1995).

universal entitlement to services<sup>2</sup>, but the reforms of the last twenty years have nurtured the development of a 'mixed economy of care' (i.e. a *fully-fledged* public-contract model) for the provision of formal long-term care in the UK. Care services purchased from the private sector – made up of both 'for-profit' and 'not-for-profit' providers – now dominate the provision of residential and nursing home care for frail older people, and have recently become the major provider of domiciliary services for older people living in the community. Local authorities have been shedding capacity at the same time as the private sector has been expanding, and although they do still retain some residual capacity for both types of provision, their main responsibilities now are to supervise the disbursement of public funds for the provision long-term care, i.e. to ensure that these funds are used effectively and appropriately, and to organise care services for people who are entitled to them.

Since the introduction of the 1993 'community care' reforms, older people seeking state financial support for admission to a care home have been required to apply to their local authorities, and the criteria of eligibility for publicly subsidised care are not at all the same as those that operate in the NHS. In this case the ability to pay *is* relevant. Eligibility is not determined – as it is for example in Germany – only by what would be the equivalent of 'clinical need', i.e. on the basis of an assessment of level of dependency. Applicants have to pass a means test *as well as* a needs test, and as a result, a greater proportion of the total costs of long-term care services are met by private means than is the case in the health care sector<sup>3</sup>.

Hence it is that whereas policy makers across the political spectrum have tended to share the view that the challenge of health service reform is to improve the performance and efficiency of the NHS, whilst retaining its central – and politically popular – characteristics<sup>4</sup>, the challenges of reform for publicly-provided long-term care are usually presented in terms of the evident contrast with the principle of universal entitlement that underpins the health service. The prevalent view on the institutions and arrangements for the provision of long-term services in this country is *not* that they should be preserved because of the principles they embody, but

 <sup>&</sup>lt;sup>2</sup> Though there *is* a universal entitlement to financial support in the form of Attendance Allowance.
<sup>3</sup> Although these estimates are difficult to make, both the Royal Commission on Long-Term Care (1999) and also PSSRU (2004) reckon that about 35% of total expenditure on LTC depends on private finance (usually out-of-pocket rather than private insurance). Much more than 35% of total expenditure, however, pays for services *provided* by the private sector. In the healthcare sector, on the other hand, more than 80% of total

spending comes from public funds, and this proportion has been increasing over recent years (NAO 2003a). <sup>4</sup> Though they have not always agreed about the appropriate measures of performance nor about the kinds of change that would constitute an abandonment of core principles.

rather that they are 'crying out' for fundamental reform. They were in need of reform before the establishment of the Royal Commission on Long-Term Care in 1997 – and are no less in need of reform now, eight years after it finally reported (see e.g. Hirsch 2005; CSCI 2006).

#### Older people as users of health and social care

#### Health care

Older people are the main users of health and social care services in the UK, just as they are in most European countries. They visit their GPs more frequently than younger adults, and are heavier users of both outpatient and inpatient hospital services (ONS 2002). It is estimated that people aged 65 years or more make up about one-third of all UK hospital admissions, and two-thirds of 'hospital bed days' (DH 2000). Their utilisation of at least some forms of health service provision has, furthermore, been increasing over time. So, for example, the proportion of older people who had recently visited a casualty department more than doubled – from 12% to 26% - between 1972 and 2001 (ONS 2002). Older people in fact account for half of the recent growth in emergency admissions to hospitals (CHAI 2006).

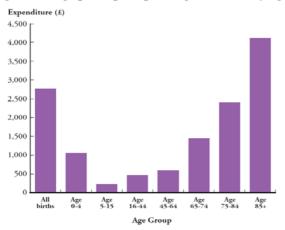


Fig.1 Average per capita spending on HCHS by age group, 2003-4

None of this is surprising of course, since the prevalence of all sorts of chronic and serious health problems is much higher in the older population than in younger adults; and it explains why *per capita* spending on health services for older people is so much higher than for younger adults. In 2003-4, 43% of all NHS spending on 'hospital and community health services' (HCHS) was allocated to people aged 65 years and above. Since only 16% of the UK population fall into these

Source: Department of Health annual report, 2006

older age groups, this means that the amount of money spent on HCHS for the average older person is between four and seven times more than is spent on the average person in middle age (*see fig.1*).

Public expenditure on HCHS (£38 billion in 2003-4), which represents about 60% of all NHS spending, excludes general dental services and ophthalmic services, as well as general medical services (i.e. GPs), drug costs and various other central administrative costs. The largest single budget item outside HCHS is the drug bill, which made up 11% of total expenditure in 2003-4 (down from 12.7% in1999 but still somewhat more than goes to general medical services). Detailed data on the age breakdown of prescription costs are not readily available, but it is clear that older people use more prescription drugs than younger people, and are much more likely to be regular users of more than one medicine<sup>5</sup>. In recent years, most of the annual increase in drug expenditure has come from the increased volume of prescriptions rather than the actual prices of the drugs. In 2004-5, for example, there was a 28% increase in the number of prescriptions of statins (a change driven mainly by the National Service Framework for cardiovascular disease), and older people are undoubtedly the main beneficiaries of this increase.

The principle that health care in the NHS is 'free at the point of delivery' does require some qualification, however, in the light of the small amount of revenue that is raised from patient charges or 'co-payments'. Along with other miscellaneous forms of income generation, this covered about 2.5% of total expenditure in 2005-6; and although charges are now levied on more services than previously, out-of-pocket expenses are still relatively low by international (i.e. OECD) standards. Users pay for a limited range of 'family health services' (but *not* medical consultations or treatment), including (i) prescribed medicines and various 'aids and appliances' (such as spectacles or dentures), (ii) routine sight tests, and (iii) dental care. All people aged 60 years or more are exempt from the standard flat rate prescription charge<sup>6</sup>, and they are also entitled to free sight tests. Exemption from dental charges is subject to an income test, and since everyone in receipt of means-tested income support is exempt, this means that about 40% of all older people are exempt from all charges.

