

# advancing opportunity:

older people and social care

Edited by Neil Churchill



THE SMITH INSTITUTE

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## **Preface**

Wilf Stevenson, Director, Smith Institute

The Smith Institute is an independent think tank which has been set up to undertake research and education in issues that flow from the changing relationship between social values and economic imperatives. In recent years the institute has centred its work on the policy implications arising from the interactions of equality, enterprise and equity.

Figures abound about the increasing age of Britain's population; and, as baby boomers reach retirement and people live longer, the changing demographics are placing ever greater strains on our social care system. Since the post-war creation of the welfare state, the percentage of the population aged over 65 has increased, from 10.5% to 15.7% in 2001, and is set to rise to 24.2% by 2051. There is already evidence of unmet need in the social care system, and the pressure on services is immense. The pressure is not only one of numbers, however. There is an expectation of high-quality support and care, from a population increasingly used to high-quality services (both public and private) tailored to their needs.

Making social care fit for the 21st century will not be easy. With a diminishing workforce (in percentage terms) and a reluctance to raise general taxation, various reports have begun to highlight the need for radical change, and to point to the consequences of not responding to this need. As Neil Churchill's introduction states, those consequences will be severe.

Building on that emerging consensus, the essays in this monograph seek to articulate more fully how and where policy change and intervention are required. The authors examine the trade-offs to be made between quality and coverage; the case for more targeted support; the concept of co-payment; and the role of the private market for care insurance. Most importantly, the essays aim to set out some positive and achievable options, which can lead to the action that is necessary to ensure the dignity and meet the aspirations of Britain's older citizens.

The Smith Institute thanks Neil Churchill (director of Asthma UK) for agreeing to edit this collection of essays, and gratefully acknowledges the support of Age Concern England and the Association of British Insurers towards this publication and the associated seminar.

## Foreword

Ivan Lewis MP, Minister for Care Services

This Smith Institute monograph has come at an excellent time and will make an important contribution to a debate on an issue that will touch the lives of the vast majority of families in our country.

The government has signalled 2008 as a landmark year in beginning a radical transformation of the adult social care system.

The changing demography of the UK means that an increasing number of people are living longer, but with more complex conditions such as dementia and chronic illnesses. By 2022, 20% of the English population will be over 65. By 2027, the number of those aged over 85 will have increased by 60%. People want – and have the right to expect – services with dignity and respect at their heart. Older people, disabled people and people with mental health problems demand equality of citizenship in every aspect of their lives, from housing to employment to leisure. The vast majority of people want to live in their own homes for as long as possible.

A combination of short- and longer-term reform will be at the heart of our commitment to meeting these challenges.

This year a three-year programme of system-wide transformation will begin in every local community. The Prime Minister will announce a New Deal for Carers. A countrywide consultation followed by a green paper will focus on a new long-term funding settlement for adult care.

Transformation programmes led by local government will seek to ensure that all citizens, irrespective of their means, have access to universal high-quality information and advice as they make difficult choices about support for themselves or family members. The perennial right of self-funders to exercise control and choice over their care will be extended to people receiving public funding through personal budgets. Local authorities, the NHS, and the third and private sectors will be expected to combine their resources in a local health and well-being system recalibrated to focus on prevention, early intervention and re-enablement.

The Prime Minister's New Deal for Carers will seek to give greater support and recognition

to the millions who devote a major part of their lives to caring for an elderly, disabled or ill relative. An unprecedented consultation with carers has identified income, respite care, their relationship with professionals and the balance between employment and caring responsibilities as key issues of concern. New priorities include the distinct needs of young carers and of "double carers", who are bringing up children while caring for an ageing relative.

Stakeholders have warmly welcomed our commitment to a public consultation and green paper on a new long-term funding settlement for adult social care. However, as the recent Caring Choices report and this collection of essays demonstrate, defining the respective responsibilities of the state and the citizen in a new system that is fair and sustainable will not be easy. We will have to consider the overall cost of a care system that offers people the quality and choice they have a right to expect; the balance between national entitlement and local discretion; the weighting given to needs and means, long- and shorter-term care; the parameters of funding through general taxation and the potential for individual contributors via new insurance and equity release schemes; and, most difficult of all, directing the highest proportion of state subsidy to those in the greatest need while seeking fairness for those whose income and assets define them as neither rich nor poor. In moving away from the current system and rejecting the bogus offer of free care for all, serious politicians in all parties should strive to achieve a consensus for change.

People's right to live their lives with maximum autonomy and dignity irrespective of their disability or illness is integral to a socially just and civilised society. That is why the Smith Institute is right to highlight the challenges facing the adult social care system, challenges that are now a social policy priority for this Labour government.

## Introduction

Neil Churchill, Chief Executive of Asthma UK

Our nation is getting older. Today, the average lifespan increased by five hours. In the past decade, it has grown by 2.2 years. Scientists say this looks set to continue into the near and possibly distant future. The increase has rightly been welcomed as good news: living for longer is generally preferred to the alternative. But our ageing population has also presented major challenges for policy makers. Our political leaders only recently faced their first major policy test on this issue, with their response to Lord Adair Turner's Pensions Commission. The second test is now looming: how to respond to Sir Derek Wanless's analysis of our social care system.<sup>1</sup>

Wanless presented a powerful case for change. Over the next 20 years, the number of people aged 85 and over in England is set to increase by two-thirds, compared with a 10% growth in the rest of the population. And yet, Wanless found there is already evidence of "significant unmet need" and merely standing still will require significant new public spending. As Melanie Henwood shows in chapter 1, his report stands in a long line that includes a Royal Commission and reports by the Joseph Rowntree Foundation and others. Looking ahead, David Brindle argues in chapter 2 that the gap between need and reality will be compounded by the growing expectations of baby boomers, who will insist on greater choice and quality.

The challenge is not restricted to longevity alone. "The linear increase in lifespan is colliding with a roughly exponential increase in degenerative disease with age," argues Guy Brown of Cambridge University.<sup>2</sup> "The result is a massive expansion of degenerative disease at the end of life". Of the 2.2 additional years we have been granted over the last decade, only 0.6 of those years are likely to be healthy, with the remaining 1.6 years spent in ill health. The number of people with dementia is projected to grow from 700,000 today to 1.75 million by the middle of the century.

And yet, as a society we are already failing older people at a time when they are most vulnerable. A glance at the headlines is sufficient to see the limitations of current policy. It was reported as we went to print that 73% of local authorities are refusing care to everyone whose needs are not considered "substantial".<sup>3</sup> The Alzheimer's Society has

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1 Wanless, D *Securing Good Care for Older People: Taking A Long-term View* (King's Fund, 2006)

2 Guy Brown "No Way to Go" in *Society Guardian*, 14 November 2007

3 "Councils Turn Backs on Care for Older People" in *The Guardian*, 22 November 2007

reported that there is a "disturbing" amount of this care which is "absolutely appalling".<sup>4</sup> Earlier, a super-complaint was presented to the Office of Fair Trading, complaining that rules on funding care are opaque, changeable and unfair.<sup>5</sup>

What do these perceived policy failings mean in practice? They mean frail people are going without care and support, when they need it to stay healthy and independent, or being rushed into residential care when other options are preferred. They mean that older people can get a dozen or more paid carers in a single year, with visits lasting less than five minutes. And they mean that frail older people are sometimes warehoused, neglected and abused in care settings that are supposed to enhance their quality of life and independence, but instead leave them ill, depressed and unable to fulfil their potential. Alison Macadam and Helen Bowers describe in chapter 3 the barriers that stop older people exercising their rights to dignity and citizenship and argue for a rights-based approach to enhance the voice, choice and control that older people have.

Clearly, there is growing concern about the quality of the service that is now provided, as well as doubts about its sustainability and acceptability. But fortunately, there is optimism too. Optimism that something can and will be done to build a social care system fit for the 21st century. As this monograph shows, there are grounds for optimism, but we face some difficult decisions.

In the case of care as well as pension reform, the government is faced with a need to renegotiate the social contract between different partners: in the case of pensions, the partnership between state, employer and individual, facilitated by the insurance industry. For social care, the partnership between national and local government and individuals who, by contrast to pensions, have so far been left largely unsupported by either market or employer. The key difference between the care and pensions policy debates is possibly that national government had the levers it needed for pension reforms. To achieve care reforms, it will face the range of workforce, incentive and localism tensions that it encountered with the NHS.

Faced with these demands, politicians will have to balance pressure for increased public spending with their instinct for the political ceiling on how much tax we are prepared to pay. John Hills, one of the pension commissioners, has argued that there are clear choices

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4 Alzheimer's Society *Putting Care Right* (November 2007)

5 Super-complaint made to Office of Fair Trading in 2004 by the Consumers Association and others

open to us.<sup>6</sup> Those choices include: maintaining social spending but concentrating it on the poor; increasing spending across the board to keep up with demographic and other pressures; or increasing spending faster than the external pressures so that services can improve.

With social care as with pensions, Labour began office by targeting resources towards the poor, but must now consider a broader response that reflects both this need and more widespread concerns. This is because policy failings affect frail and vulnerable people of different incomes, and the threshold for state funding is widely seen to be unfair. Moreover, reformers argue that policies need the support of the middle classes in order to be sustainable. A glance at newspaper coverage on care shows such support is clearly lacking.

The case for change seems to be recognised by politicians of all parties. "Demographic pressures and a largely unreformed social care system are leaving too many older people with inadequate support," argues Ivan Lewis, the health minister responsible for care.<sup>7</sup> "The quality of provision is patchy, from service to service and area to area." Other politicians seem to agree that merely maintaining the status quo is not an option. Norman Lamb, Liberal Democrat spokesman, has criticised lack of funding for older people's care and argued for hospitals and social care to work more closely together.<sup>8</sup> Although the Conservative Party has not announced its policy on this area, its public services improvement group highlighted that failure to deliver social care outcomes "would undermine the delivery of the fully-engaged scenario in the NHS" to which it is committed.<sup>9</sup> It seems that all parties are responding to the realities set out by Lord Bruce-Lockhart (see chapter 11), whose local political experience of managing priorities on inadequate resources led him to be an early champion for care reforms.

This seems to put the mainstream debate squarely in John Hills' final scenario: a relative increase in spending, in order to improve services. This requires an increase in funding over and above the additional £14 billion that Wanless says is needed in 20 years just to maintain the current level of provision.

All agree that reform must precede these additional funds, and here there are important

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6 Hills, *J Inequality & the State* (Oxford University Press, 2004)

7 Ivan Lewis "Now the Elderly Will Get Equal Rights" in *The Observer*, 24 June 2007

8 Speech, November 2007

9 Public Services Improvement Group *Restoring Pride in our Public Services* (2007)

trade-offs to be made between different policy goals within a finite spending envelope and the need to achieve fairness across, as well as between, generations.

One trade-off is likely to be between quality and coverage as priorities for public spending. Reformers want to increase the quality of care and make paying for care fairer, for more people. The partnership model, favoured by Wanless, involves a benchmark of care set at an "economically justified" level. The right benchmark could improve both quality and fairness. Setting the benchmark too low could reduce the cost of care for more people but might fail to increase the quality of care being purchased, without additional top-up payments. Alternative policy measures face the same dilemma. And yet the need to improve and not just maintain quality is at the heart of the debate. In chapter 4 Gordon Lishman argues that quality must be at the heart of reform: the rights and needs of many old people are now routinely being denied, in ways that ignore basic human rights and leave people unheard, dissatisfied and vulnerable to neglect and abuse.

Another set of trade-offs comes when we consider different approaches to raising quality. Professor Jill Manthorpe points out in chapter 7 that the median gross hourly pay rate for most care workers is scarcely above the minimum wage. There is no doubt that high turnover and vacancy rates affect quality of care. Can we build the social care workforce of the future without a significant wage rise for nearly a million care workers? How big a share of new resources will need to go to workforce reform? But other means of raising the quality of care will cost too. Anne McDonald, in chapter 5, demonstrates how improved commissioning, direct payments and individual budgets can improve the quality of provision, if local authorities are suitably funded for it. Additional funding will also be needed to provide the brokerage and information services proposed by Stephen Burke in chapter 9. Which measures will have the biggest effect on quality?

Of course there will be trade-offs between winners and losers, especially when there is concern both to support the poorest but also to improve fairness across broader society. Stephen Haddrill, writing in chapter 6, proposes a number of measures to broaden the private market for care insurance; many of these measures could be popular with individuals of modest means who are left reeling at the huge fees demanded of self-funders. But policies like term limits for self-funding would benefit those with assets, not the poor. At the other end of the wealth spectrum, Sir Derek Wanless's report suggested integrating benefits like attendance allowance into the care system to improve the targeting of resources. But new analysis by Professors Richard Berthoud and Ruth Hancock in chapter 8 shows that some disabled people would lose out from this reform.

Could this be considered fair?

There are also trade-offs to be made between current and future needs. More focus on prevention could help prolong healthy life expectancy and delay the onset of ill health. Such services could help people stay in their own homes and out of more expensive forms of residential care. A broader emphasis on prevention and well-being will counter the pathology of rising costs associated with rising expectations, better medicine and the ageing of our population. Yet the economic benefit of those health improvements will not be felt for some time, and there is an immediate need to improve the availability and quality of services for people who already have very poor health and little independence. This lies at the heart of debates about respective funding for health and social care, public health and acute services. Pilots have been set up to demonstrate the economic case for investment in prevention, and joint appointments and structures are being explored at a local level. But with any finite resource, and limited budget timeframes, which services will take priority?

Perhaps the greatest similarity with the pensions debate is that there is no easy solution and a new partnership will depend on how people respond to the concerns they now express. A combination of policy reform and additional financing will be needed to achieve the desired policy goals of most reformers. Even if we are successful in prolonging independence, more accessible and better-quality care will cost more and individuals will have to pay – through some combination of taxes and private contributions. What prospects will politicians face if they make the case for additional spending, either through taxes or private payments? Can individuals be persuaded to plan ahead for their care needs, when they were deemed unlikely to do so for their pensions? What will it take to win a public debate in favour of deep reform?

Many parts of the world are experiencing fast ageing populations and long-term care has become a global policy challenge, like pensions before it. In chapter 10 Professor Caroline Glendinning considers what lessons we can learn from reform overseas and concludes that one ingredient of successful reform is strong political leadership. This has enabled system-wide reforms to be implemented in countries as politically diverse as Germany and Japan.

Does that leadership exist in the UK? Sir Derek Wanless, writing in chapter 12, expresses himself cautiously optimistic and argues that the government's commitment to a green paper represents a tipping point in the debate. The recent concordat on funding,

announced by the government, the NHS and the Local Government Association, is another positive sign that change is possible.

There remains much more to do to achieve lasting reforms and many difficult questions to answer. I hope the ideas and analysis in this monograph are useful contributions to the detail as well as the principles of the next phase of that debate. Despite their unique perspectives and policy prescriptions, all the contributors would agree that the cost of inaction would be severe.

## Chapter 1

# The emerging debate on social care

Melanie Henwood, Independent Health and Social Care Consultant

## The emerging debate on social care

The report of the Royal Commission on Long Term Care in 1999<sup>1</sup> signalled a sea change in political and public debate. The government rejected the report's core recommendation that personal care should be free to all people needing it. Scotland, by contrast, accepted the recommendations; Northern Ireland has also stated its determination to implement a manifesto commitment to free personal care. Far from the royal commission report marking the end of uncertainty and confusion over long-term care, the failure of the government to accept the major recommendations ensured that multiple loose ends were left dangling. As further reviews have indicated, it is increasingly clear that the present situation is untenable and fast unravelling.

This paper reviews developments and debate in the wake of the royal commission and considers likely prospects for the way forward. The 2007 comprehensive spending review announced the government's intention to "develop a reform strategy" for funding social care. A green paper is to be produced setting out key issues and options for reform. It is therefore especially timely to contribute to this debate as it enters a new phase with potentially wide-reaching implications for current and future generations.

### Paying for long-term care

The royal commission on the funding of long-term care was established in December 1997 with the remit to address "a sustainable system of funding of long-term care for elderly people" and to recommend how such costs should be shared between public funds and individual responsibility. The publication of the 2007 comprehensive spending review announced plans to consult on "reform of the public support and care system focusing on older people, to ensure a sustainable system that targets resources effectively, is affordable and promotes independence, well-being and control for those in need".<sup>2</sup> The similarity of the terms of reference for both reviews is striking, and an immediate – if slightly cynical – response might be to question the need for such additional investigation. Over the past decade there has been a significant volume of research and consultation on such matters; in place of yet more consultation and further delay it might be argued that what is needed now is action.

The royal commission highlighted the unfairness of the existing system, particularly

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1 Sutherland, S *With Respect to Old Age: Long Term Care – Rights Et Responsibilities: A Report by the Royal Commission on Long Term Care*, Cm 4192-1 (The Stationery Office, 1999)

2 Department of Health *2007 Pre-Budget Report Et Comprehensive Spending Review, Annex D2* (2007)

because it penalises people who have savings or own their own homes. The system was judged to offer little choice, to encourage people to enter care homes rather than remain at home, to be overly complex and to offer no sense of security. Private-sector funding and insurance were not viewed as viable options at an acceptable cost, and the case was argued for a system of pooling risk across all citizens "through services underwritten by general taxation, based on need rather than wealth".

The recommendations did, however, make a distinction between the costs of "personal care" and those associated with housing and living costs, and argued that while the former should be paid for from general taxation following an assessment of need, housing and living costs should be subject to a co-payment and means tested. This would not mean that people needing long-term care would have all the costs of that care met in the same way that they would in hospital, as the commission argued:

*We do not think however, that this is desirable or necessary. Not would it be a proper use of limited public funds. People who receive care at home have to meet their living and housing costs themselves. The same should apply for people in residential settings [...] The costs of personal care as such are however quite different. These are the costs which unpredictably and through no fault of their own, old people have to incur when unfortunately they can no longer be looked after at home or cannot be sent home after hospital treatment. They reflect the true risk and 'catastrophic' nature of needing long-term care. In our judgment it is right for the state to exempt personal care from means testing altogether. This is our key recommendation.<sup>3</sup>*

The recommendations from the royal commission were not unanimous; had they been so it might have been a different story. A minority report (or a "note of dissent") was signed by two of the commissioners. The major point of disagreement concerned the recommendation on free personal care; it was argued that the additional burden on public expenditure would not increase spending on services for older people, would fuel demand for care, and would subsidise "the better-off members of society and their heirs, at the expense of those most in need".<sup>4</sup>

The government rejected the core recommendation to make personal care free on the same grounds cited in the minority report – that it would be too costly, would not

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<sup>3</sup> Ibid, paras 6.31-6.32

<sup>4</sup> "Note of Dissent" by Joel Joffe and David Lipsey, para 4, in Sutherland, S, op cit

necessarily improve standards, and would not help those least well-off. Instead, alternative proposals were advanced in the belief that improved “standards of care and fair access to services will generate more important benefits of health and independence for all older people, now and in the future.”<sup>5</sup>

Moreover, it was claimed that investment in intermediate care services and in other preventive and rehabilitative services, together with changes to the charging rules for the first three months of residential care, would together constitute “a sustainable framework for future generations. It will ease the financial burdens on older people and their families, and drive up standards for everyone.”<sup>6</sup>

Clearly, as the latest announcements for consultation on reform indicate, no such “sustainable framework” was established. While important changes and new investment patterns *have* been established, these *have* done little or nothing to address the fundamental inequity and difficulties that beset paying for long-term care – hence the resurfacing of the question of reform.

The response to the royal commission did, however, make an important change to arrangements for paying for nursing care. As the commission had pointed out, it was entirely anomalous that nursing care should be charged for in nursing homes but nowhere else (that is, not in hospitals and not from community nurses). The government accepted that there could be no justification for charging people in care homes for their nursing costs, and duly introduced legislation to provide for the costs of registered nursing care (the registered nursing care contribution, or RNCC).

These arrangements were phased in from October 2001, but were beset with difficulties. In particular, the three bands of RNCC that were introduced were controversial, and indeed perverse effects were identified in the consequences of a person's need for nursing care actually reducing because of good nursing and rehabilitative care, which could lead to them dropping from one nursing band to another and having to pay a larger contribution towards their care costs. In effect, the system worked to reward dependency rather than to encourage and support improved independence.