<sup>&</sup>lt;sup>5</sup> In 1998 38% of people aged 75+ were regularly taking four or more prescribed medicines (Health Survey for England 1998). Most people aged under 45 years are taking no prescribed medicines (Scottish Health Survey 1995).

<sup>&</sup>lt;sup>6</sup> When other forms of exemption are taken into account, approx. 85% of all prescriptions are free of charge (Dixon & Robinson 2002).

#### Long-term care

Whereas most older people have regular contact with the health care system (GPs are paid to provide an annual health check for everyone aged 75 years or older), at any one time only a minority make use of personal social services (PSS). In England about 15% of the older population (1.2 million older people according to CSCI 2005) use social care services organised by their local authority, with around 206,000 (i.e. about 2.5%) being supported to live in residential or nursing home care (CSCI 2006). The total number of older people who live in institutional care - including self-funding residents of care homes – is estimated at 4% for the UK as a whole (Wittenberg *et al* (2004)<sup>7</sup>. Among the 'older-old', the levels of service utilisation are of course much higher: about half of all people aged 85 yrs or more are residents in care homes, with one half of the rest receiving home-based services. Survival into late old age carries a high risk of dependency on intensive long-term care services.

In 2005, local authorities in England provided or purchased over 3 million hours of home care per week for 392,000 households<sup>8</sup> – mostly for older people. The use of domiciliary services is much more widespread than this figure would suggest, however, since a great deal of private home help is purchased directly by the user. The 2001 GHS estimated that 650,000 older people in England (i.e. approx. 7.5%) had paid for private home help in the previous month, though prevalence of self-reported ADL or IADL dependency was much lower than this. Wittenberg *et al* (2004) reckon that altogether about 20% of the 65+ age group living at home receive domiciliary services – though this figure does include community nursing as well as home care services arranged by local authorities and privately purchased home help<sup>9</sup>.

Although social service budgets are not susceptible to quite the same kind of age breakdown that the Department of Health regularly applies to health care, 'older people's services' are the largest single budget category within adult social services, and in 2003-4 they absorbed 43.6% of gross public expenditure on PSS, almost twice as much was spent on 'services for families and children', and considerably more than was spent on younger adults with mental or physical disabilities (*see fig.2*). And because residential care is more expensive than domiciliary care, the

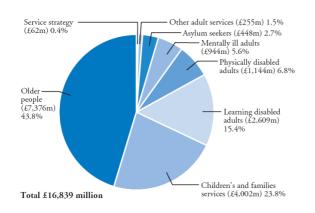
<sup>&</sup>lt;sup>7</sup> This PSSRU estimate also includes the very small number of older people who reside in NHS long-stay beds.

<sup>&</sup>lt;sup>8</sup> This refers to the numbers of hours of care purchased in a particular survey week (i.e. an average week).

<sup>&</sup>lt;sup>9</sup> The figure cited in the Wanless Social Care Review is *much* lower than this (4%) – so much so indeed that the discrepancy is frankly puzzling – which puts the UK at the bottom of the OECD league table for provision of formal home care services to older people (Wanless 2006).

lion's share of the PSS budget is spent on residential care (43.8%), even though more people - across all age groups - are recipients of domiciliary care and/or day care.

Like many European governments, the UK government is committed, - and this is a longstanding policy goal - to shifting the balance of provision for older people with relatively high levels of dependency – and so in need of intensive support – away from institutional care to home-based care. What most older people say they want for themselves is to stay in their own homes for as long as possible; and what government wants is that the numbers of frail elderly people being supported in their homes should be the maximum compatible with safe and appropriate care. There is inevitably some uncertainty about what proportion of older people with a need for intensive care can be supported to live in their own homes. This does not prevent government from setting targets however, and the target set in 2002 was to increase the provision of *intensive* care packages for people living at home to the point where 30% of the total being supported either at home or in residential care would be in this category (Laing & Buisson 2003).



#### Fig.2 Local authority spending on personal social services by service category, 2003-4

Source: Department of Health annual report, 2005

#### The travails of the NHS

#### An under-performing and underfunded health service?

Although the NHS has long been admired both for the ideals of fairness and social solidarity that it embodies and also for its ability to contain costs, it has become increasingly vulnerable over the last twenty years or so to criticism for the quality of care that it has provided. The fast pace of technological improvement in medicine, increasing public expectations, and consistently unfavourable comparisons with other countries have all served to highlight a variety of failings and problems, especially in hospital provision, that for most commentators – and indeed, for the voting public - have presented compelling evidence of an under-performing and under-funded health service.

The length of waiting times for specialist services and inpatient treatment (e.g. elective surgery) has been pre-eminent among these concerns for a long time now, but there have been plenty of other recurrent difficulties and chronic shortcomings. Long waiting times are at least partly the result of lack of 'capacity', of both doctors and beds, and this has often been highlighted as one of the main causes of various problems with performance. Certainly the UK has long had one of the lowest ratios of practising physicians to population in the OECD (NAO 2003a). A gradual decrease, over many years, in the number of acute hospital beds – with associated increases in bed occupancy rates (i.e. improved efficiency) – also undoubtedly played its part in regular winter crises of bed shortages as the rates of admission of older people followed their usual seasonal spike. It is not only beds and healthcare professionals that are required, however, for a 'high-performing' health services. Repeated criticisms of the effectiveness of cancer services – with relatively high death rates and low five-year survival rates (NAO 2003a) - have tended to confirm the widely-held view not only that waiting times are too long, but also that the NHS has been stingy (compared to other European countries) in its provision of more expensive forms of treatment.

The fact that older people are such disproportionately heavy users of the NHS means that they have tended to bear the brunt of these shortcomings and failings, which were especially visible in the recurrent winter bed crises. It seems clear, furthermore, that the flow of resources into the provision of effective medical care for older people was for many years too restricted. In the years between 1985 and 1996, NHS spending *per capita* on people aged 65+ increased more slowly than spending *per capita* for younger adults – with the effect that the proportion of health spending allocated to older people decreased (Seshamani & Gray 2003). The poor quality of hospital services for older people was a focus for repeated media campaigns by pressure groups throughout the 1990s, and they did not let up when the new Labour Government came to power in 1997. All in all, it became increasingly difficult to contest what was repeatedly asserted by pressure groups such Age Concern and Help The Aged, namely that older people had to bear more than their fair share of the impact of resource constraints on service provision and development. The evidence that the NHS systematically discriminated against older people

(especially the older-old) in its provision of care was accumulating at the same time as it became increasingly unacceptable to justify differential treatment for older people on grounds of age. Hence it was that when the Government eventually published its National Service Framework (NSF) for Older People<sup>10</sup> – one of ten NSFs intended to provide clear standards against which services could measured – it declared its intention to make age discrimination in health care "a thing of the past", and to "ensure that older people are treated with respect and dignity".

#### A step change in resources and the reform imperative

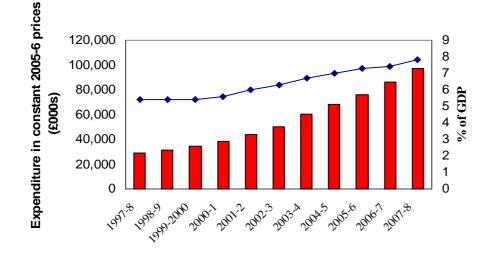
When the Labour Government Prime Minister, Tony Blair, announced in January 2000 that NHS spending would be increased to bring funding up to the average for health care in the EU, he was acknowledging that expenditure had lagged too far behind public expectations and that the NHS had quite a lot of 'catching up' to do if it was to improve performance. An extra 2-3% of GDP was to be added to the annual health spend of the UK over a 7-8 year period (see fig.3). The Wanless Review into health care spending, which was completed two years after this announcement and commissioned by HM Treasury, extends this time horizon by providing an assessment of "the resources required over the next two decades to ensure the NHS can provide a publicly funded, comprehensive, high quality service available on the basis of clinical need and not ability to pay" (Wanless 2002:13). The assessment is based in part on the resources that would be required to achieve specific objectives outlined in the five disease-based NSFs (cancer, CHD, diabetes, renal disease, mental health). Although the review identified demographic ageing as a source of potential upward pressure on future health care spending, it followed current thinking in the research community by assigning more weight to the impact of increasing public expectations and technological improvement. The main priority for the short term was to increase spending and improve the quality of care, and there was a good case for ensuring that a substantial proportion of the additional resources that were to be devoted to raising standards of care in the NHS should be directed at improving older people's access to high-quality and effective care<sup>11</sup>.

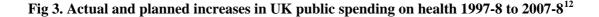
What was presented (not unreasonably) by the Labour Government as a "step change in resources" was to be accompanied by a "step change in reform". In other words, more resources

<sup>&</sup>lt;sup>10</sup> The NSF is described by government as a "ten year programme of improvement [to be] implemented through local health and social care partners, and national underpinning programmes".

<sup>&</sup>lt;sup>11</sup> Much of this would come *via* the disease-based NSFs, but not all of it. In 2003-4, for example, the Government earmarked an additional £900 million for intermediate care (see below).

and the very substantial increase in capacity that has come with them are not enough to put the NHS on the right track in the longer term. It is necessary also to improve productivity – to achieve what the Conservative reforms of the early 1990s set out to achieve, namely 'better value for money'; and this policy imperative is no less urgent now that it was in 2002 (Wanless *et al* 2007).





At the heart of this step change in reform – though the most radical initiatives apply only to the NHS in England – are a major shift in the balance of power towards primary care and the declared intention to give real weight to patient choice in deciding who should provide secondary care<sup>13</sup>. Although there is considerable continuity in this respect with the reforms instigated under the previous Conservative Government, the present Government has more fully developed the commissioning function of primary care providers through the establishment of Primary Care Trusts, 'collectives' of GP practices, which have much larger budgets and hence much more clout than did the previous GP fundholders. The aim is to develop a form of "regulated market in which central government sets the terms within which providers and commissioners operate and independent regulators monitor quality and standards" (Klein 2007: 43). What the 2002

Source: HM Treasury

<sup>&</sup>lt;sup>12</sup> For *total* health expenditure, it is necessary to add private spending to these figures, which is estimated at about 1.4% of GDP over this entire period. In its current public spending plans, the Treasury will rein back on the growth in health spending after 2008, which is when the "years of fiscal plenty will come to an end" (Klein 2007 39). It is estimated that total spending on health will amount to 9.5% of GDP in 2008.

<sup>&</sup>lt;sup>13</sup> The 'traditional' approach left the decision about referral to specialist care to the GP, who usually chose the closest service with the appropriate level of expertise. Most specialist services were (and still are) concentrated in large 'general hospitals' distributed across the country on a population basis.