Both the medium and high bands of RNCC had been defined in practice guidance using

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<sup>5</sup> Department of Health *The NHS Plan: The Government's Response to the Royal Commission on Long Term Care*, Cm 4818-II (The Stationery Office, 2000), para 2.6

<sup>6</sup> *Ibid*, para 2.7

similar wording to the criteria for NHS continuing healthcare.<sup>7</sup> Not only was this the cause of much confusion, but people potentially could be banded as "medium" or "high" when in fact they were receiving a level of nursing care beyond that which could be deemed incidental and ancillary (and hence should be the responsibility entirely of the NHS, and not of social care).

Since 1 October 2007 new arrangements for funded nursing care have been introduced. In place of the three bands (high, medium and low), a single band for NHS-funded nursing care has been established (at the weekly rate for eligible care home residents of £101).<sup>8</sup> People who received the low or medium band prior to 1 October 2007 will be transferred automatically to the new band. People who have been receiving the high band of RNCC will continue to receive the higher level until their case has been reviewed under the new national framework for NHS continuing healthcare.

It is impossible to consider the issue of paying for long-term care without also considering the relationship with NHS continuing healthcare. In many ways this interface highlights the inherent difficulties around the question of who pays. While personal care is charged for and subject to a means test, NHS continuing healthcare is fully funded and the person using the service makes no contribution to the cost of their care, regardless of their means.

The new national framework for NHS continuing care provides the same basis for assessing eligibility throughout the country, replacing the system of allowing this to be defined by 29 strategic health authorities in England. However, while this represents a significant improvement in addressing anomalies and the postcode lottery between different parts of the country, the contrast with the approach to social care (with locally determined eligibility criteria and decisions about which bands of need are addressed under the framework of fair access to care) is all the more stark.

Since the report of the royal commission the debate has continued to advance and has been led by, among other bodies, the health select committee of the House of Commons, the Joseph Rowntree Foundation, and the Wanless review commissioned by the King's Fund.

### **The emerging debate: evidence from reviews**

The health committee undertook an inquiry into NHS continuing care in 2005 and argued

<sup>7</sup> Department of Health *NHS Funded Nursing Care: Practice Guide & Workbook* (2001)

<sup>8</sup> Department of Health *NHS Funded Nursing Care: Practice Guide 2007* (2007)

that it is impossible to resolve the issues without first establishing a fully integrated health and social care system. The committee also drew attention to the fact that reductions in the number of long-stay hospital beds over two or three decades "has meant that people who would previously have been looked after without charge in a hospital are now instead being cared for in fee paying nursing or residential homes, or in the community".

While there are many positive aspects to these trends – not least the development of more appropriate care, none the less, as the committee remarked, "care that was previously provided in the NHS [...] is increasingly being provided outside the NHS", with the costs of that care being "shunted from the NHS to local authorities and individual patients and their families"<sup>9</sup>.

Witnesses to the inquiry, including the minister, were unable to provide the committee with a clear definition of the distinction between health and social care. The focus on identifying whether needs should be viewed as health or social care can impede any attempt to look holistically at people's needs for care.

The committee argued that as long as there are two systems (health and social care) operating according to different principles, "the highly controversial issue of which patients qualify for fully funded NHS care, and which have to contribute some or all of the costs of care, will remain". Accordingly, the committee recommended that the government remove the "wholly artificial distinction" between a universal and free health-care service operating in parallel to a means-tested and charged-for system of social care.

The government's response to this recommendation was to point to the fact that the separation of health and social care has stood since 1948, and "to dismantle this would be a fundamental and costly change to the structure of the welfare state".<sup>10</sup> This is a poor argument – the idea that simply because something has existed for almost 60 years it should remain in place for ever more, regardless of whether it is fit for purpose, is non-sensical. Indeed, the opposite argument could be made; precisely *because* the system has been in place so long while the context in which it operates has changed substantially, there could be a case for revisiting the fundamental principles and structures.

The Joseph Rowntree Foundation has also made a central contribution to the debate about the future of long-term care. A major inquiry was conducted more than a decade

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<sup>9</sup> House of Commons Health Committee *NHS Continuing Care*, sixth report of session 2004-05, HC 399-I (2005), para 41  
<sup>10</sup> Secretary of State for Health *Response to Health Select Committee Report on Continuing Care*, Cm 6650 (2005), p3

ago, arguing for an overhaul of the funding of long-term care.<sup>11</sup> More recently the foundation has again made the case for change, highlighting inadequacies of the structure of long-term care alongside insufficient resourcing of the present system.<sup>12</sup> The recommendations offered by the foundation address fundamental reform to secure a sustainable and rational funding structure, alongside interim changes to reduce immediate difficulties with the system. Incremental changes are recognised to be insufficient of themselves but may be important in preparing the ground for wider reform.

A recurrent theme in the work by the foundation and other key commentators in this area is that any alternative system of funding long-term care needs to command public support. Thus, it needs to be seen as fair, and to be something towards which people are prepared to contribute. The case for change rests on three central issues:

### **Inadequate overall funding**

The Joseph Rowntree Foundation identifies evidence pointing to unmet need because of inadequate funding. This relates to poor service quality, inadequate supply of support (notably in the lack of "low-level" services), and affordability problems which necessitate people on modest incomes having to pay large charges to get access to care in their homes.

Demographic projections (particularly the growth of the population aged over 85) indicate that long-term care costs could increase fourfold between 2000 and 2051 (from £12.9 billion to £53.9 billion in real terms). On the basis of current policy much of this increased cost would fall on individuals.

### **Incoherent and complex funding**

As the royal commission also argued, long-term care funding is extremely complex and difficult for the public to understand. In particular, the overlap between social care funding and NHS fully funded "continuing care" remains an area of enormous confusion and apparent inequity. The distinction between health and social care is also (as noted above) anomalous.

### **Lack of rationale for cost sharing**

It is highly probable that some form of cost sharing between public and private funding is inevitable. However, at present the basis for this sharing is unclear and widely resented

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<sup>11</sup> Joseph Rowntree Foundation *Inquiry into Meeting the Costs of Continuing Care* (1996)

<sup>12</sup> Joseph Rowntree Foundation *Paying for Long Term Care: Moving Forward* (2006)

by people who find themselves losing virtually all their assets and savings before they can qualify for state help. The issues around the necessity of selling houses to pay for care, and running down capital assets, have been widely rehearsed – not only by the foundation and other reviews, but also in the media.

On the basis of these three central problems the foundation's analysis concluded that "users neither understand nor accept the existing basis for funding long-term care".

The challenges of long-term care are not unique to Britain; they are shared by all advanced societies that have ageing populations. Systematic reforms have been introduced in Japan and Germany and the foundation argues that in both cases a coherent and transparent system has been established. In Japan there is a co-payment system that clarifies responsibilities and requires everyone to contribute a given proportion of their care costs (with the tax-funded system paying for 90% of the costs of care both in care homes and in the community). The foundation argues that a similar model could work in the UK, with a more universal system of public subsidy paying for most care costs regardless of people's means. It is estimated that moving to a system in which the state paid for 80% of all care costs would cost an additional £2 billion a year.

The Wanless review of social care examined the costs of providing care for older people over the next 20 years.<sup>13</sup> In estimating future resource requirements the review drew attention to some fundamental questions: What is social care? What is it trying to achieve? And for whom? A number of possible scenarios were presented, reflecting different levels of ambition. Even on the basis of maintaining the current service model (that is, merely to stand still) total costs are projected at £10.1 billion in 2002, rising by 139% to £24 billion by 2026. More ambitious models could see the cost rising to £31.3 billion.

The Wanless review also examined alternative ways to fund social care. Three main options were identified. With free personal care the state would contribute around 78% of total care costs; with a partnership model (in which the state is responsible for a minimum guaranteed proportion of costs) the state would contribute 71%, and under a limited-liability model (means testing for the first three or four years of care, followed by free personal care) the state would contribute 60% of total care costs. All three models were believed to have strengths and weaknesses, but the Wanless review considered the partnership model to offer the best option. Implementing this change would require a

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13 Wanless, D *Securing Good Care for Older People: Taking a Long-term View* (King's Fund, 2006)

radical shift not only in the care system but also in the benefits system.

Both the Wanless and Joseph Rowntree Foundation reviews have offered alternative approaches to funding long-term care, based on clear statements of values and principles. The present system of means testing protects the poorest people, but is harsh in its impact on people who are just outside the means-testing limits, who are obliged to draw down their savings and assets, but who have a limited ability to pay for their own needs. The partnership model is not as expensive to implement as free personal care, but is more expensive than means testing and would therefore require additional public funding compared with the current system.

The report of the royal commission in 1999 did not present a partnership model as one of the alternative approaches to paying for care (although it did explore a limited-liability option). Accordingly, it recommended that free personal care represented the best of the options considered. As noted at the outset of this paper, Scotland chose to implement this recommendation. Another chapter in this collection explores the lessons from the Scottish experience in greater depth, but it is important to note some of the key developments.

The concept of "free personal care" is in many ways erroneous. Research on the implementation of the model in Scotland has confirmed that there is confusion and often a mistaken belief that *all* social care is free (where in fact the "hotel costs" of residential provision are still means tested and charged for).<sup>14</sup> Eligibility for free personal care is limited to people older than 65, and this inequity is the focus of understandable dissatisfaction among other people needing care and support. This also raises an important point of principle in considering any reform of long-term care funding: it is imperative that any change applies to every person who may need support, not only older people.

Payments for personal care and nursing care in care homes are fixed at £145 and £65 a week respectively. Since free personal care was introduced in Scotland there has been a significant increase in demand for care. During the first three years of implementation there was a 62% increase in the provision of free personal care at home, and a 29% increase in residential provision.<sup>15</sup> It is possible that some of this "extra" demand indicates substitution is taking place for care that was previously provided by informal carers. It is also likely that there was hidden unmet need which is now being addressed because

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<sup>14</sup> Bell, D, Bowes, A and Dawson, A *Free Personal Care in Scotland: Recent Developments* (Joseph Rowntree Foundation, 2007)

<sup>15</sup> *Ibid*, p5

people are not deterred by charges from seeking help. Implementation of free personal care in Scotland has not been without difficulties and, while care may be "free", access has been managed by waiting lists or "priority registers".

Work undertaken in Scotland by the Caring Choices coalition indicates that there are wide variations between local authorities in their implementation of the policy, with consequent problems of unequal access to care and support across Scotland.<sup>16</sup> From the outset local authorities in Scotland have faced various challenges in meeting the costs of free personal care. There are on-going questions about the adequacy of the funding formula operated by the Scottish Executive which has reinforced regional variations in expenditure, and historical patterns of spending have had unforeseen consequences for free personal care.<sup>17</sup> This situation also reflects the inadequacies of data to allow the establishment of an accurate funding baseline.

### **Conclusions and next steps in reform**

The government's commitment to setting out a process for public engagement with a view to a green paper on social care identifying key issues and options for reform is welcome. It is unfortunate that it has taken so long to reach this position, which might have followed on directly from the report of the royal commission in 1999. None the less, as the above discussion has indicated, the period since 1999 has been enriched by on-going examination of these important issues.

For well over a decade there has been recurrent debate on how best to pay for long-term care. For much of that period analysis was hampered by the absence of reliable data and economic modelling. However, the considerable work undertaken – particularly by the Joseph Rowntree Foundation and Wanless – has provided an extensive resource of demographic and financial data. It is important that in setting out to address a reform strategy, the government takes full account of the totality of evidence already available.

It is evident that there are a number of different ways in which long-term care might be funded; as the Wanless review in particular has demonstrated, the choice is not simply between the present means-tested system and an alternative of free personal care. Other options exist, not least a partnership model that could combine a universal model of entitlement supplemented with a progressive system of means-tested individual contributions.

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16 Caring Choices report on event held in Edinburgh on 4 October 2007

17 Bell, Bowes and Dawson, *op cit*, p55

It is essential that the options for reform are addressed not only in terms of finding a new funding mechanism, but also in terms of identifying a new system that will deliver the desired outcomes for long-term care. The government appears to recognise this in stating its three requirements for reform, namely that it must promote independence, well-being and control for those in need of support, be consistent with the principles of progressive universalism, and be affordable.<sup>18</sup>

Other tests might also be applied to evaluate any proposals. The royal commission, the Joseph Rowntree Foundation, and the Wanless reviews have all assessed options against clear statements of values and principles.

The green paper will provide an opportunity for wholesale reform. This is not the occasion for further incremental change; such has been the pattern in social care ever since the reforms of the 1990s, and the present confused and inequitable muddle is the direct result. The establishment of a national framework for NHS continuing care underlines once again the impossibility of addressing the health aspects of long-term care while failing to also address social care. The NHS is a sacred cow of British politics, but that should not deter the government from having the courage to address long-term care in the round.<sup>19</sup>

The Wanless review acknowledged that the interface between NHS continuing care and long-term social care remained problematic; its proposals for a partnership model would mitigate the difficulties but not remove them. As the review noted, "the gradient of the financial cliff-face between the two" would be significantly reduced but it would not be removed. The Secretary of State for Health has declared that there should not be any "no-go areas"<sup>20</sup> in the debate leading to a green paper, and if this is really the case, radical thinking is required. At the same time, it has also been stated that some form of means testing is inevitable. Squaring this circle will be extremely challenging, and while recognition that the current arrangements are unsustainable is welcome, greater clarity is still needed about the actual parameters of the debate.

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18 "Stronger Communities and a Better Quality of Life", chapter 6 of 2007 *Pre-Budget Report & Comprehensive Spending Review* (HM Treasury, 2007)

19 Henwood, M *NHS Continuing Care in England: Background Paper to the Wanless Social Care Review* (King's Fund, 2006)

20 Speech by Rt Hon Alan Johnson MP to the National Children and Adult Services Conference in Bournemouth on 18 October 2007

It is now incumbent on the government to tackle the problems resulting from two parallel systems and not to fall back on the simplistic response that things must remain as they are because that is the way they have always been. It is time to build a new consensus as the foundation for a social contract fit for the 21st century; that does not mean abandoning everything that was established in 1948, but it does mean there must be willingness to revisit first principles. Failure to do so will ensure recurrent crises in long-term care as each minor revision reveals its inherent limitations.

The challenge at hand is to establish a new model, grounded on principles of social justice, which shares responsibilities between individuals, the family and the state in ways that treat all citizens equally regardless of the nature of their needs for care; which is accepted as fair (both between individuals and across generations); and which is transparent, sustainable and affordable. Radical change is required; getting it right would be a legacy from the Labour government every bit as important as that bequeathed by the Beveridge report in 1942; getting it wrong would be a monumental failure and a betrayal of current and future generations.

## Chapter 2

# What do consumers want from care?

David Brindle, Public Services Editor at *The Guardian*

## What do consumers want from care?

One of the silly-season newspaper articles of summer 2007 was the story of David and Jean Davidson, a couple in their 70s, who had taken to living in a Travelodge. They liked the budget hotel chain so much when they first sampled it in 1985 that they had stayed there pretty much ever since.

At first, the Davidsons spent three or four nights a week at a Travelodge on the A1 at Newark, Nottinghamshire. But 10 years ago they moved to a newly opened one in Grantham, Lincolnshire, and took up full-time residence, returning to their flat in Sheffield only every fortnight or so to collect their mail. They invariably took their meals at the Little Chef restaurant adjacent to the hotel and received visits from friends and family. In 22 years, they reckoned to have spent £97,600 on their accommodation.

Eccentric? Well, the media plainly thought so, pointing out that for the same outlay the couple could have bought a two-bedroom terraced house in the area. But the Davidsons' rationale repays close reading. "We have everything we need here – and the staff are like family now," Mr Davidson, 79, told reporters. "We get great rates because we book well in advance and all our bed linen is laundered too." Mrs Davidson, 70, said: "I really like living here because it's so convenient and our room is on the ground floor so there are no stairs or lift to deal with. We don't get hit with huge heating bills and it's safer than a lot of places these days. For us it's a cheaper option than an old people's home and we're well looked after."<sup>1</sup>

Economy, security, convenience and friendliness – these are factors that most older people no doubt rate highly in their lives. But for many these are elusive qualities both in domestic settings and in residential care. To the Davidsons, the Travelodge may have been not only cheaper than a care home, but actually nicer.

Of course, living in a budget hotel is unlikely to seem quite so appealing, or practical, to those more frail or dependent than the Davidsons, though there is no reason why domiciliary care should not be available in such locations. But the couple's choice says a lot about the preferences and expectations of older people in the 21st century. Mr Davidson may have been just old enough to have served in the navy at the end of the Second World War, but the so-called 1948 generation – those who lived through the

<sup>1</sup> *The Times*, 11 September 2007

privations of war and were simply awestruck by what the new welfare state offered – is passing. The post-war baby boomers want a better deal.

These are people who have grown accustomed to material comforts, to privacy, to choice. The average Travelodge may seem déclassé to national newspaper journalists – several of whom were dispatched to live in one for 24 hours to tell a predictably sorry and self-pitying tale – but it plainly does offer these things. And, unlike at least the popular image of institutional care, it is properly staffed, odourless and clean.

According to the conclusions of a research report published by the Institute for Social & Economic Research a week or two after the Davidsons enjoyed their 15 minutes of fame, "what might have seemed aspirational in the 1960s is considered a basic necessity today". And, more contentiously, the report observed that fraternalism – a cornerstone of the 1948 settlement – had largely receded from popular discourse. "Instead people speak overwhelmingly in terms of individual career trajectories, individual lifestyle and consumption choices and an individual assessment of their social position in relation to other individuals."<sup>2</sup>

Even those who took issue with such a sweeping conclusion would surely concede the point in part. And it is possible to see this growing individualism already reflected in changes in systems of care and support. Most obviously, options of direct payments and individual budgets enable the users of services to make choices about the type of help they receive, when they receive it and from whom they receive it. Equally, extra care housing enables the individual to continue living independently in their own home, with their own front door, yet still receiving the kind of support they would get in residential care.

Extra care housing, or housing with care, in fact provides a good example of the way change can come about in the care sector through demand and supply factors. Providers, in the form of local authorities and housing associations, very often found themselves struggling to attract older people and their families to care homes and traditional sheltered housing. Many sheltered units were of studio or bedsit design, out of step with modern expectations and unsuitable for increasingly dependent older generations. By redeveloping care homes and sheltered stock as extra care accommodation, the market has adjusted.

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<sup>2</sup> Pahl, R, Rose, D and Spencer, L *Inequality & Quiescence: A Continuing Conundrum*, ISER working paper no 2007-22 (Institute for Social & Economic Research, 2007)

Precise definitions of what constitutes an extra care scheme do vary, but conservative estimates suggest there are some 30,000 units now available in more than 1,000 developments by almost 300 providers.<sup>3</sup> According to one leading provider, Housing 21, the average age of residents is 81 and they receive, on average, nine hours of care a week. Although critics say the model is suitable only for less dependent people, Housing 21 estimates that 17% of its extra care residents either have or are suspected of having a form of dementia and one in two uses a mobility aid.<sup>4</sup>

In a further demand-driven market shift, there is now growing interest from housing associations and for-profit providers in extra care schemes on a leasehold basis for older people who have grown accustomed to owning their own property and do not see why they should revert to renting in retirement. Some schemes now offer a combination of leasehold and rental units, in common with the favoured mixed-tenure model in mainstream social housing, and shared ownership may enable individuals to hold a majority stake in their property while freeing up some equity for other purposes.

In responding to societal change in this way, the care sector is doing neither more nor less than other public services. In health, the expert patients programme is the formal manifestation of a trend towards self-care, which is defined by the Department of Health rather extravagantly as not only care taken by the individual for their own health or well-being, but also care extended by them to "their children, family, friends and others in neighbourhoods and local communities". In practice, self-care is that which is administered by the individual in relief of their own condition, as promoted by the programme.

Piloted from 2002 and mainstreamed by the Department of Health two years later, the expert patients programme is a lay-led self-management programme for the 15 million people who live with a long-term condition such as heart disease, cancer, arthritis, diabetes or mental illness. By understanding and managing their condition, expert patients are empowered and, it is suggested, their quality of life is enhanced and they suffer fewer acute episodes.

When the NHS was created in 1948, the explanatory leaflet delivered to the nation's then 13 million homes told people they had to "act at once" to register with a family doctor in order to take advantage of the extraordinary opportunity of free healthcare. On the first

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3 Elderly Accommodation Counsel, at: [ExtraCareHousing.org.uk](http://ExtraCareHousing.org.uk)

4 Evans, S and Vallyelly, S *Social Well-being in Extra Care Housing* (Joseph Rowntree Foundation, 2007)

day of the service, one Birmingham GP and his staff barricaded themselves in their surgery for fear of the crowds (needlessly, as it turned out).

We still love the NHS, as politicians who seek to reform it know all too well, but the uncomplaining gratitude and deference of those who had known what went before is being replaced by a more questioning consumerism. One survey found that whereas 91% of people over 65 were satisfied with their healthcare, the figure fell to 74% among 25- to 34-year-olds.<sup>5</sup> Such generational differences in attitude can be anticipated across the public services.

There is, of course, already an enormous difference in the demographic landscape from that which pertained 60 years ago – with even more seismic upheaval to come. And it is this, quite apart from people's changing expectations, that is driving our reappraisal of the provision and funding of social care.

In 1948, just 10.5% of the UK population was aged 65 or older. By 2001, the proportion had risen to 15.7%. It is projected that by 2051 the figure will be 24.2% – almost one in four of us, compared with little more than one in 10 at the birth of the welfare state.<sup>6</sup> This, as older people's groups rightly remind us, should be a cause for celebration: that so many people are living longer lives is testament to our healthier lifestyles and environment, medical progress and the quality of our public services and housing. But old age still invariably means increasing frailty, dependency and a need for care and support. Moreover, such a fundamental shift in the balance of the population has profound consequences for how we supply and finance that care and support.

The statistics merit close examination. In 2006, there were 9.4 million people in the UK aged 65 or older. This is projected to rise to 18.2 million by 2051, as the post-war baby boomers move into retirement. The old-age dependency ratio – the number of retired people against the number of those of working age – has not yet started to change significantly, standing in 2006 at 30 per 100. But because of the sheer numbers of these baby boomers – 17 million, or 29% of the population – it will do so sharply over the next decade, as the baby boomers are replaced in the working-age population by the much smaller numbers of people born since the 1960s. It will then fall back, as the change in the women's state pension age takes effect, before rising again after 2020.

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<sup>5</sup> Department of Health *National Service Framework for Older People* (2001)

<sup>6</sup> Office for National Statistics *2006-based National Population Projections* (2007)

From the perspective of social care, what is especially significant is that the largest percentage growth in population is now occurring among those aged 85 or over. Numbers are projected to rise from 1.2 million in 2006 to 4.7 million in 2051. By 2031, life expectancy for men (75.9 years in 2002) is projected to be 82.7, while for women (80.5 years in 2002) it is projected to be 86.2. There are now 10,000 centenarians, compared to just 100 in 1911, with a projection of 57,000 by 2031.

We are only just starting to explore what all this will mean for our society. One consequence will be very dear to the hearts of politicians: in a 2009 general election, according to calculations by charity Age Concern, people aged 65 or over are likely to represent 43% of all those who cast a vote in England and Wales. The proportion of over-64s of the total numbers on the electoral register will have increased in no fewer than 448 seats and many more of them than average will use their vote: at the 2005 poll, 75% of over-64s did so.<sup>7</sup>

In interviews by Age Concern, care and support emerged as a key issue in determining voting intentions. "My main worry is health and who is going to look after me," said one man in Dorset. "You work all your life, and pay into the system, and then all you seem to get is below-standard care," said a woman from North Yorkshire. It is doubtful that people would have articulated such concerns 20 or 30 years ago, but today they are more expectant of living into old age and they know that is likely to mean at least an element of dependency.

In 1972, 21% of the population reported having a limiting long-standing illness. By 2004, that had risen to 35%.<sup>8</sup> Forecasts suggest that by the middle of the century half of us will be living with such a long-term condition. And while life expectancy has been rising, the increase in healthy life expectancy has not kept pace: in 1981, a man could expect to live 82.1% of his life in good health and a woman 79.1%; by 2001, those proportions had fallen respectively to 80.1% and 78.0%.<sup>9</sup> Analysis conducted for the Wanless social care review for the King's Fund found that in even relatively optimistic scenarios, the proportion of over-64s who will be disabled will increase over the years to 2026.<sup>10</sup>

What will such disabilities be? The main causes are arthritis, stroke, coronary heart disease and, perhaps most terrifying for many people, dementia. The Alzheimer's Society projects

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7 Age Concern England *Winning in 2009 – The Importance of the Baby Boomers* (2006)

8 Office for National Statistics *General Household Survey* (2006)

9 Office for National Statistics quoted in Wanless, D *Securing Good Care for Older People* (King's Fund, 2006)

10 Ibid

that by 2010 there will be some 870,000 people with dementia in the UK, rising to more than 1.8 million by 2050. The Wanless analysis calculated that the incidence of severe cognitive impairment rises steeply from 1.5% of the 65-75 age group, and 3.1% of those aged 75-84, to 40.2% by age 95 or above.

By tradition, much of the responsibility for caring for older people with dementia or other disabilities has fallen on the family. About 6 million people, six in 10 of them women, have informal caring roles. But the fragmentation of the family unit, combined with the growing proportion of women in paid employment (now 70%), calls into question whether current levels of caring can even be sustained – let alone increased.

Some 7 million people in Britain now live alone, compared with 3 million in 1971. Then, one-person households represented 18% of the total and 50% comprised three people or more. By 2006, one-person households had risen to 29% of the total and only 35% comprised three people or more. By 2011, it is projected, 32.7% or very nearly one in three households will be one-person.<sup>11</sup>

It is important not to overstate this trend: eight in 10 people do still live in a family household, compared with nine in 10 in 1961. But the concept of family has changed: 24% of children are being brought up in one-parent homes and the parent in such households is under increasing pressure from the benefits system to enter, and remain in, the labour market. If the system increasingly makes no concessions for the care needs of (at least older) children, it seems unlikely to do so for dependent older relatives.

A final point on family: even where there is willingness to help with informal care, people may not be well placed to do so. These days, adult daughters and sons rarely live "just round the corner from mum and dad"; however much the telephone and internet may compensate for geographical distance while parents remain fit and active, technology is yet unable to help with household tasks or care.

Letters to *Society Guardian* frequently articulate the frustration and helplessness of people living far from increasingly dependent relatives. In one (unpublished) letter, a woman who lives 120 miles from her 90-year-old father and 82-year-old mother, who has early-stage dementia, wrote: "Apart from the visits I make as frequently as possible to collect and return laundry, deliver food and change the beds, they are isolated with no-one to call on."

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<sup>11</sup> Office for National Statistics *Focus on Families* (2007)

Poignantly, the writer added: "My mother, of course, is certain that she is still in her 50s and quite able to run the household, ride her bike, bake cakes every day, whilst in reality she is in a permanent state of confusion and sits staring vacantly at the television for much of the time." Social services had assessed the couple and declared their needs insufficient to warrant support.

Very often, as perhaps in this case, the demand from older people or their carers is for low-level support: someone to pop in to check on things, a nail-cutting service, or a hand to tidy the garden. This was set out in a report by the Joseph Rowntree Foundation,<sup>12</sup> which argued that the concentration of domiciliary care on people with high-level needs was having the unintended consequence of forcing people with lesser needs into residential care. But even with low-level help, and/or informal care, there may come a point when a residential or nursing home is the preferred option.

What people want then, in a residential setting, is not unrealistic; indeed, it may be little more than what the Davidsons value about their Travelodge. What appears to anger, or frighten, individuals and their families is receiving sub-Travelodge quality for two or three times the price. People may be persuaded to accept the need to eat into savings or assets to pay for their care, but it will be much easier to make the case if perceptions of standards of that care – and of the attitudes of care workers – are improved.

Another unpublished writer to *Society Guardian* described how her mother, again with dementia, had been well cared for in a residential home in her last days. It was not the facilities that mattered, she made clear, but "a simple respect for human dignity and a genuine desire to make the lives of the residents as comfortable and happy as possible".

The writer said: "Unfortunately, mum was there just four weeks before she died. In that time, however, her coat was on the hat-stand in the hall, as it was now her home, and she was regularly taken into the garden for fresh air and a change of scenery. She was clean and dressed in pretty, smart clothes. They helped her find her sense of humour again."

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12 O'Neil, A *That Little Bit of Help* (Joseph Rowntree Foundation, 2005)

## Chapter 3

# A rights-based approach to improving the life chances of older people

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<sup>1</sup> [www.opp-uk.org.uk](http://www.opp-uk.org.uk)

## A rights-based approach to improving the life chances of older people

This chapter sets out the need for a rights-based approach for addressing the inequity that exists within public policy, public services and in day-to-day service delivery for older people who need support to lead their daily lives.

This is a hugely complex and often controversial area. We do not try in this short paper to undertake a comprehensive analysis of the entire landscape of rights and responsibilities of and for older people in the UK. Instead we focus on how rights and responsibilities can support self-determination and promote citizenship for older people who need support; and ultimately improve their health, well-being, and what many refer to as quality of life but we prefer to call "life chances".

This is explored against an underpinning vision of equality, participation and inclusion for our growing and increasingly diverse population of older people.

### Overview

The concepts of citizenship and self-determination are central to equality and to health, independence and well-being for all. This phrase, "health, independence and well-being", is at the heart of most recent government policies and initiatives in health, housing support and social care. It has featured specifically in strategies and frameworks intended to improve older people's services over the past 10 years.

**Table 1: Policy levers for taking a rights-based approach for older people**

Government policy and key reports	Critical statements on older people's rights
Human Rights Act 1998, introduced in October 2000	The Human Rights Act incorporates into UK law a range of civil and political rights set out in the European Convention on Human Rights, including the right to life (article 2), the right to private and family life (article 8), freedom of expression (article 10), the right to marry and found a family (article 12) and the right to education (set out in Protocol 1, article 2 of the convention). Quinn et al (in <i>Human Rights Et Disability</i> , 2004) highlight the four key values of human rights as dignity, autonomy, equality and solidarity (defined as priming people for participation in all mainstream processes of society).

<i>The NHS Plan</i> (Department of Health, 2000)	"Increasing funding and reform ... aim of redressing geographical inequalities, improving service standards and extending patient choice"
<i>The National Service Framework for Older People</i> (DH, 2001)	"The department's policy for older people and their carers seeks to promote social inclusion and control over their lives, ensuring respect and choice. This enables older people to live independently for as long as possible, to benefit from tailored care and support, and experience an enhanced quality of life."
<i>Older People Shaping Policy &amp; Practice</i> (Joseph Rowntree Foundation, 2004)	"Much policy and practice are still based on the assumption that older people are a 'burden'. This is problematic for older people and means that resources fail to deliver their definitions of quality ... Despite modernising initiatives, barriers in attitudes, approaches and resources remain within the way that health and social care services operate ... Older people are citizens with important roles in supporting families and within communities. They are also the biggest providers of support to other older people."
<i>Opportunity Age: A National Strategy on Ageing</i> (Department for Work & Pensions, 2005)	"As we take decisions for the future, we must – in fairness to all – balance the interests of today's older people with those of younger generations. We must also balance the rights older people can expect – security, an adequate income and decent housing – with a continuing and growing contribution from them as citizens and as elders of society." (Executive summary) "Much depends on individuals themselves and on striking the right balance between rights and services that empower them, and clarity about the degree of personal responsibility that we should all exercise as we age."
<i>A Sure Start to Later Life</i> (Social Exclusion Unit, 2006)	"Everyone, including older people, has the right to participate and continue throughout their lives having meaningful relationships and roles. Older people's vital role and responsibility to help build social capital will become ever more apparent as our society ages."
<i>Our Health, Our Care, Our Say: A New Direction for Community Services</i> (DH, 2006)	"Sets a new direction for the whole of the health and social care system – a radical shift in the way services are delivered ... Our society is based on the belief that everyone has a contribution to make and has the right to control their own lives. This value drives our society and will also drive the way in which we provide social care."

<p><i>A New Ambition for Older Age</i> (DH, 2006)</p>	<p>"Although overt age discrimination is now uncommon in our care system, there are still deep-rooted negative attitudes and behaviours towards older people. Within five years our ambition is to ensure that older people and their families will have confidence that in all care settings, older people will be treated with respect for their dignity and their human rights."</p>
<p><i>A Recipe for Care: Not A Single Ingredient</i> (DH, 2007)</p>	<p>"As choice in social care is increasingly driven by direct payments to people to allow them to buy their own services, NHS commissioners will need to match these developments by providing a range of options to patients."</p>
<p><i>Living Well in Later Life: A Review of Progress Against the National Service Framework for Older People</i> (Healthcare Commission/ Commission for Social Care Inspection/Audit Commission, 2006)</p>	<p>Five key themes are identified in this cross-cutting review of progress on implementing the National Service Framework for Older People:</p> <ul style="list-style-type: none"> <li>• tackling age discrimination;</li> <li>• involving older people;</li> <li>• designing and delivering services around older people;</li> <li>• living well in later life; and</li> <li>• leading organisations through change.</li> </ul> <p>Three areas requiring further attention are highlighted, including:</p> <ul style="list-style-type: none"> <li>• tackling discrimination through ageist attitudes and increasing awareness of diversity issues;</li> <li>• demonstrating that the National Service Framework standards are met; and</li> <li>• increasing partnership working both in degree and in effectiveness.</li> </ul>
<p><i>A Framework for Fairness: Proposals for a Single Equality Bill for Great Britain,</i> discrimination law review (Department for Communities &amp; Local Government, 2007)</p>	<p>A consultation paper setting out the government's proposals for a single equality law for Great Britain. The equalities review, chaired by Trevor Philips, was carried out in parallel with the discrimination law review and looked at broader issues leading to an unequal society.<sup>2</sup></p>

2 *Fairness & Freedom: Final Report of the Equalities Review* (HMSO, 2007)

<i>Meeting the Aspirations of the British People</i> , pre-Budget report for the comprehensive spending review (HM Treasury, 2007)	"Excellent public services are at the heart of the government's vision of a society in which economic prosperity is underpinned by social justice, providing stability, security and opportunity for all."
Dignity in Care initiative (multiple strands led by DH)	"Through our work on dignity in care we want to create a zero tolerance of lack of dignity in the care of older people. We want to inspire and equip local people, be they service users, carers, relatives or care staff, with the information, advice and support they need to take action to drive up standards of care with respect to dignity for the individual."

The above synopsis illustrates the range of hooks and levers that currently exist in both government policy and associated initiatives designed to aid its implementation and to reduce inequalities.

Yet in spite of this rhetoric of equality, inclusion and (in some cases) rights and entitlements to high-quality services, older people who need support (especially those with high support needs) are still too often marginalised and excluded from society, as some of the national and high-profile reports, also referred to in table 1, indicate. One example of this is the cumulative exclusion and lack of citizenship experienced by older people with high support needs (such as those living in care homes) from developments that are designed to improve their care and support. Older people are also most often referred to in policy and practice developments as needing "dignity and respect", "quality of life" and protection from abuse. Even in those policies that are designed to afford equal treatment and responsiveness, older people are seen as vulnerable and as leading more limited lives, with consequently fewer options for support and opportunities for a good life than younger people with the same level of need for support.

This paper argues that one way to address these long-standing issues and inequities is to promote and embed a rights-based approach to increasing the voice, choice and control that older people have over any support they need to lead their daily lives.

We begin this process by examining the broader concept of citizenship, and "active citizenship" in particular, which we highlight as a key foundation stone for developing self-directed support and the wider goal of self-determination. We then turn to the field of human rights as it tends to be applied to or for older people, especially older people

who need support in their daily lives. This includes balancing assumed and legally enshrined rights with both explicit and implied responsibilities. Within this we focus on continuing barriers to older people exercising these rights and responsibilities, before ending with five proposed areas for action to dismantle these barriers on the road to improving the life chances of older people.

Key amongst these proposed actions is the importance of raising our collective game – societally, politically and professionally – in addressing residual and persistent ageism in public services and community life. We call for an Age Equality Duty, which firmly establishes a legal framework for rooting out discrimination on the basis of age across all goods and services. We also point to the need for a common language around rights, and the importance of what the British Institute of Human Rights refers to as a rights-based approach, in improving the life chances of older people who need support in their lives.

### **Citizenship and older people**

The *Oxford English Dictionary*<sup>3</sup> defines citizenship as “membership of a state or commonwealth, either native or naturalised”.

And the Institute for Citizenship states that one of the main aims of citizenship education is “for people to think of themselves as active citizens, willing, able and equipped to have an influence in public life”.<sup>4</sup>

This statement highlights that meaningful participation is at the core of active citizenship; not just involvement, but having a real influence in “public life”, which includes the development and delivery of policies and services that impact on individuals’ abilities to participate in public life.

In the context of rights and responsibilities for older people – who are a significant (and growing) population of consumers of public services – this notion of active citizenship is critical, suggesting the need for concerted action both on the part of older people themselves and on the part of public bodies, older people’s and other “age sector” organisations that uphold the civil and political rights of all citizens.

The word “membership” in the dictionary definition emphasises another key aspect of

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3 *Concise Oxford Dictionary* (Oxford University Press, 1990)

4 *Education for Citizenship & the Teaching of Democracy in Schools*, final report of the Advisory Group on Citizenship (Qualifications & Curriculum Authority/Advisory Group on Citizenship, 1998), para 1.5

citizenship: a citizen is a member of a group or community of people who have *certain key things in common* – such as where they live, how they are governed and which laws they are subject to. Respect and consideration for others by individuals are key characteristics that help to bring groups and communities together to work well in partnership, and are therefore important aspects of citizenship. As well as setting out an expectation that along with rights, people have responsibilities towards each other, this also frames the whole concept of citizenship as a dynamic rather than passive state. To be a citizen is by its nature to be active, to be contributing to as well as benefiting from the community in which you live.

Making a positive contribution within a group or community is therefore a key feature of active citizenship – an area of great importance to many people, helping them to feel valued and a sense of belonging. Many volunteers, for instance, report that they get at least as much out of volunteering as the people they support.<sup>5</sup> This is an area that has a particular resonance for older people as they are more likely to volunteer, but also because it can feel more and more difficult to contribute if increased support is needed to live your daily life and wider areas of life seem to be closing down – as happens for many (particularly the oldest) older people.

The area of responsibilities is intrinsically tied up with these definitions of citizenship: we are individuals, but at the same time we are all part of a larger group – or groups – and as such have certain responsibilities within these groups. The Human Rights Act reflects this in differentiating between the types of rights outlined below; especially between absolute rights, which can never be interfered with, and limited or qualified rights, which are limited in certain circumstances or may be curtailed if it is felt an individual has the potential to threaten the rights of someone else or cause harm within society by pursuing those rights in a certain way – for example, where someone's right to freedom of expression could threaten another person's right to respect for private and family life. This illustrates that we must balance our own rights with responsibilities and respect for those of other citizens within our society.

Respecting other people's rights is an increasingly important area in a society that is becoming more and more diverse, playing a crucial role in maintaining and promoting community cohesion, peace and tolerance. The concept of treating others as we want to be treated ourselves illustrates the balance of our rights and responsibilities perfectly.

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5 Bowers, H et al *Making a Difference through Volunteering: The Impact of Volunteers Who Support & Care for People at Home* (CSV Press, 2006)

For those of us who have been working with and on behalf of older people, with a focus on equality, participation and inclusion, the concept of responsibilities alongside rights is neither new nor unfamiliar. Older people have consistently told us that what they want, and what they need in order to feel valued and equal citizens, is to be "part of the solution" rather than being seen as the problem, or as a burden on cash-strapped services with limited capacity to cope with rising demand due to an ageing population.

The Older People's Programme worked with older people, policy makers, public service commissioners and practitioners in 2002 to identify seven dimensions of "living well in later life". Older people formed the majority voice in this diverse stakeholder event, which brought people together to work on defining "quality of life" *by* as well as *for* older people. The agenda rapidly shifted from one of concern about quality of services, and quality of life in this context, to a far broader one of potential, the wider public service arena and a focus on the key aspects of a good life as we all age. These seven dimensions – "the magnificent seven" as they became known in the report of this work<sup>6</sup> – are set out in the box.

### **Seven dimensions of living well in later life**

1. Being active, staying healthy and contributing
2. Continuing to learn
3. Friends and community, being valued and belonging
4. The importance of family and relationships
5. Valuing diversity
6. Approachable local services
7. Having choices, taking risks

This work is now being applied and further developed within nine localities across England (involving local authorities, their NHS partners, older people's organisations and local communities) as part of a drive towards person-centred thinking and planning with older people who need support. In other words, personalising services and support (as set out in various of the policy frameworks referred to in table 1, above) is effective only if and when it enables older people to carry on living their lives. And these dimensions are what

<sup>6</sup> Bowers, H, Easterbrook, L and Mendonca, P *Living Well in Later Life: An Agenda for National & Local Action to Improve the Lives of Older People in Britain in the 21st Century*, unpublished report (2002) for the Joseph Rowntree Foundation's Older People's Programme, and acknowledged in *Older People Shaping Policy & Practice*, a report by the Older People's Steering Group (Joseph Rowntree Foundation, 2004)

older people consistently tell us are important to them, and what make them feel valued and full citizens with rights and responsibilities.