White Paper – *Delivering the NHS Plan* - envisaged was a more devolved NHS, with a diversity of public, private and voluntary providers all paid by results, and a much expanded and effective role for patient choice. As things now stand, the programme of reform is far from complete, and may indeed stay uncompleted – not least because of the ongoing tension between pressure for more central control (to ensure achievement of nationally set targets for service quality and as a guarantee of geographical equity) and pressure for more decentralization and local autonomy (see, e.g. Lewis & Dixon 2005; Dixon & LeGrand 2006).

The pivotal role of Primary Care Trusts in the new 'primary care-led' NHS builds on the position of General Practitioners as the first point of contact for patients and the gateway to hospital and specialist medical care, and despite the occasional unfavourable comparisons with some other countries which provide unmediated access to specialist services, this is often seen as one of the main strengths of the NHS, not least because everyone has the right to be registered with a GP. Most GPs are independent contractors rather than salaried employees, though the nature of their contract means that they are paid for the care they provide to a *population* (i.e. everyone registered with them) rather than on a fee-for-service basis. They are furthermore strongly encouraged (with financial incentives) (i) to transform their practice into a primary care centre by acting as a base for other health professionals such as nurses and physiotherapists, (ii) to develop preventive care for their populations, and (iii) to carry out as many procedures as they can for themselves rather than refer patients to hospital.

#### Delayed discharges, bed-blocking and intermediate care

The idea that older people inappropriately occupy acute hospital beds when their needs would be better served by other forms of care is by no means confined to the UK. Nor is it new. Indeed, in this country it is virtually coeval with the NHS (Victor *et al* 1993). The issue did acquire, however, a new degree of urgency and importance after the introduction of the community care reforms at the end of the 1980s – and it has remained ever since one the most visible symptoms of systemic difficulties in the coordination of health and social care services for older people in this country. No doubt the problem was fuelled in part by increasing demand (i.e. more frail older people), but it was also, and unquestionably, exacerbated by the decreasing supply of acute hospital beds over this period, which was happening at the same time as the NHS was getting rid most of its non-acute (or 'continuing care') beds for frail elderly people. For a hospital network with very high bed occupancy rates to function efficiently, it is imperative to avoid unnecessary

hospital admissions (not uncommon with older people), and to ensure the minimum stay compatible with effective treatment for those who do need hospital admission. It is also imperative, however, to avoid unsafe discharges, which in turn requires all sorts of procedures and protocols to ensure that all discharges are properly planned and take full account of longterm care needs in community. On the one hand, therefore, there are the risks of premature or inappropriate discharges, and on the other, 'bed-blocking'.

The core of the problem is that many older people (especially those in the 75+ age groups) who no longer require the kind of medical treatment for which they were admitted to an acute bed remain incapable of looking after themselves without help. Some of them will have levels of physical or mental dependency that typically require long-term placement in residential or nursing home care; some of them will have care needs that fall some way short of this, but nonetheless live in circumstances (e.g. lack of potential carer; inappropriate housing) that effectively prevent their discharge home; and some will be in need of non-acute health care such as rehabilitation or terminal care (Victor et al 1993). The scale of the problem – and its knock-on effect for the management of acute hospitals is considerable. An excessively large chunk of the resources (just under £1 billion per year according to a recent report from the think-tank IPPR<sup>14</sup>) spent on hospital care is being ineffectively used to do something that would be better done elsewhere and in another way. The National Beds Inquiry estimated that about 20% of the 'beddays' for people aged 65+ were provided for patients who no longer needed the resources of an acute hospital, but were not ready to be discharged to their own homes (DH 2000). And in 2003 the National Audit Office reported that nearly 9% of older people occupying hospital beds had been declared fit to leave hospital but had not done so; and about 1/4 of these were waiting for care home placements (NAO 2003b).

What makes for delay in *all* these cases is a mix of organisational issues and lack of appropriate capacity: there may, for example, be a lack of appropriate settings in which to provide the non-acute care that is needed – or a lack of capacity to provide it in the person's home; or the hospital may be waiting on the completion of the arrangements for transfer to residential or nursing home care – or perhaps there is a shortage of available places in the locality; or the arrangement of coordinated 'packages' of domiciliary-based care is taking a long time – and rehousing takes

<sup>&</sup>lt;sup>14</sup> Farrington-Douglas & Brooks (2007)

even more time. Although the expansion of capacity in acute hospitals over the last few years<sup>15</sup> – i.e. more beds – should help relieve some of the pressures that make for 'bed-blocking', it clearly does not get to the root of the problem. The hope is that it can be resolved by (a) promoting the development of 'intermediate care' options<sup>16</sup>, and (b) imposing financial penalties on local authorities that fail to organise appropriate long-term care services in a reasonable time<sup>17</sup> (i.e. where LAs are responsible for a delayed discharge, they should also be responsible for the cost of keeping a patient in an acute bed).

In 2002, intermediate care was identified in the so-called *concordat* between the Department of Health and the Independent HealthCare Association as one of the key areas in which the NHS and the independent sector could work together, i.e. the NHS would pay for temporary admissions to residential or nursing home care beds and see to the provision of appropriate rehabilitation services aimed at enabling patients to return home. Temporary admissions to residential care facilities have indeed been increasing (up by 25% in 2004-5), and according to the Commission for Social Care Inspection (CSCI 2006), most temporary admissions of older people are for the purpose of intermediate care rather than respite care<sup>18</sup>. Even so, the independent sector feels that it has been left out in the cold (Laing & Buisson 2003), since most of the money earmarked for intermediate care appears to have gone to the development of a range of service models that offer alternatives to admission to a care home (e.g. 'hospital-athome' or day care rehabilitation).