This agenda is also now increasingly enshrined in public services performance frameworks, not least the new public service agreement framework introduced as part of the 2007 pre-Budget report on the most recent comprehensive spending review. It is tempting in this new performance regime, with its emphasis on local devolution and priority setting, for authorities and their partners to focus on PSA 17, on later life. Whilst this is relevant, we would also emphasise the need to focus on local priorities and agreed outcomes and to use the full range of targets and indicators from across the entire performance framework to achieve these, as follows:

### **Public service agreement levers for a rights-based approach with older people**

- *PSA 15*: Addressing disadvantage experienced by different individuals and communities, including the level of choice, control and flexibility in independent living, and fairness of treatment by services.
- *PSA 16*: Adults in contact with secondary mental health services in settled accommodation, including older people with mental health support needs (both dementias and depressions) living in supported accommodation.
- *PSA 17*: Tackling poverty and promoting greater independence and well-being in later life, including healthy life expectancy at age 65, over-65s satisfied with home and neighbourhood, over-65s supported to live independently.
- *PSA 18*: Promote better health and well-being for all – proportion of people supported to live independently, access to psychological therapies.
- *PSA 19*: Better care for all – patient/user experience, referral-to-treatment times, people with long-term conditions supported to be independent and in control of their condition, patient-reported experience of GP access.
- *PSA 21*: Cohesive, empowered and active communities – percentage of people who feel they can influence decisions in their locality, percentage of people who feel that they belong to their neighbourhood, thriving third sector, percentage of people who have meaningful interactions with people from different backgrounds.

### **Self-determination: increasing the voice, choice and control of older people who need support in their lives**

Self-determination – being in charge of your own life and able to shape your own destiny – is central to equal citizenship and active participation. You cannot participate without a voice; you need to have choice and control over your life, and any assistance you require

to go about your daily life, in order to participate and to contribute; and you cannot contribute to or experience citizenship without participation.

But what does self-determination really mean, and how does this relate to the lives of older people?

Without self-determination (having a voice, being able to exert choice and maintain control over your life) older people, especially those who need support, are much less likely to participate or be included in civic, community and family life. They therefore cannot experience full and active citizenship in the way that they themselves have set out that they wish to (see above), and which we argue they have a right both to expect and to experience. In order for older people to both access and exercise these rights (and the consequent responsibilities that sit alongside them), citizenship and self-determination need far greater prominence in public policy and practice debates and developments affecting them.

Older people who need support can often feel that their self-determination is diminishing alarmingly – and that they have to follow a certain path (for instance, moving to a care home or attending day care) as a last resort, because there does not appear to be any other choice given their circumstances – despite their own aspirations and wishes. Support options that enable choice and control and which are relevant to and meet the needs and aspirations of older people are therefore crucial. Support to plan ahead in life generally, as well as help with support planning, could be more systematically applied and encouraged to ensure that older people experience and receive the kind of enabling and empowering services they want and need. These approaches can also facilitate older people who require support to have a much greater voice, and to exercise choice and control over that support. Person-centred thinking skills and practical tools (such as person-centred planning) are therefore a fundamental development priority that needs to be embraced and embedded for all older people across all public services.<sup>7</sup>

Diversity of background, circumstance, character and personal preference is a key consideration for increasing self-determination. We are all individuals, with different preferences, and have a need to make our own choices – to not be “herded” with other people with whom we may have little in common except for factors such as age. Older

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7 Bowers, H, Bailey, G, Sanderson, H, Easterbrook, L and Macadam, A *Person Centred Thinking with Older People: Practicalities Et Possibilities* (HSA Press, 2007)

people are as diverse as any other group of people, yet often suffer from limited options, diminishing choices and limits to personal control.<sup>8</sup> This can lead to some older people and those around them having increasingly low aspirations and expectations, which in turn has huge negative impacts on life chances and quality of life for individuals.

It is vital that those commissioning and providing support options and other services embrace diversity by opening up choices that offer a wide range of options for older people. Above all, assumptions about what older people want or what they can cope with (for example, in the use of the terms "as long as possible" or "as appropriate") need to be challenged and eliminated from national policies and strategies on ageing. Instead, the opportunity for real involvement both in public life (influencing the choices available to the wide population of older people) and in personal choices for support is vital for all older people, regardless of the scale of their need for support.

### **Human rights and older people**

The Human Rights Act, passed in the UK in 1998 and implemented from 2000, is one of the most widely publicised areas of rights in this country. It covers a number of different types of rights, including:

- absolute rights, such as the prohibition of slavery and forced labour and the right to protection from torture or inhuman and degrading treatment;
- limited rights (which are limited under specific circumstances), such as the right to liberty; and
- qualified rights, which can be challenged if there is a legitimate basis such as the protection of public order or prevention of crime. Examples of qualified rights are the right to freedom of expression and to respect for private and family life.

The British Institute of Human Rights has described the government as having two main ambitions for the Human Rights Act: first, to give UK citizens the ability to "pursue their human rights claims in the courts here, rather than having to journey to Strasbourg"; and second, to "see people empowered to challenge public services that failed to treat them with respect". It is this latter aim that we draw particular attention to here.

In theory, older people have the same human rights as younger adults within our society.

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<sup>8</sup> Age Concern's submission to the 2007 comprehensive spending review, Age Concern policy papers, reference 2406 (2007)

The Human Rights Act, as pointed out by Tessa Harding in her eloquent leaving speech on retiring from Help the Aged in 2006,<sup>9</sup> affirms the "equal dignity and worth" of every individual, regardless of their age or any other characteristic, and that, under the terms of the act, everyone has the right to have their life protected, to be free from inhuman and degrading treatment and to their private and family life.

Successive reports, stories and media coverage illustrate only too clearly that this is far from the reality of many older people who need support, especially those who receive support in residential settings or who have needs to a degree that their main or sole contact is with staff and agencies providing care services. The majority of these services are increasingly provided through contract by private- and voluntary-sector organisations that are not currently bound by the Human Rights Act, even if they have been contracted by local authorities to provide this care. As many older people receive such services, this has significant implications for the human rights of older people and their potential for using the act to improve their experiences – one of its fundamental aims. The good news is that this exemption has been challenged strongly, and there is a growing impetus to change the act to close the loopholes that do exist.

Standard 1 of the National Service Framework for Older People,<sup>10</sup> "rooting out age discrimination", was one of the first explicit examples of government policy taking a clear and robust view on age discrimination in the provision of and access to services. Whilst this was a first crucial step in addressing age discrimination in public services (in this case, health and social care services), it was not, and has never been, bolstered by a legislative framework that outlaws discrimination on the grounds of age. The European Equal Treatment Directive passed in October 2006 (the Employment Equality [Age] Regulations 2006 in this country) contributed towards this, but is limited in its scope. Successive calls for this to be extended to all goods and services have not yet been taken up.

Despite the loopholes that currently exist, many organisations are bound by law to treat all people in a manner that is not inhuman or degrading – one of the absolute rights in the Human Rights Act. Even where this is not covered strictly by law, the language of human rights can be used to demonstrate to providers of services how they could be improved through taking a rights-based approach with the people who receive those services.

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9 Harding, T *The Long & Winding Road: Towards Dignity and Equality in Old Age* (Help the Aged, 2006)

10 Department of Health *National Service Framework for Older People* (2001)

In a recent report prepared by the British Institute of Human Rights for the Joint Committee on Human Rights, a range of concrete examples and underlying societal, cultural and structural issues are highlighted that illustrate the present lack of profile for and understanding about the human rights of older people who need support – in this case with regard to their health.<sup>11</sup>

Earlier reports of work undertaken by the British Institute of Human Rights on supporting positive practice using a rights-based approach with older people also provide practical illustrations of using rights-based arguments and language to achieve the following outcomes:

- Couples being able to continue living together according to the right to family life, when moving to live in a care home.
- The provision of a care package at home for a woman as an alternative to admission to residential care (which a hospital had originally tried to pursue).
- A female resident in a care home being able to take baths and showers when she wanted, following the installation of a hoist. Previously the care home had only provided strip washes, as it was argued that staff were not able to lift this woman safely.<sup>12</sup>

These reports and case studies illustrate the powerful nature of both direct and indirect ageism; but also the potential for change using a rights-based approach both within training and education for staff and in public education and awareness for older people and their families. In addition, such cases have an important role to play in demonstrating where this approach either has or could have made a positive difference to older people's quality of life by enabling their self-determination and by making close links with developments in person-centred thinking skills and practices – a government commitment set out in this year's pre-Budget report (see table 1).

The new Equality & Human Rights Commission, launched on 1 October 2007, replaces the previously three separate entities with a rights-based agenda: the Commission for Racial Equality, the Disability Rights Commission and the Equal Opportunities Commission. The remit of the new commission extends beyond those of these three organisations to challenging discrimination and supporting equality in several areas or "equality strands", namely race, gender, disability, age, religion and belief, and sexual orientation. Its overall

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<sup>11</sup> British Institute of Human Rights *The Human Rights of Older People in Healthcare – Call for Evidence* (2007)

<sup>12</sup> British Institute of Human Rights *Older People & Human Rights* (2007)

purpose is to "reduce inequality, eliminate discrimination, strengthen good relations between people and protect human rights".

The British Institute of Human Rights has welcomed the new body, which also has a "responsibility for promoting and protecting human rights" and views its launch as "an exciting opportunity to breathe fresh life into fundamental ideas about human rights and to develop concrete ways to put these into practice".<sup>13</sup>

It remains to be seen if an age equality agenda will become a central focus of the new commission's work. Many people are watching with interest to see whether age will take equal place alongside race, disability and gender as fundamental equality strands all now embedded in law. Our call to arms for a much stronger focus on age equality and eliminating both overt and covert discrimination on the basis of age – for example, using rights-based and person-centred approaches to public service commissioning and delivery – is one example of this expectation, and is outlined in the final section of this paper.

### **Proposals for the way ahead – taking a rights-based approach to improving the life chances of older people**

As we all know, older people are significant consumers of health, social care and other public services. Well-documented demographic trends, most notably referred to as our ageing society, will ensure that this significance will only grow in the foreseeable future.<sup>14</sup> Yet older people continually tell us, and we have consistently observed, that public services do not serve our ageing population well.<sup>15</sup> There is therefore also a growing need to examine both the equality of access to and experience of services and support for people *across all ages*; and how the broad range of inequalities that exist can be tackled. It is within this context of current inequity that the benefits and challenges of a rights-based approach are considered in this final section on priorities for the future.

We have argued that a rights-based approach can be used effectively by and for older people to help improve both their quality of life and their overall life chances. However, there are a number of key barriers that can prevent this from happening as effectively as

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13 British Institute of Human Rights *The New Equality & Human Rights Commission: What Will It Do for Our Human Rights?* (2007)

14 Wanless, D *Securing Good Care for Older People: Taking a Long-term View* (King's Fund, 2006)

15 Help the Aged *Underfunded, Undervalued & Unfit: A Fresh Approach to Social Care for Older People in England* (2007); Commission for Social Care Inspection *Making Choices: Taking Risks*, discussion paper (2006)

it might. We present here a set of five proposed actions for improving the life chances of older people, using a rights-based approach that improves self-determination and helps to achieve citizenship for all older people who need support in their lives.

First of all, it is acknowledged that the whole area of "human rights" still attracts a bad press, attacked by some politicians and parts of the media who point to extreme cases where the act has been cited in controversial circumstances. This can alienate and discredit the potential for many older people to benefit from a wider consideration of their own rights within society. A focus on how "ordinary" lives could be supported and enhanced is needed to counter this situation, as is a recognition that the Human Rights Act is not just designed to be used within the courtroom but can have great value in many day-to-day settings and circumstances experienced by older people needing support on a daily basis. Practical examples, illustrative stories and a robust evidence base that build this picture of the potential for positive improvements in older people's daily lives are required to dismantle this barrier.

Second, it is still the case that most of us, not just older people, do not know our rights, nor understand how this knowledge may help us if our rights are infringed and our citizenship curtailed. If we do not know what we are entitled to as citizens and how we should be treated, how can we ensure that we are receiving the right sort of services and support to help us to live the kind of life we want? We all need to take an active interest in knowing our rights – and our responsibilities – particularly if reliant on assistance and/or equipment in daily life. Knowing your rights, your entitlement to support – and the responsibilities that go with these – can enhance our own self-determination and involvement as active citizens. A public education and awareness programme targeted at older people and their families is required to equip them to build knowledge and confidence around rights and entitlements; to be aware of their responsibilities and roles in increasing their own self-determination and that of those around them; and to take a much greater role in increasing the voice, participation, choice and control of all older people who need support.

Third, and building upon the need for older people to have a stronger voice in this debate, much more needs to be done to ensure that older people who need support are actively engaged in shaping public policy and service delivery at national, regional and local levels. Mechanisms for participation do exist, whereby older people have a voice and influence in decision making at all levels (for instance, Better Government for Older People, older people's forums and older people's councils). However, these mechanisms

and forums still tend to be dominated by already active and engaged, articulate older people, and exclude those whose voices are seldom heard. Within this we would prioritise older disabled people, both those living in care homes and those living at home with very intensive care packages or in other forms of supported accommodation; older people with different forms of dementia and other mental health difficulties, including psychoses; older people from black and minority ethnic communities; and older people who live transient lives, such as homeless older people and travelling communities.

Real improvement in services and support for older people depends upon the active and meaningful involvement of a wide cross-section of the very people who will be using these services in both their design and delivery. In other arenas, this has led to the rise and prominence of "user-led organisations". Older people's organisations and preference for "peer support" need to be viewed alongside these developments, and further attention given to how older people's direct participation in service development, not least in the personalisation agenda, can be enhanced, supported and promoted. Only in this way will services and support meet the actual aspirations and needs of our growing and hugely diverse population of older citizens.

Fourth, loopholes do exist in the legislation relating to rights that have a particular impact on older people, especially those receiving care from non-statutory providers. There has been a clear response from many organisations and individuals indicating a growing body of opinion that these situations are unacceptable, and that moves to close the loopholes are required to ensure all providers of services and support are covered by legislation. We endorse these proposals and call again for a review of both rights-based and equality legislation to ensure that age equality and the full application of the Human Rights Act is addressed across the board.

Recent progress in the area of age discrimination in terms of age equality legislation in employment is very welcome. However, the whole area of age discrimination goes much wider than this – a situation that is, thankfully, now receiving more attention and acknowledgment than ever before. Nevertheless, much more does need to be done to combat the continuing stereotypes of older people, what they want and need, how they want to live and the kind of support they rightfully demand. The baby boomer generation will doubtless demand different services and responses from the generations that went before them.

However, this reliance on improving public services in the face of an increasing pressure

from articulate and confident "midlifers" is not enough to guarantee that things will be different for them as they age or if they need support in later life. Not if we continue as we are. Importantly, it also does not address the need for change now, for the current generation of older people who deserve better, who do demand their rights to be full and active citizens to be recognised and upheld; who do have a contribution to make to family and civic life; and who used to hold the same expectations as everyone else before these became ground down to a fine dust as a result of persistent and pervasive ageism – ageism that can be translated as lower expectations, limited options and few opportunities for the same life chances as everyone else.

Finally, we believe a rights-based approach is naturally aligned with the current focus on personalisation, not only within health and social care but across all public services. It does, however, require some greater focus and attention to make these links explicit and non-threatening, and to demonstrate the benefits of combining person-centred approaches with a rights-based approach. It should also be seen as part of the growing toolkit of approaches and practical solutions to transforming public services, both in terms of their structure, governance and their underpinning values and guiding principles, and fundamentally in how they allocate resources through individual budgets, direct payments and other mechanisms that deliver choice and control for individuals needing support in their lives. There is a need to ensure that older people do not lose out here, in taking full opportunity of the new options for support that are increasingly made available to younger people, often with the same levels of need for support but for whom a much wider range of options, opportunities and possibilities exist.

There will, of course, always be limitations to the resources available to bring about real and lasting change in the way services are commissioned and provided – particularly those funded by the public purse. This can often be an initial barrier to change, especially given the current negative and misleading preoccupation with the "demographic time bomb". However, this is also an area that is too often used as an excuse to justify denying people (particularly older people) their basic rights. Creative solutions to shared problems, including financial restraints and competing priorities, can be a catalyst for fundamental change, particularly when local communities – and our resourceful older generations amongst them – are involved in both finding and then implementing these solutions.

We need to move away from territorial discussions (often leading to poor decisions made on behalf of older people, rather than by older people) about limited resources associated with limited options, to a situation where older people who need support are enabled to

explore different avenues, with assistance if required (for example, from an independent broker or advocate, family member or other nominated and trusted representative), using different resources and income streams – including even, for some people (such as those who fall outside existing eligibility criteria), their own.

Even if resources are not available to provide an ideal situation for someone, improvements can often be made within services or support that more effectively enhance quality of life, meet individuals' needs and aspirations, and reflect and respect their rights. Adopting a "rights-based, person-centred approach" within organisations and by individuals who support older people – including practices which support the ethos and principles of the Human Rights Act – is absolutely key to achieving this.

In summary, then, the agenda for change presented in this chapter is a fivefold framework for using a rights-based approach to improving the life chances of older people, as follows:

1. A robust evidence base needs to be assembled combining personal stories, illustrative case studies and more systematic reviews of how the Human Rights Act can be and is used to improve the life chances of older people, and combat ageist practices.
2. Alongside this, a public education and awareness programme that seeks to increase knowledge and confidence and ultimately enhance self-determination (as a prerequisite for full citizenship) is required, focusing on older people and their families, but also embracing wider audiences, including public service commissioners and providers, older people's organisations and policy makers, politicians and commentators at a national level.
3. Mechanisms for engaging older people in policy making and implementation should be reviewed and improved to ensure that the voices of older people who need support are present, heard and increasingly influential.
4. The existing legislative framework on equality and rights needs to be reviewed with the aim of closing all remaining age-related loopholes in the Human Rights Act, but also to set out an age equality duty designed to root out discrimination on the basis of age for good.
5. Further work is required to develop and articulate what a rights-based, person-centred approach means, and what it involves, both in policy and in practice, for older people who need support.

## Chapter 4

# The need to improve quality

Gordon Lishman, Director-general of Age Concern

## **The need to improve quality**

In the world of long-term care, "quality" is about the most basic elements of human life. That means physical safety: not being pushed, pulled and manhandled by another person in order to get you to do what they want when they want you to do it. It means having enough food to eat and enough water to drink to avoid the risk of malnutrition or dehydration, and food that is prepared with your tastes in mind. It is about being able to go to the toilet when you want and in privacy. It involves other people treating you with dignity, however well or badly you manage the problems, trials and opportunities of daily life. Fundamentally, it is about reacting to vulnerability and need with respect, care and tending, rather than with exasperation. Bad care dehumanises both victim and perpetrator. It is far too common.

One of the reasons I like the language of human rights is that it makes it clear that we are talking about the most basic things in life and not just optional extras that add "a bit of quality" to an acceptable basic service. The rights to life, to a private and family life, and freedom from degrading treatment are fundamental. A government, a country and a society that cannot guarantee those rights to its vulnerable citizens is failing in a core duty. I am looking forward to the wider use of human rights legislation to stimulate changes in quality; case law is likely to be more effective than exhortation.

There is no doubt that in England in the first decade of the 21st century we are failing a large number of people who need care and support. In institutional settings and in their homes, many old people are routinely treated in ways that deny their rights and fail to meet their everyday needs in a caring and effective way.

Television producers and journalists can easily uncover a new scandal by sending an undercover reporter to a hospital or home. The Commission for Social Care Inspection reports on problems in homes and services. Relatives and sometimes residents write and talk to Age Concern about their worries and experiences. It is clear that we are dealing with a structural, systemic problem, not occasional failures in a system that generally works well.

### **Respect and dignity**

The language of respect and dignity is one response to these issues. Respect is what older people say they expect; dignity is noticed in its absence. The courts, ombudsmen and others have used the language in specific cases and a body of case law is in place.