#### The travails of long-term care

#### The importance of informal care

It is common practice to define long-term care services in a way which sets them apart from health care services: long-term care services provide the kind of help that people need when they

<sup>&</sup>lt;sup>15</sup> The National Beds Inquiry asked whether the NHS had gone too far in reducing beds – and although it was argued that the reduction in average length of stay more than offset the decrease in capacity, the final conclusion was that the NHS needed more beds.

<sup>&</sup>lt;sup>16</sup> The provision of intermediate care is one of the eight standards laid down in the NSF for Older People. So too is the achievement of 'person-centred care', which aims to ensure that "older people are treated as individuals and that they receive appropriate and timely packages of care, which meet their needs as individuals, regardless of health and social services boundaries".

<sup>&</sup>lt;sup>17</sup> Community Care (Delayed discharge) Act 2003.

<sup>&</sup>lt;sup>18</sup> 32,700 temporary admissions in 2004-5.

are dependent on others for assistance with some of the essential activities of daily living (OECD 2005). This includes more severely disabled people who need help with 'personal care' (e.g. toileting and bathing) and less severely disabled people who need help with a range of activities that are necessary for what the Americans call 'homekeeping'. The possibility of receiving help with homekeeping activities indicates the extent to which publicly subsidised long-term services have changed across the *entire* developed world over the last thirty years or so: formal long-term care is no longer provided *only*, or even primarily, in institutional settings.

This shift towards the provision of long-term care services which enable people to continue to live 'in the community' has also brought with it (besides a whole host of organisational problems) an increased awareness of the importance of what is now almost universally called 'informal' care – long-term care that is provided usually by family members at home. Not only is it generally accepted that the bulk of long-term care in most developed countries is provided informally by family members (at no direct cost to the taxpayer), but it is also widely accepted that in recent years the burden of care on families has been growing steadily (see e.g. CSCI 2006). Older people with the kinds of care need that would previously have triggered a move to institutional care are increasingly being cared for at home, often by a family member (usually a spouse or an adult child) sometimes by formal services, and sometimes by a combination of the two.

The 'demand' made by the CSCI in its 2006 annual report, that it wanted to see carers placed at the centre of the adult social services strategy, lends support to the views of pressure groups and critics of government who argue that government rhetoric on this matter – that it aims to ensure that carers are not overstretched and that they should remain able and willing to provide the support they do - has yet to be translated into effective support (see e.g. Clements 2007). The refusal of government to adopt one of the most important recommendations hat the Royal Commission on Long-Term Care, namely that local authorities should be 'carer-blind' in assessing eligibility for formal long-term care<sup>19</sup>, means that service providers till prioritise disabled older people who live alone and have no family carers. It does not mean, however, that government 'takes for granted' the care provided by family members. Recent legislation has given them important rights in law: in particular the right to have their views taken into account by a social services department when it is considering how best to make provision for a frail

<sup>&</sup>lt;sup>19</sup> i.e. that the level of support from formal services should not be conditional on the level of support from informal carers.

older people; and the right to a 'carer's assessment', which will determine whether or not they are entitled to help with caring.

#### The entitlement to publicly subsidised care

The main responsibility for providing publicly subsidised long-term care in the UK lies with local authorities, who pay for it out of their cash-limited budgets and assess eligibility for provision. The fact that they pay for it out of cash-limited budgets means that there is inevitably some rationing of provision, notably of domiciliary services, and so in recent years, an increasing proportion of total spending has been allocated to older people with more severe dependency needs (Means *et al* 2002). It has become harder for older people with lower levels of dependency to secure publicly subsidised home care. What has happened over the last decade or so is that the number of home care contact hours funded by local authorities has been steadily increasing whereas the number of households receiving care has been on a downward trend.

The financial criteria for eligibility for means-tested support for long-term care depend on geography. For (non-NHS) institutional care, the details of the means-testing system are determined by *national* rules, and the UK is made up of four nations (essentially Scotland operates a different set of rules from the rest of the UK). There are, however, no national rules for determining who should be eligible for publicly-subsided domiciliary care, which means that they vary from one local authority to another. According to the Audit Commission (2000), about two-thirds of councils exempt those on lowest incomes from charges, with the rest levying some sort on charge even on people who are in receipt of income support. Although these variations have prompted much criticism over the last few years, not least by the Audit Commission itself, leading to the publication of new guidelines for local authorities on how to assess financial capacity to pay for domiciliary services, the government has held back from instituting a common set of rules for financial assessment.

The principle that care should be free at the point of delivery applies to health care, therefore, but not to long-term care – except for those elements of long-term care that are still the responsibility of the NHS. All community nursing and therapy services (both heavily used by elderly people and very important for community care) are the responsibility of the NHS, as are the costs of the

nursing care provided in private and independent sector care homes<sup>20</sup>. There are, furthermore, some people with complex care needs in *inpatient* continuing care facilities provided by the NHS, in which case the NHS provides assistance with the essential activities of daily living as well as medical and nursing care<sup>21</sup>. Outside these facilities, however, and they are limited in number, means-testing applies. It applies everywhere in the UK to the so-called 'hotel costs' that are charged to individuals in institutional care (and also to the costs of help with homekeeping for people who live in the community). Nursing care, on the other hand, is not subject to meanstesting anywhere in the UK, even for those individuals paying full hotel costs in private residential care. As for 'personal care', Scotland operates a different system from the rest of the UK. Entitlement to publicly subsided personal care is means-tested in England, Wales and Northern Ireland, but not in Scotland.