In November 2006, the government in England launched a "dignity in care" campaign endorsing the courts' and ombudsmen's approach. Coinciding with the launch, guidance was published by the Commission for Social Care Inspection containing 10 standards, number three of which requires authorities to "treat each person as an individual by offering a personalised service" and in the explanatory text states that this requires that the care and support provided should "consider individual physical, cultural, spiritual, psychological and social needs and preferences" and should "respect individual needs, preferences and choices, and protect human rights".

The requirement to treat all patients with dignity and respect is assessed as part of the annual health check against the Department of Health's core standard on patient focus.

This is not the first time in my recollection that the government has turned to exhortation and the regulators to make a difference. I hope that I am not unduly pessimistic in writing that I do not see any significant reason why this initiative should have a longer-term, more sustainable outcome than its predecessors. Where the core problems are systemic, built into the fabric and structure of services, more fundamental diagnosis and treatment is required.

### **The challenge**

Why are we apparently incapable of identifying the underlying problems and creating the changes to turn this situation around? How can we manage the increase in demand for care support that demographic change will bring within the next few decades?

The first step is to frame the debate in terms that are based on coherent analysis and which are capable of being answered. It is interesting that much of the media coverage, sometimes very good at highlighting abuse, seems much less certain when it comes to finding answers. Unusually for the British media, they find it difficult to allocate blame consistently. That reflects the reality that the problems are systemic rather than the faults of particular individuals.

The underlying reality is not fat-cat profiteering; it is not about an uncaring private sector taking over services from a caring state (very clearly so, for those of us who remember the public institutions that preceded the changes of the 1980s); it is not a failure of regulation; it is not about a small number of uncaring bad apples among staff. Nor is the problem one of uncaring or incompetent politicians and officials in national or local government. In my experience, which goes back a long time and encompasses most

of the bodies involved, virtually all the people who have the responsibility to address these issues are indeed serious, caring, intelligent, thoughtful, focused and well-meaning.

Why, then, are we failing? It is worth recognising that the challenges are not easy to answer: governments throughout the world – not just in rich countries – are struggling with the same issues. I have no doubt, however, that quality is bound up with the economics of care financing. That relates not just to the total amount of cash in the system, but also to the incentives to encourage good behaviour.

### **Money**

The first reality is that there is not enough money in the system to provide an acceptable level of quality care for everyone who needs it now, much less in 10 or 20 years' time when I may be a beneficiary. There is also a widespread and accurate feeling that the risks are not equally shared and that they strike randomly with little connection to income or wealth. People with savings or other assets not only pay for their own care; many of them are subsidising others who are supported by public authorities.

The debate about paying for long-term care has something in common with that on income in retirement. In both cases, no finance minister who wants to stay in office will ask the public to pay the level of tax that will provide the level of spending needed to meet the whole need from general (or hypothecated) taxation and ensure a sufficient quality of care. However regrettable, their electoral calculation is probably right. That is why I have argued for a new "settlement": not a consensus on every detail of policy, but a broad and deeply based agreement about the structure, the overall architecture of a system that can guarantee the quantity and quality of care for everyone who needs it when we need it. A crucial element in that settlement will be incentives to maximise quality.

As other essays argue in this book, the new settlement is very likely to involve some degree of "co-payment" – a new partnership between the individual and the state which is underpinned by a sense of "contract" between the parties, including the intermediaries who enable appropriate saving and investment. As well as paying its contribution, the state must accept some responsibility for making the overall structure work. That will involve ensuring that there is a working market in the savings products – whether "lifetime savings" or more specific – which will enable people to plan their contributions. It will also involve regulation and inspection, but that process should aim to improve quality and good practice and should identify the exceptions to a general rule of high standards. Regulation on its own cannot carry the burden of raising standards across the

board in a system where the incentives work against quality.

One of the most fundamental flaws in the current system is information asymmetry, which undermines the capacity of vulnerable individuals, and their carers and advisers, to take difficult decisions often under considerable pressure of time and emotion. A key feature of the new settlement will be to ensure that market information about price and quality is available both at the time of initial purchase of elements of long-term care and later as new choices are required and people assess the continued quality – or lack of it – in the support they are receiving.

Several other essays argue that the quality of the workforce in long-term care is critical in achieving even minimum quality. There are important issues about the roles of regulation and the bodies that oversee training and recruitment. It is, however, unquestionable that a long-term, sustainable, skilled, caring workforce will require higher investment than is currently being made. Overworked, short-term employees, paid at about the national minimum wage and recruited in other countries as a means of entry to the UK labour market, are unlikely to be the backbone of long-term quality care at the level that is needed. In bringing together the partners of co-payment, it will be recognised that investment in the care workforce will be a significant extra cost along with the costs of ageing populations.

There are those who would find the total money needed simply by increasing general taxation or by switching spending away from areas that are less popular with them personally. Those are reasonable arguments: all you have to do is to found a political party around that platform, persuade a plurality of your fellow citizens to vote for your taxation and social policies, form a government and go ahead. Alternatively, you can take over an existing party. I suspect, however, that you may not get there in time to meet my care needs – or those of my children.

We do not live in a Rawlsian world where each of us makes decisions without knowing whether we or others will be the beneficiaries of what we decide. Being human, we are more willing to pay money to achieve higher quality for ourselves than to pay from our own pockets to achieve that quality for others. Each of us believes we are more deserving than most other people. It follows that it is more likely that we will insist upon and receive the quality we want if we help to pay for it and if we can control the delivery of services to ensure that we as individuals, our carers, our insurers and our advocates demand and monitor that quality. And it is only when that combination of new money, demand and

monitoring gets into the system that we will get to even the minimum level of quality we require.

### **Incentives**

The current incentives, perversely, work against quality. When the service is cash-limited, the tendency for public-sector buyers of care is to keep costs down in order to buy some service for more people. That means using the monopsonist power of major buyers to control fee levels. It also means slicing units of home care ever more thinly in order to spread them more widely. It currently involves local authorities in raising the criteria thresholds ever higher for access to care and so offering no service and no quality to those people who do not reach those levels of need.

People funding their own care are already paying more for the same service. Why should they put even more money into the system if it does not materially alter their position? Care providers have to concentrate hard to meet minimum standards and even then many fail, not least because they can only afford to recruit staff at pay levels that provide few incentives to spend extra time and energy in treating people well.

The commitment to “personalised” or “self-directed” care, in which people have the means to demand and purchase the packages they need, should be a driver towards improved quality. At the least, if it works it will mean that people get the components they want in a care package. However, if that package is cash-limited, that will still mean less care and lower quality. People must have the opportunity and the means to add to that core from their savings or other resources. They must have efficient vehicles for saving or realising assets. They and their carers must also have access to high-quality information, advice and advocacy.

The cost to the state, which can be reasonably predicted and contained, is in enabling those markets; enabling effective advice, information and advocacy and remedying information asymmetry; inspection and regulation; and ensuring that citizens who cannot contribute at the time they need care are supported to receive care at a standard that guarantees quality.

Achieving the settlement will involve negotiation and discussion with the providers of financial services products and the providers of care services. The representatives of the financial services industry will argue for a secure environment, protection against catastrophe and moral hazard, and the right to make a fair profit against the risk involved.

The government, along with consumer representatives such as Age Concern, regulators and others, will be looking to pool risk widely to ensure that quality services reach the full range of people who will need them. In encouraging the interest and engagement of financial institutions, the government should not lose its core focus of reaching out to the vast majority of those who will need care, and of ensuring fairness and high quality.

As with incomes in retirement, a challenge for the state lies in the interim period: what can be done for people who need care now and who have not been motivated or enabled to save appropriately? The issue is more acute than in the case of pensions because more people should be able to contribute to their own costs by using capital assets if and when relevant products are developed.

There is a generous answer, which is also the one for a government that wants to get the credit for creating the change as well as getting right the longer-term architecture. That is, in the economists' jargon, transfer payments, diminishing over time and ensuring that people in need now will get the support they need at the same level that later generations can expect. That was the approach of the Attlee government to pensions in 1948 and the credit they received is part of the history of the British welfare state.

### **Immediate action**

The debate for a long-term settlement is urgent, but will take time. The participants do not share a common language or frame of reference and disparate interests will have to be brought together to agree the settlement. The proposed green paper and then the process of developing answers will be difficult and will require careful and sustained leadership.

What can be done in the meantime to improve quality and to ensure that resources are used efficiently and effectively? The first answer is to invest now in helping people to avoid unnecessary entry into a long-term programme for care. We know the major reasons why people go inappropriately into residential and nursing care and some of the remedies are obvious. Continence management can make a major difference in helping someone to stay at home. Multidisciplinary assessment of need in the community will enable people to stay at home with a well-designed package of support rather than going too early or inappropriately into a residential setting. Rehabilitation and "intermediate care" enable people to stay at home, particularly with competent support for family and social networks. Early diagnosis of dementia, backed by support for sufferers and carers, can enable better long-term management. Housing modifications should be seen in the

context of payback periods for people who stay out of long-term residential and nursing care.

Investment in the prevention of secondary falls and other preventive measures can save people from going into hospital, from which they are too often transferred quickly and under pressure into residential care. I am personally much more angry about the way in which older people and their carers are put under intolerable pressure to find a residential care place in a very short time with wholly inadequate information, advice and support than I am about whether or not they can pass on the value of their homes to their descendants. There is a reservoir of unspoken guilt among middle-aged and older people in England about the decisions they have made about "putting mum into a home" which leads them to try to put those decisions out of mind as quickly as possible.

Each of the initiatives set out in the two preceding paragraphs is backed by authoritative research which demonstrates payback within a short period; sometimes even within the same year. The payback in the relief of human suffering is much greater.

In a rational world, we would be looking for lifetime effectiveness, helping an older person, her carers, advisers and advocates to take the right decisions now for the longer term. That is not how bureaucratic systems work. Managers in health and social care do not invest in order to save money for other organisations. Particularly in the NHS, there are few incentives to invest in methods that will save costs or improve lives in future years. When faced with pressure on this year's budget and faced with structural reorganisation and job uncertainty every two years or so, why should any manager plan for even the medium term? Most importantly, where are the incentives to advise patients and users on how to maximise their lifetime health and independence and where are the incentives to take that advice?

There are two areas where the direction of current policy runs counter to the flow of resources: advice, information and advocacy; and preventive services. In both cases, policy makers and practitioners have seen the advantages, the potential returns in cash and human happiness and the necessity of investment for future value. Unfortunately in both cases, the budgetary pressures on local authorities and local health services are driving money away from what is needed to spend on short-term acute-sector targets. That is not prudent policy making.

There is one core message from this essay: acceptable levels of quality in long-term care

for an ageing population will only be achieved in the context of a settlement for the long term that includes positive incentives to maximise quality. There are too many perverse incentives in the current system.

Achieving that settlement requires engagement with all the participants in the debate: departments of state, service providers, service commissioners, local government, professionals, financial services institutions and their representatives, service users, carers, advocates and the wider public. It is not an easy task. On the other hand, all of us would rather grow old than suffer the only known alternative. And we would prefer that we could then enjoy services that respect our dignity and human rights and care for us with professionalism, patience, the time that is needed and quite a lot of personal affection and liking.



## Chapter 5

# The changing partnership on care – the role of local authorities

Anne McDonald, Programme Director for Community and Well-being at the Local Government Association

## The changing partnership on care – the role of local authorities

### Background

Local councils are the main publicly financed funders of care and support to disabled adults and older people. In England that responsibility rests with the 150 “top-tier” authorities (unitary, metropolitan and shire councils) that have a responsibility for social services. Those councils share central government’s vision, expressed in the white paper *Our Health, Our Care, Our Say* that in the future “far more [health and social care] services will be delivered – safely and effectively – in settings closer to home; people will have real choices in both primary and social care; and services will be integrated and built around the needs of individuals and not service providers”. Beyond that vision for social care, councils are community leaders who see every resident as a citizen who deserves to be treated with dignity and respect and receive the services that enable them to lead healthy, independent lives and facilitate economic and social participation.

### A new approach

This vision of individuals having choice and control over the support they receive, so that they can live their own individual life, is a challenge to the traditional way in which councils provide services. It will require a complete culture change. The council and its staff will need to move from a culture of care management to individual advice, support and brokerage. Local services will have to change from an inflexible menu of available services to a flexible, individually tailored approach, potentially drawing on a number of small and third-sector providers. Finally, there needs to be a continued shift from crisis response and institutional solutions to earlier support for everyday life that preserves or enhances the quality of life.

In addition, if councils are to deliver the “progressive universalism” that is one of the criteria for the reform of social care green paper announced on 9 October 2007, then they will have to shape and develop the market for care for all their residents – not just those who meet the criteria for council support, which is based on either level of need or lack of finance.

### Market development and cultural change

The main drivers for change in the balance of control over delivery between the individual and the council are the changes that are putting the purchasing power in the hands of the individual. The most straightforward of these is the system of direct payments, which gives the individual a sum of money per week instead of social services. People can then

purchase help and support to achieve agreed outcomes for themselves. The number of people receiving direct payments had increased to 42,000 in 2006, 10 years after their introduction. But the numbers have increased slowly considering that there are potentially 1 million people who could be eligible for direct payments. Recipients are mainly younger disabled adults, who use direct payments to support a lifestyle that enables them to work and have an independent home and social life. They have been less attractive to older people and those with mental disabilities because of the need to manage the finances and often to become an employer.

In 2004 the concept of "individual budgets" was developed, building on direct payments and other approaches for encouraging self-directed support. Thirteen pilot sites, led by local councils, were set up to test the concept of bringing together a range of funding streams that the individual receives (such as social care, housing-related support and benefits) into a single budget, with the individual designing and controlling the use of that budget by the council. Although these pilots are still to be fully evaluated, the positive experience of individuals with an individual budget and the perception that self-directed support is key to the overall transformation of social care, mean that individual budgets will be part of the future of social care. The experiences of the pilot sites indicate the challenges this will pose to the traditional system of providing social care.

### **Individual budget case study**

A couple in their 80s both have multiple physical and mental health issues and the husband is registered blind. Mr T is the primary carer, and their daughter gives them significant support. Traditional social services provided support to help with getting up, but this could vary between 9am and 12 noon, meaning they could not plan the rest of their day. Mrs T regularly spent some time in a care home to give her husband much-needed breaks, but the separation distressed them both.

Using an individual budget their daughter developed a support plan that included employing an assistant during the week for domestic help as well as care, and their daughter helping at weekends; going to a hotel together for a break, with an agency visiting the hotel to provide care; and installing equipment to make things easier and reduce the risk of falling (previously Mrs T was falling at least once a week).

If councils are to become enablers of a system of self-directed and bespoke services, which individuals can purchase with their direct payments or individual budget, then they will no longer be able to commission "one size fits all" services from large providers. They will probably have to decommission outdated styles of support, such as institutional care for adults with learning disabilities, which may have been directly provided by council staff. They will have to move to developing and encouraging a local care market that can offer innovative and bespoke services, allowing people to choose the type of support they want. Often this type of service will be provided by local organisations, such as voluntary organisations or social enterprises, which can provide small-scale, high-quality services for local people.

This will require a culture change in council commissioning, although many councils are already experienced in developing the local market in care homes and domiciliary care in order to be able to contract sufficient, cost-effective and flexible services for their clients. Both officers and elected members will need to embrace the relinquishing of control of service provision to become much more of a partnership with local people; not only with the individual users of services, but working with local people, users and carers to design services that local people will want to use.

In order to achieve quality, innovation and change, commissioning will need to become more of a developmental relationship between commissioner and provider rather than purely purchasing. The shift to see all public-sector service provision as a commissioning exercise from multiple providers means that there is a proliferation of support from central bodies, the local government sector and private consultancies to help the development of commissioning skills. In particular, support for the individual budgets programme has led to the micromarkets project, which is identifying good practice in developing thriving local "micromarkets" of very small providers and developing good commissioning practice that local councils can use to invest in and foster such markets.

However, a recent discussion paper by the Commission for Social Care Inspection suggests that there is a sense of inertia among some local social care commissioners about developing innovative models of care, pointing to a need to consider commissioning very differently in order to provide services that are personal to local people. Some of the suggestions include the council commissioning agencies or independent managers to provide an advice, information and assessment service, or a system of council assessment directly linked to a choice of agencies that would put together the appropriate package.

There is an aspect of market development where the aspirations for transformed social services come together in synergistic way. The extension of choice and control through individual people gaining purchasing power from the council brings a wider benefit to those who have to purchase their own services because they fall outside councils' means-test threshold, or choose to do so to remain independent of the state. As councils move to supporting a pluralistic and bespoke local care market, then this must include opportunities for local self-funders to purchase from the same providers. Indeed, in council areas where the majority of those needing care will be funding it themselves, developing such an open market will be necessary to ensure that it is viable for providers.

Recently many councils have been criticised for the lack of information and help they provide for those who have to make their own care choices because they do not meet the financial criteria for council support. As councils develop pathways of advice and support for those with individual budgets, these can be made more generally available, providing a truly universal service and, hopefully, helping to remove any stigma surrounding receiving council services.

Finally, there are on-going concerns about the quality of some services and the ability of the system to ensure that quality improves. Within the changing landscape of social care this will need to be addressed through improved and intelligent commissioning by councils working with providers to ensure that quality is maintained or improved. In addition, the increasing number of users involved in commissioning decisions should keep a more individual and personal check on the quality of care, so long as effective feedback and information flows at the local level.

But it is not only those commissioning services who will need to change, but also front-line staff working with individuals. Social workers, who now concentrate on assessment and care management, will have to become facilitators, advocates and brokers. They will enter much more of a partnership with the person and their family or other informal carers, judging how much help is needed to support them in deciding the outcomes the package of support should deliver and the best way to achieve these and in brokering the package.

While many welcome a return to the reason they became social workers, the scale of the change to professional processes and mindset should not be underestimated. The provision of domiciliary care is unlikely to remain as an impersonal and unpredictable 15-minute visit if recipients are in control of the commissioning. Again, this could be a

positive change for care workers, who report much more job satisfaction if they have time to build a relationship with those they are supporting. However, there will be staff who are at present providing services that will have to be redesigned or decommissioned, and there will potentially be additional staff costs attached to achieving these changes.

### **Shift to well-being and prevention**

Most people who use social services (and most of those who do not meet the current need or financial eligibility thresholds) say they want supportive services that maintain their independence and quality of life and minimise the risk of a crisis that would result in hospital or care home admission. The simplest example of this is a service that maintains an older person at home without a risk of a fall, leading to hospital admission with a broken hip. This may be as simple as handrails, well-fitting slippers and some simple exercises to strengthen muscles and balance. These services have been shown many times to provide good value for money, simply in the number of hospital admissions they avoid, without considering the impact of the hospital stay on the older person's well-being and overall health.

But there has been a continued call for evidence that, in general, prevention is more cost-effective than cure in older people's services. The Partnerships for Older People projects were set up to test this. In 2006, 19 councils and their NHS and third-sector partners put in place a comprehensive system of investment in services that aimed to reduce hospital admissions, length of hospital stay and use of residential care, and to improve older people's quality of life. The early findings from these sites are that these pilot sites have a significant effect on emergency hospital bed use and an average potential cost saving in the order that for every £1 spent on older people in the community, £1 is saved in hospital bed days.

The evaluation is rightly cautious about this conclusion 15 months after the commencement of the projects, but it must be remembered that this cost-effectiveness does not include any adjustment for most people's preference for support to live at home compared with a costly and painful hospital stay, from which many older people would emerge with a diminished quality of life. However, a major obstacle to the shift from acute and institutional care to care and support nearer people's homes is the difficulty in releasing funds from the hospital sector to sustain such a shift. There are many perverse incentives in the system. Even where health and community services are regarded as a local continuum, where it might be imagined that funding would flow to the most cost-effective configuration, acute services continue to exert a draw on funding. In areas where

health and social care budgets stay completely separate, in the hands of the primary care trust and local council, there is no incentive for either partner to invest in actions that will save funding for the other.

### **Partnerships for Older People case example: At home, not alone**

Norfolk Council, in partnership with the primary care trust, ambulance trust and fire service, is providing a range of services, combined with access to the community alarm service. These include night- and day-time crisis care at home and planned care at night; a contacting and prompting service for anyone needing support with medication; routine daily contact for those with long-term conditions and more intensive contact for those recently discharged from hospital; a follow-up service for anyone who has fallen; a volunteer service providing small items of equipment helping people with dementia to stay at home safely; a telephone club that provides social contact and telephone shopping delivered from local shops; and a home security service. Together these provide a network of services that help a largely rural population stay at home, but also feel supported and connected.