What has made the means-test for publicly subsidised long-term care so controversial is that it incorporates an asset test, which takes into account housing as well as financial assets. The asset threshold for entitlement to full state support is set quite low ( $\pounds 12,500$  in 2005/6); and a very substantial increase in this threshold was yet another of the rejected recommendations of the Royal Commission. Anyone with assets worth more than £20,500 is liable to pay the full costs of their residential care (excl. nursing care) $^{22}$ . Pensioners with assets whose value lies between these ranges pay a proportion of the costs of their care. Although financial assets and income must be used to pay home charges, residents are not required to sell their home, even if it has been included in the assessment and they are liable to pay full fees. The local authority makes what is in effect an interest-free loan, and the costs are recovered when the estate is wound up. Laing & Buisson (2003) estimate that 25% of all care home residents are self-funding i.e. pay the full costs of care. The Office of Fair Trading put the figure somewhat higher than this (32%) and also estimate that one-third of residents with local authority funding (i.e. one quarter of all residents) top up their fees with support from a 'third party (OFT 2005). In other words, they or their family – are not happy with the level of care that can be purchased with local authority funding alone.

<sup>&</sup>lt;sup>20</sup> Since 2001 older people in care homes who are not eligible for means-tested support for the costs of their accommodation are assessed to determine their need for nursing care. The NHS pays for the costs of whatever nursing care they receive according to a fixed scale related to level of dependency (i.e. the NHS pays a subsidy to the care home).

<sup>&</sup>lt;sup>21</sup> Eligibility for what is called 'NHS continuing care' has been a matter of dispute (including legal dispute) for some years now. The essential principle, however, is that someone is eligible for NHS continuing care if their *main* care need is for medical or nursing care.

<sup>&</sup>lt;sup>22</sup> The value of a home is, however, disregarded for the first 12 weeks of admission for permanent residence. It is estimated that about 30,000 people benefit from this rule each rule.

The effects of the means-test are to some extent – but only to some extent – offset by the availability of a non-means-tested benefit paid to people aged 65 yrs or more who need help with daily living activities as a result of a disability, i.e. the *Attendance Allowance*. This is paid at two rates depending on the severity of the disability, and all self-funding residents in care homes are likely to be eligible, almost certainly at the higher rate. Although the rationale for the benefit is to help older people with the costs of additional care they might need, receipt of the benefit is in no way dependent on the purchase of additional care. The total amount paid out in Britain in 2004-5 was £4 billion, with about 1.4 million current claimants in February 2005. There is surprisingly little information available about how this money is used, though the evidence suggests that the majority of claimants do *not* use formal domiciliary services (Poole 2006). The money, in other words, serves mostly as a supplement to pension income.

#### A mixed economy of care

Residential care capacity peaked in 1995, having been inflated by the 'perverse incentives' of the pre-Community Care funding regime, and it has been shrinking (slowly) ever since. Laing & Buisson (2003) estimated that there were just over 500,000 available places in 2003. Most of these (69%) were in the private sector, more or less equally split between residential care homes (which provide personal care only) and nursing homes. The voluntary sector (i.e. charitable trusts that operate on a 'not-for-profit' basis) is much smaller – with 14% of beds – though it still has more places than are retained under the direct management of local authorities (about 10%). The rest are NHS 'continuing care' beds, and in 2003 the NHS had 30,000 long-stay beds for frail and mentally ill older people.

At the same time as residential capacity has been cut back, the use of domiciliary long-term care has been increasing. That is to say, there has been a steady increase in the number of home care contact hours i.e. the volume of services has been increasing. There has also been a massive shift in the identity of the providers – away from local authorities providers who dominated the 'market' in 1993 to the independent sector who now provide services to about two-thirds of all households that receive publicly subsidised home care (Wanless 2006) – which has prompted the development of a regulatory framework for domiciliary services to parallel the system in place for inspecting care homes (see below).

#### Users' views and users' choices: quality assurance, consumerism, and empowerment

#### Age and user satisfaction

It is sometimes said that the baby-boomers in old age will prove to be more critical and demanding of the health and social care services they receive than their parents' generation have been (e.g. Huber & Skidmore 2003). They will expect to be more actively involved in decisions about their care and will be altogether less accepting of second-rate services. The implication is that the often observed positive correlation between age and satisfaction with healthcare depends on a cohort/generation effect rather than an age effect<sup>23</sup>. People who had some experience of life's hardships before the establishment of the NHS tend to be grateful for the healthcare they receive. The generation born in the nineteen sixties has a quite different set of attitudes and expectations – and will carry these through into later life.

Whether or not this proves to be the case, it is certain that providers of health and social care in this country aim both to 'empower' the users of their services and to incorporate their views on the care they receive into the ongoing processes of quality assurance that are intended to monitor standards and guide the improvement of services. Regular soundings are taken at a national level of public satisfaction with the NHS and at local (i.e. Trust) level of patient experiences of care within it, and for several years now they have regularly shown a discrepancy between the levels of satisfaction reported by *patients* and what the general *public* thinks about the state of the NHS. Although UK citizens appear to be to be fairly happy with the care they receive as individuals, public confidence in the service appears to have been draining away, partly no doubt because of the effects of a chronic shortage of resources, yet partly also perhaps because of the development of a "more confident and reflexive consumerism" (Taylor-Gooby & Hastie 2003: 237). This long-term trend towards higher levels of dissatisfaction can be seen in all age groups, old as well as young (Calnan *et al* 2003).