A key learning point from the Partnerships for Older People projects is that this type of change takes time and commitment on the part of all the partners involved, with initial investment to enable the change that can deliver savings elsewhere in the system in the longer run. What they have not yet effectively demonstrated is that this change can become sustainable, because they have not, in general, been able to overcome the perverse incentives and move to a long-term shift from reliance on the acute sector to community services that support an improved quality of life for older people.

### **Integrated commissioning and aligning incentives**

The drive to design services around the individual and consider wider well-being and the shift to prevention and community services rather than institutional crisis response both mean that local services need to work together with agreed priorities and actions. This is also the only way to overcome some of the perverse incentives described above. There are practical benefits from joint commissioning across the whole spectrum of health and local council services: better access to the range of local services, redesigning services to provide an integrated service to local people, and bringing together expertise and purchasing power to get better value in health and social care services.

Realistically, the push for better commissioning and greater productivity in a tightening

fiscal climate will also accelerate the pace of change, as local partnerships seek efficiencies, better outcomes and better value for money from the range of services the partnership provides.

Over recent years most localities have moved to closer partnerships between councils, primary care trusts and local third-sector providers, brought together in the local strategic partnership. The requirement in the Local Government & Public Involvement in Health Act 2007 for the council and primary care trust to develop a joint strategic needs assessment, and use that to inform the sustainable community strategy and priorities within the local area agreement, also cements this relationship. However, there are a wide variety of organisational arrangements in place to give form to this partnership. This reflects the different local structures, histories and relationships, and also that no one organisational structure has either been imposed or shown universal applicability for every situation.

Partnerships have developed at three organisational levels: operational delivery, strategy and governance. The most prevalent model is a locally decided and agreed partnership between the council and NHS partners at one, two or all of these levels, supported by partnership agreements under section 75 of the National Health Service Act 2006. For example, in Barnsley, joint commissioning posts have been created to support a successful drive for improvement by the council and primary care trust working together. There are a number of concerns about these partnerships, mostly around the fact that they can fall apart under financial or other pressures for one or both partners and the energy and commitment needed to sustain them. But, despite this, they generally work well, and local partners find them adaptable to support incremental improvement and better outcomes without the upheaval and risks of reorganisation.

In a number of areas this partnership has either opportunistically or deliberately evolved to merge the senior management of health, social care and related services. There are several joint appointments of primary care trust chief executives and directors of adult social services. Successful joint appointments and related governance arrangements need high levels of trust and commitment by the partner organisations. Some early examples broke down in the face of conflicting priorities and performance requirements from the council and NHS partners. A more formalised development of a section 75 partnership is a care trust, where local authority and NHS services merge within one new NHS trust, effectively cementing the partnership by creating one organisation. Four care trusts were established in 2002, when this organisational model became possible, and they have been followed by a further six.

Not many areas have pursued this model, not least because the pain of structural reorganisation is not seen to be worth the gain to the partnership, but also because of primary care trust and council reorganisation and difficulties with NHS finances, which have prevented some far advanced plans coming to fruition. Very recently North East Lincolnshire has created a "care trust plus", covering adult social care and community health and moving public health into the local authority. It is intended that this should allow health and social care services to work in a focused and coherent way, while integrating public health with all the council services that have an impact on the determinants of health and health inequalities to align incentives around prevention and health improvement.

More recently, a "super-authority" is being developed in Herefordshire. This involves appointing a single chief executive for the unitary council and the primary care trust. Initially the joint chief executive will separately be accountable to each organisation, with an informal public services partnership overseeing strategy and performance. The intention is to secure legislation to formalise the merger by creating a new legal entity in due course. The argument for this radical proposal is to protect local services and allow long-term development, with a strong drive for a financially viable organisation with reduced management and governance costs.

Finally, there are some examples of councils and NHS partners setting up social enterprise providers. Of course many, and increasing numbers of, councils support local social enterprises to provide the local, flexible services described above. But some areas, most notably Surrey and Milton Keynes, are seeking to extend this by transferring NHS and council services into this type of organisation. This is proving difficult because staff have generally been reluctant to transfer, but as the overall system becomes more pluralistic and potentially some of the technical hurdles around, for example, pensions and insurance are removed, then such flexible arrangements may become more attractive.

#### **Case example: Sunderland Home Care Associates**

Sunderland Home Care Associates is a domiciliary care agency that has been an employee-owned social enterprise since 1998. It provides services to 300 people, under contract to the council, by private arrangement and through local colleges.

Generally a move to local partnership working has been seen as the best way of aligning the potential perverse incentives mentioned earlier. In addition the reduction in central

involvement in the performance framework for councils and the NHS has reduced the risk of targets or priorities that pull elements of the local system in different directions. In the 2007 comprehensive spending review announcement, the government announced a single set of 198 indicators to manage performance delivery outcomes (down from an estimated 1,200) and no mandatory targets for adults within local area agreements, which cover outcomes that local government is delivering alone or in partnership.

While councils are very committed to the move to personalisation of services, this transformation of service delivery comes at a time of ever-tightening social care budgets, particularly when compared with the demographic increases in both older people and younger disabled adults. The 2007 spending review provided an average increase of 1% in real terms in the funding provided to local authorities. This will represent an additional £2.6 billion in the third year of the settlement, while local government calculated that the demographic pressures on social care alone would cost an additional £2.68 billion. Since many other local services are also under financial pressure, it is simple to see that the funding available for social care will be insufficient in many parts of the country, even with the introduction of service redesign and other efficiencies.

As mentioned above, a green paper on the reform of social care was announced at the same time as the comprehensive spending review. The purpose of this would be to reform the system to one that targets resources effectively, is affordable over the long term and promotes independence, well-being and control for people. This is long overdue and seeks to address the continuing squeeze on social care resources; however, it does not address the very real pressures on councils over the next three years.

## **Conclusion**

This is a time of great change for social care. The majority of councils, their staff and their private and third-sector partners are committed to moving to a system of high-quality, personalised support for people who receive social care, with an increasing amount of control over that care in the hands of the individual, their informal carers and family. It is happening at a time of financial and demographic pressures on the sector and this will mean that the change will need careful management and committed leadership if we are to achieve the radical difference to the quality of care and support that older and disabled people and their families receive in the future.

## Chapter 6

# The changing partnership on care – the role of the market

Stephen Haddrill, Director-general of the Association of British Insurers

## The changing partnership on care – the role of the market

### Market experience to date

For people who need to fund their own long-term care, the financial options can be expensive and confusing. The availability of financial products in the market for long-term care is limited. Problems of risk assessment, cost and regulation have made the market an unattractive proposition for the financial services industry.

This in turn has created a vicious circle. In small markets it is harder for insurers to spread their risk. Product pricing is also made harder by the rapidly changing demographics of an ageing population and the high cost of care. The only certain thing about the Government Actuary's Department predictions on ageing is that they will change within a year of being made.

In addition, the market is highly regulated and current regulation requires separate and complex exams regardless of the level of risk attached to products. In consequence, few advisers offer long-term care insurance, further reducing customer access to this market.

Despite this, the industry could play a significant role in helping to fund the long-term care needs of consumers in the years ahead. Clearly, to achieve this, a new model for the industry will be needed to break the current vicious circle of unquantified longevity risks, tight regulation, high operating costs, few participants and tiny market penetration. The question is: how can we turn this cycle into a virtuous circle?

While the market has struggled to work, its potential role has become more relevant in the long-term care partnership between the individual and the state. The demands on state funding have increased. Families, friends and charities were the traditional providers of long-term care. The mobility of the workforce and the increasing need for a double income within families has reduced the availability of unpaid carers and this trend shows no sign of slowing down. Although planning for the future is of benefit to people across the whole of their lives, few plan for their possible long-term care needs. Many are unaware of the need to do this, assuming that the state will pick up the bill.

Long-term care has never been a free-to-all, state-provided service.<sup>1</sup> In 2006 the average annual fee for private nursing in England was £25,552 and £18,420 for a residential home.<sup>2</sup>

<sup>1</sup> National health services are free to all at the point of need.

<sup>2</sup> *Financial Times* research conducted in April 2006

Individuals are expected to meet the entire cost of their long-term care if their total assets exceed £21,000. This includes the value of the individual's home unless close relatives live in the house (for example, their husband or wife). The state will meet the total cost of an individual's care only if total assets are less than £12,750.

State provision may not cover need comprehensively but its complexity also puts people off using the private market.

First, individuals cannot easily determine how much insurance they need because of the complexity and variation of the level of support that local authorities and the state provide.

Second, the state does little to encourage private provision. There are few incentives: while the taxation system supports saving for pensions it does not do so for long-term care. The pension rules are inflexible and do not easily allow people to use their pension assets to pay for the cost of long-term care. Unlike some other countries, there is no mechanism for employers to help their employees meet the cost of care.

Third, the absence of a single assessment process across state and independent funding arrangements means that consumers cannot easily determine when products would pay out.

Finally, individuals must be covered until death. It is not an option for an individual to have their care withdrawn. The care pathway should provide for the needs of the individual, regardless of who funds it. There is a need to provide a better, seamless transition if the individual were to move from self-funding to state funding.

The industry has a recognised ability to drive up standards. Along with the care pathway, regardless of whether funding is from the state or private sources, individuals should be assured that they would receive care in private facilities of a high standard. In other sectors, for example the motor industry, insurers have played a significant role in raising standards of repairs for the benefit of consumers. These same principles could be applied to the provision of care services.

### **Existing funding options**

At present there are three market options for funding long-term care insurance:

- *Pre-funded policies* – These are either pure protection insurance that has no investment element, or investment bonds that are a framework for investing funds over a long period of time. These are specifically tied to a pure protection insurance contract and can be funded either by single or regular premiums. A small market exists in the UK, served by one company.
- *Immediate needs insurance* – This is the only significant long-term care insurance funding mechanism. It is bought at the time the individual actually needs care. This is an investment-based product. It provides a regular income stream in exchange for a single lump-sum payment. Individuals buy it to set off the risk of them living longer than their funds can support. Insurers carry out a health check and set an appropriate single premium.
- *Equity release* – Individuals use equity-release schemes to purchase an impaired equity or an immediate needs insurance product to fund nursing care fees. One example is the Joseph Rowntree Foundation scheme. This is a public fund where capital payments and annual fees from each resident are pooled to fund care and support services for all the residents. There is a flat rate fee that will not rise even if a resident needs permanent residential care. (Residents can opt to pay for care as needed.) The objective is to achieve a balance between those residents who need care and support and those who do not make many demands on its care services.

### **Proposed market reforms**

To create an environment where the private sector can take a significant role in the future funding of long-term care, the Association of British Insurers would encourage the government to engage in the following:

- *Risk sharing* – sharing the risks of longevity and increasing cost with the financial services industry.
- *Incentives* – offering incentives for people to make their own provision, such as a higher asset ring-fencing limit and/or ring-fencing the person's home.
- *Use of pension assets* – putting flexibility into the pension system to allow more use of pension assets. This will also allow employers to help employees fund long-term care.
- *Proportionate regulation* – a move to a proportionate, principle-based regulatory regime for simpler, more affordable products based on the first two points above.

### **How each reform might work**

#### **Risk sharing**

Longevity risk should be shared between the public and private sectors to encourage

insurers to re-enter the market, make long-term care provision more affordable, and allow insurers to offer simple, affordable products.

Risk sharing could work in a number of ways, for example:

- *A passport system* – whereby a person could transfer part of their entitlement to state support to a care provider of their choice, topped up by private provision. For example, a person could choose to pay for a private nursing home using their own private funds and the money they would have got for a state-run home. The state's money would only be transferable if agreed rules were met, for example, that the private nursing home was a registered accredited provider.
- *Time-bound arrangements* – whereby the private sector would pay for the first period of care (say, the first two years) and the public sector would take over the cost thereafter if required. To make this successful, a seamless transition over the funding changeover would be needed, with common criteria for assessing the need for care.
- *Pooled risk* – whereby the overall cost of a group of individuals would be shared financially in an agreed proportion between the public and private sectors.

The options could be to have:

- products that underwrite care costs for a set period, or an alternative means of capping risk, along with the state;
- products that meet costs up to a given level, with the state providing a safety net beyond that;
- models in which care is provided alongside investment in retirement housing equity, such as partial equity release products that enable care costs to be met without the housing resource having to be totally surrendered; or
- models where the housing equity of members of a community scheme might be pooled to share risk while retaining some equity for members of the scheme on death. This would be a development of the Joseph Rowntree Foundation's Hartrigg Oaks scheme.

### Incentives

The taxation system could have the same incentive for long-term care saving as for pensions saving. A tax benefit would broaden the appeal of the product. This could reduce adverse selection. Due to the current small size of the market and the cost of care provision, the people who have taken out the product may have been the ones who were at greater risk of needing care.

Risk sharing would help to reduce the cost to consumers of making private provision. However, the industry believes that without compulsion, where payments could be levied on an individual or the whole population based on income and/or choice of care package, consumers will need further incentives to make personal provision for the cost of their care needs.

One option would be to offer people a higher threshold for means testing and/or some exemption for their main residence if they make appropriate provision for themselves. This could include having insurance to cover all or part of their future care needs.

This offers a win:win:win scenario for the individual, the state and the insurance industry:

- *For the individual (and their family)* – the reassurance that the state will not take their home to pay for care will give peace of mind.
- *For the state* – the person will have made provision for the cost of care and should not therefore need to rely on state funding. Exempting the primary residence and offering a higher limit for the means test should not, therefore, have a significant cost.
- *For insurers* – the scheme would be a significant incentive to encourage the individual to take out such an arrangement.

However, in principle, a scheme might include a pre-funded insurance scheme or an immediate needs annuity scheme.

### Use of pension assets

Some consumers would benefit from being able to use their pension assets to make provision for meeting the cost of long-term care.

People with below-average pension-fund benefits are likely to need to use their entire pension benefits to fund their retirement. However, people with larger schemes may prefer to use part of their pension fund to pay for the cost of care provision later in life if the pension rules allowed them to do so.

Crucially, this would allow employers to help their employees provide for the cost of requiring care later in life through the pension regime. Employers who already funded pension schemes would have the opportunity of additionally providing long-term care benefits that their employees could choose from as part of the same scheme. Importantly, this would bring the issue of potential care requirements to the attention of employees.

There are many ways that the pension system could be modified to allow this to happen. One approach would be to allow people to take out a policy to cover the cost of care – purchased directly by the pension fund. Alternatively, it would be possible to design a pension annuity so that the person gave up a proportion of the fund at retirement to provide benefits to pay for care benefits later in life.

For example, say someone has a pension that could provide an income of £20,000 a year in retirement from age 65. He or she chooses to take a lower initial income (say, £18,000 a year) so that when he or she reaches age 85, or meets agreed criteria if needing care sooner, the income increases to £40,000 a year.

### **Proportionate regulation**

The regulatory environment has been a catalyst for closing down the long-term care market in the private sector. When long-term care became regulated, the only regulatory regime that then existed was for investments.<sup>3</sup> Accordingly, long-term care insurance became regulated as an investment product.<sup>4</sup> However, because the investment regime was not entirely appropriate for long-term care, additional requirements were imposed.<sup>5</sup> This leaves long-term care as the most heavily regulated product in the UK, with the toughest hurdles for advisers.

In practice, this means that very few qualified long-term care advisers now exist. This provides a significant barrier to people receiving good-quality financial advice. Indeed, most participants pulled out of the market when this additional regulation was introduced.

If the market is to be revived, we need to ensure we have a more appropriate regulatory framework that protects consumers and enables their interests to be met by the market. One approach would be for the public and private sectors to work together to develop products that meet certain standards and could then be offered to consumers under a proportionate regulatory regime. Risk sharing and the possible incentives described above would help to achieve this.

### **Preconditions for market reform**

For the market to be reformed, the industry would need:

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3 The Financial Services Authority's insurance conduct of business rules

4 Most insurance products are regulated under the FSA's insurance conduct of business rules.

5 Chartered Insurance Institute – CF8 certification

- clarity about where the boundaries of public provision would lie in order to help define the target market beyond it;
- a proportionate regulatory framework, which would help build public confidence but avoid disproportionate cost;
- a clear framework and time scales for the evaluation and understanding of the nature of the contribution and responsibilities of their partners in local or central government; and
- clear support from the government in promoting awareness of the need to address long-term care costs among individuals as well as in trusted intermediaries, for example, via the NHS, citizens' advice bureaux and so on.

### **Benefits of market reform for individuals, society and the government**

The next generation may become more aware of the need to plan for their parents' potential admission into a home. We now have an opportunity to target the next generation of potential long-term care recipients and their children to create a different climate of opinion.

Creating the environment where employers and individuals can play a significant part in the future funding of long-term care through private provision would have substantial benefits.

The private sector could play a full part in driving up standards in the provision of private care. The state and private medical insurance firms commission services from state and privately run hospitals and clinics. Facilities are required to maintain comprehensive service standards. Long-term care providers and facilities that accept funding from state as well as private sources would be expected to ensure the same minimum quality of care for all individuals.

Using the initiatives based on risk sharing and incentives, the arrangements could be tailored to dovetail with the current social services and increase funding to include the provision of advisory services for the policy holder and their family on the prevention of the need for care and its eventual provision. This could include, for example, meeting the cost of a home visit advisory service to give advice on home safety to prevent falls. In turn, this could help to reduce the overall cost of care and support people who want to stay in their own homes for longer.

It would also help to remove a perceived unfairness about the current system where a disproportionate part of the cost is borne by those who live alone and whose house is sold

to provide funding for care. As home ownership and single occupancy are trends that are both continuing to increase, the perception of an inherent unfairness in the system may make it politically unsustainable in the long term.

However, if people were to have the option to ring-fence their home by making their own provision to provide for their care, this would help to sugar-coat the pill of selling homes by providing meaningful choices for people in this area.

Overall, such a package of measures could have a significant effect on creating an affordable, sustainable long-term care system in the foreseeable future.



## Chapter 7

# Workforce reform

Professor Jill Manthorpe, Director of the Social Care Workforce Research Unit at King's College London

## Workforce reform

### What workforce will be needed to deliver a new vision for social care?

*Generosity and condolence define what professionals brought to my mother. Iconic images of this include the district nurses caressing mum's hand and talking to her while she slept, and the sheer skill of the women care workers. This was despite their high workloads, scandalously low wages and the fact that although car use was essential, these carers were getting the same mileage allowance as 20 years ago. It was through stories like that we glimpsed some of the chaos and demoralisation that threatened their generosity. Their true achievement was to be so humane in the midst of chaos.<sup>1</sup>*

The workforce is central to social care, not simply because its pay consumes the majority of resources but because the relationship between social care staff and people using services often determines its effectiveness and outcomes, and influences for good or ill the lives – and, indeed, deaths – of people using social care and their families' well-being and memories. This brief chapter can only touch on the central features of today's social care workforce. To answer the question about what workforce we need for the future presumes that we know a good deal about the workforce that we have. This is, sadly, not true. Knowledge of the social care workforce is limited and this gives rise to myths and misunderstandings.

Unpaid carers are not covered in this chapter, nor are volunteers. Neither are the many disabled and older people who provide care for themselves, perhaps with the assistance of special aids and appliances. This is not to downplay their contributions to social care but the focus here is on paid staff. What they are termed varies, but overall this chapter will focus on care assistants, home care workers and social workers. Support workers or personal assistants are also covered. As any look in the small ads of a local newspaper or shop window will show, these workers are in short supply. Will the future look any different? This chapter offers a series of possible scenarios.

### Profile

The "traditional" or "core" social care workforce numbers 922,000 people in England.<sup>2</sup> Of these, around 559,000 are thought to be providing support to older people.<sup>3</sup> Our

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1 Harry Ferguson "Kindness Amid the Chaos" in *The Guardian*, 24 October 2007

2 Eborall, C *The State of the Social Care Workforce 2004*, second Skills Research & Intelligence annual report (Skills for Care, 2005)

3 Wanless, D *Securing Good Care for Older People: Taking a Long-term View* (King's Fund, 2006), p121.

At: [http://www.kingsfund.org.uk/resources/publications/securing\\_good.html](http://www.kingsfund.org.uk/resources/publications/securing_good.html)

knowledge of this sector is limited, making predictions a matter of extreme guesswork.