The independent regulators for health and social care, established by the Labour Government in 2000, also take regular soundings of the views of patients and/or users, both by undertaking annual national surveys, and by taking active steps to involve patients and users in their audits of local services. The Healthcare Commission, the 'health watchdog' for both the NHS and the

<sup>&</sup>lt;sup>23</sup> Calnan *et al* 2003 conclude from an analysis of trend data from the British Social Attitudes survey that the evidence to date provides no support for this view.

independent healthcare sector in England<sup>24</sup>, is well aware, therefore, of the strong correlation between patient satisfaction and age, especially since it conducted its own analysis of the factors influencing variations in patient experience as a follow-up to the Department of Health's strategy to deliver "choice, responsiveness and equity in the NHS" (CHI 2004). Older people are consistently more positive about the health care they received than younger patient – irrespective of the nature of the service being provided.

#### The regulatory framework for health and social care

Although the Healthcare Commission is the primary agency charged with monitoring the progress of local services against the standards laid down in the NSFs, the content of the NSF for Older People clearly requires that in this particular area of care provision it should collaborate with the other main agency in the new regulatory framework, the Commission for Social Care Inspection (CSCI). The collaboration and coordination that they expect to find in health and social care services is reflected in their own activity as regulators (CHAI 2006).

The parallels between health and social care in the consolidatory changes in the regulatory framework made by the Labour Government after 1997 to some extent elide what might otherwise appear as a very important difference in the roles of the Healthcare Commission and the CSCI, namely that the CSCI is monitoring standards in a sector dominated by private and independent providers. The care home inspections, which were previously the responsibility of local authorities<sup>25</sup>, are now undertaken by a new national regulatory agency in much the same way as health facility inspections are undertaken by a new national regulatory agency. Where the Healthcare Commission uses the NSFs as its baseline for assessment, the CSCI uses a set of national minimum standards for care homes (DH 2003) and for domiciliary care agencies (DH 2000). The significance of the dominant position of the private sector providers in long-term care can still be detected, however, in the controversy excited by the care home standards (as opposed to the NSF for Older People). Critics of the standards (e.g. Pollock 2004) discern the unwelcome influence of the private sector in government decisions (a) to 'water down' the content of the original standards (by dropping the requirement for minimum staffing ratios and reducing to 50% the proportion of care home staff that should have appropriate, and nationally

<sup>&</sup>lt;sup>24</sup> This is the immediate descendant of the Commission for Healthcare Improvement. Scotland, Wales and Northern Ireland have their own equivalent agencies, the NHS Quality Improvement Scotland, the Health Inspectorate Wales, and the Regulation and Quality Improvement Authority.

<sup>&</sup>lt;sup>25</sup> LAs retain responsibility for health & safety inspections in residential care homes.

recognised qualifications), and (b) 'backtrack' on agreed specifications for room sizes and room sharing<sup>26</sup>.

#### Choice and empowerment

Listening to the views of users or patients, and incorporating them into the process of quality assurance, is of course not the same as 'empowering' them. Empowerment implies choice and control – and the expansion of choice has become one of the key principles guiding public service reform, not only in the UK, but in much of the OECD. The aim is to improve the efficiency of providers and their responsiveness to users of services. In the NHS the space in which choice must operate is that between GPs and the referral to specialist services, and the key step in the expansion of choice has, in principle, already been made: from 2008 all patients needing non-urgent treatment (e.g. joint replacements or cataract removals) will be able to choose any provider that has been accredited by the Healthcare Commission at the time of referral. What happens then is that the money 'follows the patient', which means that some providers may find themselves in serious straits. Whether or not such a move is likely to threaten geographical equity – as hospitals built to serve relatively deprived populations struggle to attract sufficient patients – is an issue that has much exercised both commentators and politicians over the last few years (Dixon, Le Grand 2006; Newman & Kuhlmann 2007).

The promotion of choice and user empowerment in long-term care requires different policy vehicles. Proper regulation of the market in private sector residential care (shared between the CSCI and the Office of Fair Trading), along with the provision of a wider range of housing options, is in this case essential, as is improved information for people trying to choose a care home for themselves or a relative. What seems, however, to have really caught the attention of policy makers aiming to promote choice and user empowerment in long-term care are direct payments. By offering older people the option of a cash payment instead of domiciliary services organised by the local authority, they offer not just choice, but control. The money may be used either to buy services from a local agency or to pay for care from friends and relatives<sup>27</sup>. Uptake of direct payments, despite their declared endorsement by users (CSCI 2005b) remains low, however, and is lower still for adults who are aged  $65+^{28}$ .

<sup>&</sup>lt;sup>26</sup> Only 'new' homes i.e. those registered after 2002 would be required to meet the new specifications.

<sup>&</sup>lt;sup>27</sup> Provided that they do not live in the same household.

<sup>&</sup>lt;sup>28</sup> 0.5% for older adult users as against 3.3% for people aged 18-64 yrs (Poole 2006).

#### Conclusion: challenges for the future

The pressures for major structural reform in the health and social care systems in this country are considerable. Many analysts believe that even in the short-term – i.e. over the next 5 years – the NHS faces a major and unavoidable challenge: it must *either* show signs of substantial improvements in productivity *or* face cutbacks *or* require further increases in the proportion of GDP committed to health care expenditure. Government has to deal with this challenge, furthermore, in the knowledge that the performance of the NHS – or more exactly, what users think of the service they are getting – has become a key test for its survival. Even in the short term, therefore, it looks as though the best option is reform. In the longer term, as Sir Derek Wanless has argued, if growth in health care spending is to be kept within reasonable bounds, it is essential to develop and implement health improvement programmes that will the demand for health care among the older population. The challenge here is partly set of course by population ageing – and the assumption that the greater numbers of older people in the population will *ceteris paribus* push up demand for health care services.