Eborall<sup>4</sup> lists many reasons why current data is so limited. These include: confusion over the boundaries of social care and other sectors; limited information from the independent sector, which is the major provider; little research on the domiciliary care (home care) sector; scant data on the casual workforce working for employment agencies working in the sector; possible overcounting of parts of the workforce, some of whom have more than one employer; undercounting through lack of information on the numbers of people working unofficially and who do not pay tax and national insurance; vague or duplicated job definitions; uncertainty about the positions of administrative, support and domestic staff; variable occupational definitions; and the merging of data from various sources – some UK, some England-only.

This woeful state of knowledge led Skills for Care (the sector skills council for adult social care in England) to decide on a strategic objective to collect "world-class data" for social care in the form of a national minimum data set. In the years ahead we will know much more. But, overall, one key reason for this lack of knowledge is the sector's lack of political importance.

Repeated calls to make social care work "highly valued", such as in the *Options for Excellence report*,<sup>5</sup> reveal how far there is to go. *Scenario one* could see a continuing tradition of seeing social care as low-status, the ultimate in pin money work, dealing with difficult people in distressing circumstances. *Scenario two* instead would see this area as highly valued: work that is high-status and hard to enter. The elements discussed below outline some of the building blocks that will determine whether we find ourselves in scenarios one or two.

### Today's problems

The vacancy rate in the social care sector is double that for all types of industrial, commercial and public employment.<sup>6</sup> The Commission for Social Care Inspection,<sup>7</sup> the body that registers, inspects and reports on adult social care services in England, has

4 Eborall, C *The State of the Social Care Workforce*, first volume of the first annual report of the TOPPS England Workforce Intelligence Unit (TOPPS England, 2003)

5 Department of Health/Department for Education & Skills *Options for Excellence: Building the Social Care Workforce of the Future* (2006), p6. At: [http://www.everychildmatters.gov.uk/\\_files/Coa210467e447bcf511284cdab79f93.pdf](http://www.everychildmatters.gov.uk/_files/Coa210467e447bcf511284cdab79f93.pdf)

6 Ibid

7 Commission for Social Care Inspection *The State of Social Care in England 2005-2006* (2006), p1.

At: [http://www.csi.org.uk/pdf/state\\_of\\_social\\_care\\_05\\_06\\_1.pdf](http://www.csi.org.uk/pdf/state_of_social_care_05_06_1.pdf)CSCI

described this as an area of "chronic difficulties".

In the voluntary and private sectors, vacancy rates seem to be lower than in the statutory sector but the turnover rate appears to be higher. Overall, vacancies appear to be higher in care homes<sup>8</sup> than in other parts of the sector. In terms of turnover, there is evidence that most social care workers leave to work for another social care employer or the NHS. Only a minority switch to the retail sector,<sup>9</sup> although anecdotal reports often suggest that this is frequent.

Shortages in recruitment and high turnover among social care staff dominate debates about the sector. Faced with these shortages, some employers have looked to international recruitment as a way of dealing with their staffing problems. While this is not new, the advent of the A8 EU accession states found new "sending countries" in addition to traditional sources such as the Philippines. This may be a stopgap solution, making social care in effect a transition industry. Will such workers continue in social care work? And will further new recruits from outside the UK or Europe be acceptable, effective or even likely?

Deep anxieties exist about the morality of importing staff to social care in the UK and the effect this is having on their own countries, so much so that there is a code of practice,<sup>10</sup> as yet only voluntary. While international workers are valued by the sector, there are also concerns about levels of training, understanding of English and cultural issues, and confidence to speak out if things are wrong.

The future of the international workforce in social care is uncertain, with little known about the "grey" or unregulated economy: where exploitation is an ever-present risk. *Scenario one* sees further use of migrant workers as the EU expands or work permits are extended; *scenario two* sees a reduction in work permits in social care because job vacancies no longer justify this and higher requirements are placed on staff for English language skills, along with agreements over comparability of skills and qualifications.

### **Social care employers**

Any discussion of the future social care workforce relates to future employers' profiles and

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8 Eborall, op cit (2005); Local Authority Workforce Intelligence Group *Adult, Children & Young People Local Authority Social Care Workforce Survey 2005* (Local Government Association, 2006). At: <http://lga.gov.uk/Briefing.asp?section=0&t1d=sx1282-a783cef3>

9 Skills for Care *National Minimum Data Set for Social Care Briefing*, issue 1: *Overview – An Oasis in the Data Desert* (2007)

10 Social Care Code of Practice for International Recruitment. At: [www.sccir.org.uk](http://www.sccir.org.uk)

needs. At the moment there are more than 30,000 social care employers.<sup>11</sup> Most (56%) are privately owned for-profit employers, 17% are voluntary organisations and 27% are statutory providers. Larger businesses are dominating this field, with a trend of closure or sale among small, independently owned care homes.<sup>12</sup> Contracting out of care services in the 1990s steered the workforce profile from being concentrated in local authorities to growth in independent businesses and voluntary-sector groups. The market has since consolidated, with concentration under fewer providers.<sup>13</sup> Other changes relate to new forms of employer and new worker roles delivering more extensive home-based services, assistive technology and extra care housing – all in line with most people's preferences to remain at home.<sup>14</sup>

Two questions arise for the future: in *scenario one*, what will be the effect of a sector that is mainly dominated by large providers; and in *scenario two*, what will be the effect of more people becoming employers? *Scenario one* is mixed; it might lead to more evenness in human resources and pay scales, with perhaps more finely tuned pay scales and opportunities for career or skill development. Alternatively, it might lead to rather routine work, with staff shoehorned into a corporate culture.

The effect of people becoming employers presents mixed workforce implications. Work in *scenario two* is again multifaceted; where an individual pays for support, it may provide pleasure in seeing a job well done, but it may also be risky for the worker involved, with limited protection under health and safety frameworks, high expectations of flexibility and the blurring of boundaries between roles as worker, friend and carer. Flexibility of support is highly valued, but continuing uncertainties about hours and pay, if staff have other responsibilities, or are having to negotiate income-support systems such as tax credits and tax, are not so easily managed.

### Gender: women's work?

Possibly the most striking feature of the social care workforce is its horizontal and vertical gender segregation<sup>15</sup> whereby women constitute around 84% of the workforce but make

11 Department of Health/Department for Education & Skills, op cit

12 Netten, A, Darton, R and Williams, J *The Rate, Causes & Consequences of Home Closures* (Personal Social Services Research Unit, 2002). At: <http://www.psr.u.ac.uk/pdf/dp1741~2.pdf>

13 Schmid, H "Rethinking the Policy of Contracting Out Social Services to Non-governmental Organizations" in *Public Management Review* vol 5, no 3 (2003), pp307/323. At: <http://dx.doi.org/10.1080/1471903032000146928>

14 Department of Health *Independence, Well-being & Choice: Our Vision for the Future of Social Care for Adults in England*, Cm 6499 (The Stationery Office, 2005). At: <http://dh.gov.uk/assetRoot/04/10/64/78/04106478.pdf>

15 Manthorpe, J and Moriarty, J "Older Workers in Social Care" in Chiva, T and Manthorpe, J (eds) *Older Workers in Europe* (Open University Press, 2008)

up only 67% of senior managers.<sup>16</sup> Horizontal segregation is used to describe the tendency for women to be in different jobs or occupations to those of men. Vertical segregation means that, within a particular occupation, women tend to hold the lower-status and lower-rewarded positions.

This is a world of women, in terms of staffing as well as recipients of care, most of whom are very old women. In *scenario one*, social care work may continue to attract women, with its opportunities for work that is highly satisfying in personal terms, if not financially rewarding, and often able to fit with childcare or other family responsibilities. However, in *scenario two* greater educational and work opportunities are available to women with growing aspirations, in combination with their other roles.

Tomorrow's social care workforce may be less dominated by women: a positive in offering choice and diversity in terms of teamwork and work cultures, but also raising questions about how men will function in care work that is often about very personal tasks. Will men in care work be compartmentalised in work that is more about support and activity, such as accompanying to or involving people in sport, employment and social activities, leaving female workers to the personal care and treatment tasks?

### **Age and experience**

The social care workforce is often described as an ageing workforce.<sup>17</sup> In the current context this is cause for concern as the retirement of older care workers is likely to prolong recruitment difficulties. Social care may wish to attract people who have taken early retirement, fostering the idea that this can be a "second chance" type of work, if it is able to fit with older people's interests and personal commitments.

Heavy work, such as lifting, might have to be rethought, but so too will pay and terms of work, as well as support for people who are new to this work who may hold ideas about risk that services users do not agree with, or who find dealing with distress and decline emotionally challenging. In *scenario one* older people, near and past retirement age, may be increasingly wooed by social care employers. They will be courted by a host of other employers, and so it is again pay, morale and conditions that are likely to be judged by this future workforce. In *scenario two* older staff become burned out, their role in mentorship is underdeveloped, and their experience is not recognised.

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<sup>16</sup> Skills for Care, op cit

<sup>17</sup> McNair, S and Flynn, M *Managing an Ageing Workforce in Health & Social Care* (Department for Work & Pensions, 2006). At: [http://www.agepositive.gov.uk/publications/Man\\_Age\\_HealthSoc\\_v5.pdf](http://www.agepositive.gov.uk/publications/Man_Age_HealthSoc_v5.pdf)

## Earnings

Direct care workers were one of the groups to benefit most from the introduction of the national minimum wage in 1999 and social care employers were among those most concerned about its impact.<sup>18</sup> Since then, while comparatively few jobs in social care are receiving the minimum wage, the proportion is far greater in the independent than in the public sector.<sup>19</sup> Rates of pay are a little higher in the voluntary sector.<sup>20</sup> Currently the median gross hourly pay rate in the private sector is £5.73 for care workers and £6.00 for senior care workers<sup>21</sup> (the national minimum wage currently stands at £5.52 for people aged 22 and over and £4.60 for those aged 18–21<sup>22</sup>). Which of us reading this book receive this level of wage?

The future again can be predicted to develop in two ways: in *scenario one* wages will remain low because the economy dips, more migrants are recruited, or other new pools of workers are "persuaded" to join (through restrictions on benefits, for example). In *scenario two* wages increase, skill and productivity rise, and the costs of doing this are met through a mix of extra public funding, reallocations to social care from the NHS, and agreements about investment in the sector. Regulation may be a lever to this, demanding greater levels of skill and insisting that continuity of care is important.

## Regulation

Regulation has been one of the major ways by which the government has sought to raise standards in social care. The Care Standards Act 2000 established a set of national minimum standards covering matters such as the level of training and the establishment of a social care register (not yet fully implemented). There are stricter standards for entry into social care, including criminal record checks. Following the establishment of the Protection of Vulnerable Adults List, the Safeguarding Vulnerable Groups Act 2006 will set up a new Independent Safeguarding Authority in 2008 to continue checks on people's suitability to work with children and vulnerable adults and to prevent people deemed to be unsuitable from working in this area.

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18 Grimshaw, D and Carroll, M "Adjusting to the National Minimum Wage: Constraints and Incentives to Change in Six Low-paying Sectors" in *Industrial Relations Journal* vol 37, no 1 (2006), pp22–47.

At: <http://dx.doi.org/10.1111/j.1468-2338.2006.00388.x>

19 Low Pay Commission *National Minimum Wage* (2007). At: [http://lowpay.gov.uk/lowpay/report/pdf/6828-Dti-Low\\_Pay\\_Complete.pdf](http://lowpay.gov.uk/lowpay/report/pdf/6828-Dti-Low_Pay_Complete.pdf)

20 Skills for Care, op cit

21 Skills for Care, op cit

22 Directgov *The National Minimum Wage: Introduction*. At: [http://www.direct.gov.uk/en/Employment/Employees/pay/DG\\_10027201](http://www.direct.gov.uk/en/Employment/Employees/pay/DG_10027201) (accessed 22 September, 2007)

A social care register, of people who work in social care and have been assessed as trained and fit to be in the workforce after checks, opens in 2008. Currently, only social workers and students are on the register but other social care workers are in the process of being added. In *scenario one* accusations of over bureaucracy lead to a major watering down of these frameworks and raise doubts as to their real ability to safeguard vulnerable people. In *scenario two* such regulation brings not just the trappings of professionalism but enhances the status of practitioners.

### Training

Training is seen as the answer to almost all the problems of social care, including difficulties of the social care workforce. It is cast as a way of improving recruitment and retention and of ensuring that workers have the skills to meet the demands of their role.<sup>23</sup> Of course, it is not a magic bullet as the provision of training may not be enough on its own to improve the quality of care,<sup>24</sup> but for a number of reasons training is seen to be crucial.

Nationally, 66% of direct care workers are working towards a relevant qualification.<sup>25</sup> Regulations have substantially accelerated the pace of training,<sup>26</sup> meaning that while incentives have their place, it is compulsion that has worked for many. The positive relationship between levels of training and outcomes is supported by service users.

*Scenario one* sees further compulsion and incentives for low levels of training, providing minimum levels. *Scenario two* sees the raising of training and qualification requirements, with greater drives to increase the employment of nurses, therapists and activities co-ordinators in social care, many with specialist skills around rehabilitation, dementia and palliative care, and expansion of leadership skills among managers and senior practitioners. For this workforce, this might stem the flow of staff into the NHS and indeed create two-way traffic and the exchange of ideas, while boosting good practice and creating learning opportunities. If social care became a sector of choice for students and staff, then for their colleagues and for people using services this would be a welcome change.

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23 Department of Health/Department for Education & Skills, op cit

24 Wanless, op cit

25 Skills for Care, op cit

26 Gospel, H and Thompson, M *The Role & Impact of the Statutory Framework for Training in the Social Care Sector*, research report 495 (Department for Education & Skills, 2003). At: <http://www.dfes.gov.uk/research/data/uploadfiles/RR495.pdf>

## Meeting consumer expectations

Other chapters of this book have outlined consumer expectations of better social care: these include making support more personalised, providing friendship for some, and offering support as well as care. Not surprisingly, expectations reflect the diversity of people using services and their current needs. Almost 24,000 people receive direct payments in England.<sup>27</sup> We are starting to know more about the characteristics of the workforce supporting these people as personal assistants or support workers, but it is highly likely that the intended expansion of direct payments and individual budgets<sup>28</sup> will increase the numbers of people operating as "own account" workers in social care. Will this be a stable workforce? Possibly not.

In addition to people receiving direct payments, a number of people employ social care workers on their own behalf or for a member of their family in private arrangements, making use of savings, income or social security benefits. Beyond some small-scale research carried out some time ago,<sup>29</sup> little has been done to quantify the profile of this sector, although the tightening of eligibility criteria for social care means that there is a larger pool of potential employers. The "grey" economy of social care in the UK, operating for cash and outside national insurance and tax payments, has not been quantified, but there may be lessons to learn from other parts of Europe where the unofficial work of migrant live-in attendants for older people has great attractions for families but can involve exploitation for workers.<sup>30</sup> Stability here may be good in the short term, but people working under hard conditions are unlikely to stay if other options present themselves.

Consumer-directed support, such as direct payments and individual budgets, are also raising issues for professional workers such as social workers and care managers. Their roles and activities will continue to change, for some possibly along the lines of picking up the pieces when things have broken down or providing a short-term solution in complex situations, as described by Duffy,<sup>31</sup> when there is no other support available. The script<sup>32</sup> for professionals remains to be written and may involve more support of citizens

27 HM Government/Department of Health *Our Health, Our Care, Our Say: A New Direction for Community Services*, Cm 6737 (2006), p82. At: <http://www.dh.gov.uk/assetRoot/04/12/74/59/04127459.pdf>

28 Ibid

29 Baldock, J and Ungerson, C *Becoming Consumers of Community Care: Households Within the Mixed Economy of Welfare* (Joseph Rowntree Foundation, 1994)

30 Palese, A, Oliverio, F, Girardo, MF, Fabbro, E and Saiani, L "Difficulties and Workload of Foreign Caregivers: A Descriptive Analysis" in *Diversity in Health & Social Care* 1 (2004), pp31-38

31 Duffy, S "Care Management and Self-Directed Support" in *Journal of Integrated Care* vol 15, no 5 (2007)

32 Leadbeater, C *Personalisation Through Participation: A New Script for Public Services* (Demos, 2004)

who are currently on the margins of eligibility or who are funding their own support but with difficulty. The provision of safety nets for individuals and the willingness of public services to tailor levels of monitoring to assessments of risk will have to be factored into workforce discussions,<sup>33</sup> possibly putting at jeopardy some of the freedoms of consumer-directed support.

New roles are likely to emerge, ones that may offer help with issues such as bookkeeping and consumer protection. *Scenario one* sees this as expertise that has to be paid for, with a two-tier consumer base developing: one supported by savings or insurance, the other reliant on residual public-sector services. *Scenario two* sees expansion of new workers who are able to navigate the ways through complex services and consumer goods in social care.

Overall, will scenario one or two come to pass? Much depends on factors outside social care and factors outside the UK. Any vision that looks at the future without taking into account workforce issues is likely to place unreasonable pressures on the workforce and to depend on short-term solutions.

### Acknowledgments

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33 Manthorpe, J, Jacobs, S, Rapaport, J, Challis, D et al *Training for Change: Early Days of Individual Budgets & the Implications for Social Work & Care Management* (in press). For details, contact: [jill.manthorpe@kcl.ac.uk](mailto:jill.manthorpe@kcl.ac.uk)

## Chapter 8

# Disability benefits and paying for care

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## Disability benefits and paying for care

### Aims

The attendance allowance (AA) is paid to 1.5 million elderly people who need help throughout the day, during the night, or both. The care component of the disability living allowance (DLAc) is paid to another 2.3 million (mostly) non-elderly disabled people who meet the same conditions, or who need help for part of the day, or cannot cook a meal. Together, these benefits cost £9.2 billion a year, according to Department for Work & Pensions online statistics for February 2007. (Here, and elsewhere in the main text of the paper, we have glossed over many details of these complex schemes. Some more precise information is provided separately at the end of this chapter; readers who are unclear about the rules should start with that description.)

This paper discusses the impact of the attendance allowance and of the care component of disability living allowance (collectively known as AA/DLAc) on the resources of disabled adults. Since the need for care is the main criterion entitling people to claim, one important question is whether they receive (enough) care. The Wanless review of care needs (of elderly people) argued that the AA might not be the best vehicle both to provide support in meeting care costs and also compensate people for other needs-related expenditures. It recommended integrating support for care costs from AA into the care system to improve targeting of resources.<sup>1</sup> The pre-Budget report of October 2007 suggested that the government was actively considering the same set of issues for disabled people of all ages.

The Wanless recommendation was in the context of the review's conclusion that "more should be spent on social care for older people"<sup>2</sup> and that the system of financing care should have less means testing. Diverting funds from AA/DLAc to social care budgets is only one possible way to finance an increase in social care spending – the issue addressed here is not whether more should be spent on care, but whether less should be spent on disability benefits as part of the same package. A full evaluation of such a shift would need to consider other possible ways to fund increased social care spending. So we do not aim to reach conclusions on policy options. Rather we hope to highlight issues that will need further research and debate before conclusions can be reached.

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<sup>1</sup> Wanless, D *Securing Good Care for Older People: Taking a Long-term View* (King's Fund, 2006), p287

<sup>2</sup> *Ibid*, p286

The provision of personal assistance to disabled people is an important issue but not the only one. Disabled people, especially those of working age, typically have lower incomes than non-disabled people. And disabled people of any age face additional costs of living that leave them and their families worse off than non-disabled people with similar incomes. Both the AA and the DLA were originally intended to contribute to these extra costs – *not* specifically to pay for care. Sir Keith Joseph, for example, introduced the allowances as follows:

*It was never suggested that £4 a week provided for in the Bill would be enough to provide professional help ... It would be a valuable additional cash resource for the long haul of chronic severe disability for households which had to bear the financial burden.*<sup>3</sup>

Similarly, the white paper introducing DLA<sup>4</sup> was quite explicit that the objective was "better coverage of assistance with the extra costs of being disabled".

It is not clear from these statements whether these extra costs were meant to include (without being restricted to) the costs of paid-for care. There has never been any suggestion that disabled people were not allowed to spend their benefit on private domestic or personal services. But after the 1988 Griffiths report<sup>5</sup> the assumption that people should pay towards care from local authorities became much stronger.<sup>6</sup> Since then local authorities have tended to take AA/DLAc into account in assessing charges for home care (while allowing for other disability related costs). So the costs of state-provided care are now seen as a legitimate call on AA/DLAc.