The long-term care system also faces the prospect of a big increase in demand over the next few decades, but the real pressures for structural reform comes from the level of public dissatisfaction with the conditions that determine eligibility for publicly subsidised care. Public dissatisfaction with the public provision long-term care does not yet carry the same weight with policy-makers, however, as dissatisfaction with the health service. Perhaps, at least in the short-term, it will be possible for government to continue to avoid the calls for an overhaul of the system without suffering too much political damage. It in the longer-term what is likely to be required is *either* an expansion of residential care capacity (will the market ensure that supply grows in line with demand?) *or* a very substantial increase in the proportion of severely dependent older people who receive intensive supported in their own homes.

#### References

Audit Commission (2000). Charging with care: how councils charge for home care. The Audit Commission for Local Authorities and the National Health Service London: Audit Commission Publications.

Calnan M *et al* (2003). Ageing and public satisfaction with the health service: an analysis of recent trends. *Social Science and Medicine*; 57: 757-762.

CHAI (2006). Living well in later well: a review of progress against the National Service Framework for Older People. A report prepared by the Healthcare Commission, the Commission for Social Care Inspection, and the Audit Commission.

CHI (2004). Unpacking the patients' perspective: variations in patient experience in England. London: Commission for Health Improvement.

Clements L (2007). Carers and their rights: the law relating to carers. London: carers UK.

CSCI (2005a). The state of social care in England 2004-5. London: Commission for Social Care Inspection

CSCI (2005b) When I get older: what people want from social care services and inspections as they get older. London: Commission for Social Care Inspection.

CSCI (2006). The state of social care in England 2005-6. London: Commission for Social Care Inspection

DH (2000). Shaping the future NHS: long-term planning for hospitals and related services. London: Department of Health.

DH (2003). Care homes for older people: national minimum standards and the Care Homes Regulations 2001. London: TSO.

Dixon A, Robinson R (2002). The United Kingdom. In: *Health care systems in eight countries: trends and challenges*. Commissioned by the Health Trends Review, HM Treasury. Prepared by the European Observatory on Health Care Systems. London: LSE.

Dixon A, LeGrand J (2006). Is greater patient choice consistent with equity? The case of the English NHS. *Journal of Health Services Research and Policy*; 11: 161-166.

Farrington-Douglas J, Brooks R (2007). The future hospital: the progressive case for change. London: Institute for Public Policy Research.

Hirsch D (2005). Facing the costs of long-term care: towards a sustainable funding system. York: Joseph Rowntree Trust.

Huber J, Skidmore P (2003). Why the baby boomers won't be pensioned off. London: Demos.

Klein R (2007). The new model NHS: performance, perceptions and expectations. *British Medical Bulletin*; 81-82: 39-50.

Laing & Buisson (2003). Care of elderly people market survey.

Lewis & Dixon (2005). NHS market futures: exploring the impact of health services market reforms. London: Kings Fund.

Means R, Morbey H, Smith R (2002). Targeting, rationing and charging for home care services. In: *From community care to market care: the development of welfare services for older people*. Bristol: Policy Press.

NAO (2003a). International health comparisons: a compendium of published information on healthcare systems, the provision of healthcare, and health achievement in 10 countries. A report compiled by the National Audit Office. London: TSO.

NAO (2003b). Ensuring the effective discharge of older patients from NHS acute hospitals. Report by the Comptroller and Auditor General, HC 393. Session 2002-3. London: TSO.

Newman J, Kuhlmann E (2007). Consumers enter the political stage? The modernization of health care in Britain and Germany. *Journal of European Social Policy*; 17: 99-111.

OECD (2003). Health care systems: lessons from the reform experience. Paris: Organisation for Economic Cooperation and Development.

OECD (2005). Long-term care for older people. Paris: Organisation for Economic Cooperation and Development.

OFT (2005). Care homes for older people in the UK: a market study. London: Office of Fair Trading.

ONS (1996) Living in Britain. Results from the 1995 General Household Survey. London: TSO.

ONS (2002). Living in Britain. Results from the 2001General Household Survey. London: TSO.

Pollock A (2004). NHS plc: the privatisation of our health care. London: Verso.

Poole T (2006). Private expenditure on older people's social care. Background paper for the Wanless Social Care Review. London: Kings Fund.

Poole T (2006). Directs payments and older people. Background paper for the Wanless Social Care Review. London: Kings Fund.

Wittenberg R et al (2004). Future demand for long-term care in the UK: a summary of projections of long-term care finance for older people to 2051. York: Joseph Rowntree Trust.

Royal Commission on Long-Term Care (1999). With respect to old age: long-term care - rights and responsibilities. London: TSO.

Seshamani M, Gray A (2003). Health care expenditures and ageing: an international comparison. *Applied Health Economics and Healthy Policy*; 2: 9-16.

Victor C *et al* 1993 The inappropriate use of acute beds in an inner London DHA. *Health Trends*, 25, 3, 94-97.

Taylor-Gooby P, Hastie C (2003). Dissatisfaction with the NHS: too few resources or the 'new consumerism'?. *Political Quarterly*; 74: 233-240.

Wanless D *et al* (2002). Securing our future health: taking a long-term view. Final report. London: HM Treasury.

Wanless D *et al* (2006). Securing good care for older people: taking a long-term view. London: Kings Fund.

Wanless D *et al* (2007). Our future health secured: a review of NHS funding and performance. London: Kings Fund.