Of course it will be open to policy makers in 2008 to change the priorities, putting more or less emphasis on the provision of care in relation to meeting additional costs. But both sets of consideration have to be taken into account in an analysis of the roles of these benefits, to assess the potential drawbacks, as well as the potential advantages, of a change in provision.

Central to the debate are the relative merits of "cash" and "care". AA/DLAc provides disabled people with regular cash, which they can spend however they wish. Historically, local authorities have addressed disabled people's needs through the delivery of care

3 Hansard, 10 July 1970, column 1013

4 Department of Social Security *The Way Ahead: Benefits for Disabled People*, Cm 917 (HMSO, 1990)

5 Griffiths, R *Community Care – Agenda for Action* (HMSO, 1988)

6 Baldwin, S and Lunt, N *Charging Ahead: The Development of Local Authority Charging Policies for Community Care* (Joseph Rowntree Foundation, 1996)

services. The growing use of direct payments and recent pilot schemes for individual budgets are intended to give clients of social services much more control and flexibility over how their needs are met. The way money channelled through local authorities is used to meet the needs of disabled people is therefore in the process of change, a point to which we return.

The supply of care has been described as a "mixed economy". Disabled people are helped in various ways by their families, by friends and neighbours, by NHS and local authority employees, and by paid carers. Some receive help in their own homes, while others live in specialist care or nursing homes. Direct and indirect costs of care are met in various ways by the disabled people themselves, by the carers themselves or by public bodies. Disabled people and their families face other additional costs, as well as the costs of care.

Sir Keith Joseph's comment on the amount of benefit in relation to the cost of "professional help" is worth emphasising. The criterion for the top rates of AA/DLAc specifies the need for help throughout the day and supervision during the night. It would cost £840 a week to support 168 hours of assistance, at the minimum wage of about £5 per hour. The Independent Living Fund, which tops up the care resources available to severely disabled people in the community, pays an average of more than £300 per week, in addition to AA/DLAc, and at least £200 worth of funding or services directly provided by the local authority.<sup>7</sup> So £65 (the top rate of AA/DLAc) could not meet the costs of the care implied by the eligibility criterion.

This mixed economy (that is, the overall combination of benefits and care services) can be compared with potential alternative policies in terms of five main criteria:

- Are the policies well targeted on disabled people, and especially on severely disabled people who are likely to have the highest level of support needs and/or highest disability-related costs?
- Are they well targeted on people and families with limited incomes?
- Do they help to promote, or at least not discourage, a supply of care appropriate to people's needs?
- Do they compensate disabled people for other additional costs of living?
- Are the processes of assessment and allocation consistent with objectives such as consistency, independence, dignity, freedom of choice and so on?

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<sup>7</sup> Independent Living Fund data, 2007; see also Henwood, M and Hudson, B *Review of the Independent Living Funds* (Department for Work & Pensions, 2007)

There has been astonishingly little research into the impact of AA/DLAc, considering the importance of these benefits both for public expenditure, and for the resources available to disabled people. The two surveys commissioned by the Department for Work & Pensions<sup>8</sup> were more concerned with the process of claiming than with what difference the benefits made to the lives of recipients and their families.<sup>9</sup> The first half of this paper draws extensively on some new analysis of the Family Resources Survey. The FRS is the only large-scale survey combining data on social security benefits, household incomes, disability and sources of care for all age groups.<sup>10</sup> But it should be noted that many of these FRS questions have hardly been analysed, and may be subject to as yet unidentified measurement problems.<sup>11</sup>

The FRS covers a sample of people in private households, and so provides no information about the needs or resources of people in care homes. Many of these receive AA/DLAc (if they are not funded by the NHS or their local authority). One of the main strategic objectives for the reform of care policy is to enable future generations of elderly and disabled people to remain in the community rather than enter care homes. If so, any transfer of resources associated with reform is likely to be away from people who would have lived in the community anyway, towards people who would otherwise have been in care homes. The FRS covers the likely losers in such a transfer, rather than the likely gainers.

The next two sections of this paper use the FRS to describe and assess the position of AA/DLAc claimants with respect to disability, and to income and living standards. The following two sections comment on reform options, focusing first on resource allocations, and second on some procedural differences between disability benefits and social services. The final section compares the advantages and the disadvantages of reform proposals.

8 Sainsbury, R, Hirst, M and Lawton, D *Evaluation of Disability Living Allowance & Attendance Allowance*, DSS research report 41 (Department of Social Security, 1995); and Hawkins, J, Goldstone, C and Bhaget, M *Knowing & Understanding Disability & Carers Service Customers*, DWP research report 439 (Department for Work & Pensions, 2007)

9 But for small-sample studies of AA/DLA claimants in various age-groups, see: Baldwin, S *The Costs of Caring: Families with Disabled Children* (Routledge and Kegan Paul, 1985); Craig, G, Dornan, P and Bradshaw, J *Underwriting Citizenship for Older People: The Impact of Additional Benefit Income for Older People*, a report for the National Audit Office, Working Papers in Social Sciences and Policy No 9 (University of Hull, 2003); Horton, C and Berthoud, R *The Attendance Allowance & the Costs of Caring* (Policy Studies Institute, 1990); Preston, G *Helter Skelter: Families, Disabled Children & the Benefit System*, Centre for Analysis of Social Exclusion paper 92 (London School of Economics, 2005)

10 Our analysis does not cover the small but important number of disabled children.

11 We will show, for example, that some FRS respondents say they are receiving AA/DLAc but report no health problems or impairments. On the face of it, they are receiving benefits to which they should not be entitled. But the possibility that either the benefits or the health problems have not been recorded accurately has to be allowed for. It is known that some survey respondents report benefits they do not actually receive, while others fail to report benefits that they do receive.

### **Impairment and the need for care**

Of course the FRS does not provide anywhere near as much detailed information on people's impairments as is required to assess their eligibility for disability benefits. Nevertheless, there is a strong correlation between impairments reported in the survey and receipt of AA/DLAc. Less than 1% of people who said they had no impairments said they were receiving the benefit; nearly three-quarters of those with seven or more difficulties were receiving it. But the same figures the other way round show that as many as 6% of benefit recipients in the survey reported no impairment. The survey provides prima facie evidence that the entitlement conditions or adjudication procedures might be tightened up (but see footnote 11).

The proportion of people saying that they had help with daily activities, and the number of hours of help received, also varied by the number and nature of people's impairments in a very similar way.

But the direct overlap between benefit and care is not as great as might be expected. Only 61% of adults receiving care are getting either of these benefits. Only 54% of adults getting care-related benefits report receiving any care. These findings indicate either that the FRS questions on care received are underreporting, or that a significant proportion of AA/DLAc recipients whose *need* for care has been recognised by benefit decision makers are not actually *receiving* the care they need.<sup>12</sup>

It is useful to analyse the FRS in terms of three main sources of help for disabled people living in their own homes – collectively referred to as "care".

- *Help provided by other members of the household living with the disabled person.* Half of disabled people receiving AA/DLAc live with a partner. Another one in eight live with someone other than a partner, commonly a parent (among young disabled people) or son or daughter (among older disabled people). Co-resident family members provide a ready supply of help, which for the most part is not paid for directly by its recipient. AA or DLA money is commonly just added into the household budget,<sup>13</sup> and this relieves the financial strain on the carer as well as on the disabled person.

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12 The Wanless review's analysis of the English Longitudinal Study of Ageing reported that 29% of AA recipients were receiving no care (Wanless, op cit, p94). The equivalent figure for over-65s in the FRS was 37%.

13 Hawkins et al, op cit

- *Help provided by friends and relatives who do not live with the disabled person.* Non-resident informal carers are obviously more important to disabled people who live on their own. They are about evenly distributed between relatives and friends or neighbours. It is not uncommon for the disabled person to pay over their AA or DLA benefit direct to such carers, not as payment for services in the sense of a market transaction but in acknowledgement of a sense of obligation.<sup>14</sup>
- *Help provided by paid workers.* Formal help recorded in the FRS includes care provided by local authority social services departments, by nurses, by voluntary or commercial agencies and by assistants working directly for the disabled person. Such care is clearly especially important to those who live alone, but can also be designed to support family carers. The characteristic of these services is that the worker is paid. AA/DLA money often contributes directly or indirectly, but would rarely be enough to meet the whole cost.

Help provided by the family (or friends and neighbours) is easily the largest source of care for elderly and disabled people. It is commonly referred to as "informal", and is free in the sense that no money changes hands – although there is plenty of evidence that much of the cost is borne by the carers themselves in terms of lost earnings.<sup>15</sup> But it is the provision and resourcing of the third type of help, by paid workers, that is the focus of recent policy debates. How well does it meet the need for care, and how does it compare with AA/DLAc at targeting resources on need?

Table 1 shows that, of course, all the within-household help available to severely impaired adults goes to those who live with another adult – though even so, only half of them report receiving it. These co-resident disabled people sometimes report help from relatives or friends outside the household, or from paid workers as well as, or instead of, within-household help. These external sources are obviously much more important to disabled people living alone.

Nevertheless, only about a third of severely disabled lone people report each of these external sources of help. And they clearly fail to make up for the lack of within-household care – those living alone typically receive only about a quarter of the total help available to those living with family. In each case, AA/DLAc recipients get more care, but it is not clear whether this is because they need more, or because it enables them to secure more.

14 Horton and Berthoud, *op cit*

15 Arksey, H, Kemp, P, Glendinning, C, Kotchetkova, I and Tozer, R *Carers' Aspirations & Decisions around Work & Retirement*, DWP research report 290 (Department for Work & Pensions, 2005)

**Table 1: Receipt of help by adults with at least three impairments**

	Lives with other adults	Lives alone
<i>Help from:</i>		
member of household	50%	n/a
other relatives and friends	11%	36%
paid workers	12%	27%
none of these	56%	56%
<i>Average total help received per week:</i>		
if receiving AA/DLA	64 hours	16 hours
if not receiving AA/DLA	15 hours	4 hours

Source: Family Resources Survey, 2004/05

Help from paid workers ("formal care") is needed either to complement care provided within the home (especially if the home carers are themselves elderly or disabled), or to substitute for it. Even where a non-resident relative or friend is ready to take part, the availability of paid-for care will often be crucial to the viability of the package of support that can be assembled. It is not clear from the FRS data how much of the cost of these paid workers is met directly or indirectly by social and health service providers, how much by AA/DLAc receipts, and how much out of the own income of the disabled person and their family.<sup>16</sup> But current social service provision represents only a fraction of either the need for or the supply of care to disabled people in the community

This conclusion can be interpreted in two ways, with diametrically opposed policy implications.

- At one extreme it could be argued that AA and DLAc reach far more disabled people; so social services' role should remain residual, addressing exceptional need in individual cases.

<sup>16</sup> It has been estimated that AA could be contributing up to 16% of the costs of formal care services provided to older people in their own homes, with a similar proportion contributed by the severe disability premium within pension credit. Local authorities contribute 54% on average and the rest – 14% – comes from recipients' own incomes. See Hancock, R, Wittenberg, R, Pickard, L, Comas-Herrera, A, Juarez-Garcia, A, King, D and Malley, J *Paying for Long-term Care for Older People in the UK: Modelling the Costs & Distributional Effects of a Range of Options*, PSSRU discussion paper 2336/2 (2007), figure 3

- At the other extreme it could be argued that a large proportion of AA/DLAc payments are going to people who can get by either with no care, or with help from their immediate families – so the money should be redistributed, through social services departments, to those in greater need.

### **The incomes and living standards of disabled people**

However, as discussed at the beginning of this chapter, the need for care may be the criterion on which eligibility for AA and DLAc is assessed, but paying for care is by no means the only objective. The weekly amounts involved are not enough to pay directly for the hours of care theoretically required. The benefit is paid unconditionally – recipients and their families can spend it on whatever they like. And disabled people face other potential additional costs, besides paying for care.

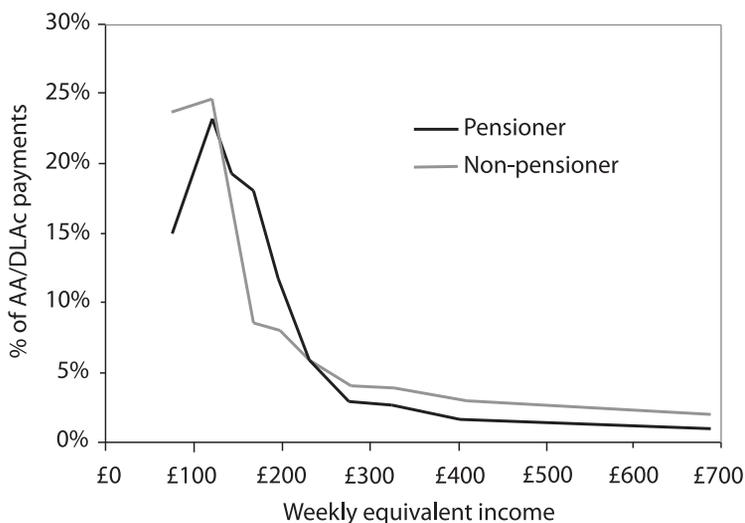
A first set of questions is: what income could AA/DLAc recipients count on if they were not receiving these benefits? Hardly any AA recipients (or their partners) have a job. Less than one in ten DLAc recipients of working age have a job, and only a quarter live in families where either partner is employed. Earnings provide a source of income for only a fraction of the families under consideration.

So most of them rely on benefits for a substantial proportion of their incomes. About two-fifths of both elderly and working-age AA/DLAc recipients depend on pension credit, or on income support, the twin means-tested benefits providing a minimum income for the two age groups. The proportion receiving means-tested benefits rises to more than half (52%) if housing benefit or council tax benefit are taken into account. Most of these families are poor enough to require income supplementation, even without taking account of their impairments.

The amounts of benefit contingent on the need-for-care criterion are quite generous by the standards of the basic income maintenance system. The minimum income made available to a single non-disabled person between 25 and 59 is £59 per week (income support); above 60 it is £119 (pension credit). For a disabled person living alone and receiving the top rate of AA/DLAc it rises by the disability benefit itself of £65, plus the severe disability premium of £48. That is, the need-for-care criterion nearly trebles the minimum income of the younger person, and nearly doubles it for the older person.

The key question is what disabled people's family incomes would be if they did not receive AA/DLA.<sup>17</sup> Figure 1 shows the income distribution of individuals receiving the two benefits, where income is calculated before adding in AA/DLA or the associated premiums. Pensioner and non-pensioner families are distinguished although their profiles turn out to be similar. Although some recipients live in fairly prosperous households, most have quite modest starting points. Nine out of ten AA/DLAc benefit payments go to households whose starting income was less than £250 per week (equivalent to a single-person household). Four out of ten would be below the Department for Work & Pensions' indicative poverty line of 60% of median income if their disability benefits were discounted.

**Figure 1: Distribution of AA/DLAc payments by (pre-AA/DLA) equivalent household income**



Note: The horizontal axis shows what the income of the household in which the individual lives would have been, in the absence of AA/DLA, calibrated as equivalent to a single adult household. The 10 data points are the decile groups of the distribution of household equivalent income, plotted at their medians. Estimates are based on the tax-benefit model POLIMOD, using FRS data for 2003/04 and 2006/07 rates of benefit.<sup>18</sup>

<sup>17</sup> Wanless (ibid, p95) shows that relatively few AA recipients have very low incomes. But that is at least partly because the AA itself, and the severe disability premium, were included in the measure of income.

<sup>18</sup> Redmond, G, Sutherland, H and Wilson, M *The Arithmetic of Tax & Social Security Reform: A User's Guide to Microsimulation Methods & Analysis* (Cambridge University Press, 1998)

The actual incomes of AA/DLA recipients are higher than these starting incomes. The intention is that this extra income should be spent on extra costs, leaving recipients and their families in much the same position as other households with neither extra needs nor the extra benefit. What are these extra costs, and how much do they add up to?<sup>19</sup> A survey of DLA recipients<sup>20</sup> reported an average of two items of expenditure per person required solely because of disability (incidental expenses of hospital visits, chemist's items and so on), and another four items in which normal expenditure had to be increased because of disability (heating, transport, phone calls and so on). But the only structured survey that has tried to put a figure on these amounts with direct questions<sup>21</sup> came up with an average total for very severely disabled people of only £28 per week (at 2007 prices)<sup>22</sup> – substantially less than the top rates of disability benefits. Either the benefits are more than generous in their allowance for extra costs, or survey respondents have difficulty in calculating them in response to a bald question. Indeed, the disability lobby lost no time in finding samples of disabled people with clearly identifiable extra costs far above those reported by the survey.<sup>23</sup>

It is increasingly argued that poverty should be measured in terms of low living standards, using deprivation indicators, rather than directly as low income.<sup>24</sup> An alternative approach is to estimate extra costs indirectly, using standard of living indicators to show how much worse off severely disabled people are than non-disabled people with the same income.<sup>25</sup> The assumption here is that the extra costs have diverted income away from the normal spending patterns of the rest of the population. One recent analysis<sup>26</sup> suggested that the drain on a single severely disabled person's resources amounted to £175 per week for a non-pensioner and £215 for a pensioner (at 2007 prices). On this basis, disability benefits (including the mobility component of DLA) fall well short of compensating people for the costs of disability, and disabled people are actually much poorer than income calculations imply.

19 For a summary, see: Tibble, M *Review of Existing Research on the Extra Costs of Disability*, DWP working paper 21 (Department for Work & Pensions, 2005)

20 Sainsbury et al, op cit

21 Martin, J and White, A *The Financial Circumstance of Disabled Adults Living in Private Households* (HMSO, 1988)

22 Inflation factor based on the top rates of AA/DLAc in payment in each year.

23 Thompson, P, Lavery, M, and Curtice, J *Short-changed by Disability* (Disablement Income Group, 1990)

24 Pantazis, C, Gordon, D and Levitas, R (eds) *Poverty & Social Exclusion in Britain: The Millennium Survey* (Policy Press, 2006)

25 Berthoud, R, Lakey, J and McKay, S *The Economic Problems of Disabled People* (Policy Studies Institute, 1993)

26 Zaidi, A and Burchardt, T "Comparing Incomes When Needs Differ: Equalization for the Extra Costs of Disability in the UK" in *Review of Income & Wealth* vol 1, no 1 (2005)

New analysis of the deprivation indicators included in the FRS (Table 2) shows that only 10% or 12% of non-impaired people not receiving pension credit or income support are in "material hardship" – defined arbitrarily as the most deprived fifth of all families.<sup>27</sup> Elderly people receiving pension credit are at greater risk of hardship. If they or their partner report an impairment, their risk of hardship rises again. If they are also receiving disability benefits (mainly AA) at the same time as pension credit, elderly people show the same rate of hardship as non-disabled pension credit recipients – that is, the AA seems to have cancelled out the increased cost of living. For non-elderly income support recipients, rates of hardship are much higher.

Again, impairment increases hardship in the absence of disability benefits; but DLA payments seem to compensate. In fact, recipients of both income support and DLA are slightly better-off than those receiving income support on its own – but more than half of them are still in hardship.

**Table 2: Proportion of families in material hardship, by benefits received**

	Elderly		Non-elderly	
	Not on pension credit	On pension credit	Not on income support	On income support
No impairment	10%	37%	12%	66%
Impaired, but no disability benefit	15%	49%	21%	72%
Disability benefit	23%	36%	32%	56%

*Material hardship* defined as the worst-off fifth of all families, using an index based on the FRS sequence of deprivation questions.

*Disability benefits* means AA, DLAc and/or DLAm.

*Families* means benefit units; that is a single adult, or a couple, with or without dependent children.

*Pensioners* means families with (either) adult aged 60 plus.

Source: Family Resources Survey 2004/05

This evidence suggests that the significant boost provided to disabled people's household incomes by AA and DLA may compensate them for the additional costs imposed by their

<sup>27</sup> We have shown elsewhere – Berthoud, R, Blekesaune, M and Hancock, R *Are "Poor" Pensioners Deprived?* DWP research report 364 (Department for Work & Pensions, 2006) – that deprivation indicators are sensitive to age as well as to income, disability and so on. The analysis reported here controls for age as well as household composition.

impairments, but leaves them little or no better off than other income support and pension credit claimants.

At the same time, it can be asked whether AA and DLA provide the best possible vehicle for supporting the extra costs of living faced by disabled people. The attendance criterion was intended as a proxy for severity, and so an indicator of likely additional costs. Research evidence provides no basis for estimating extra costs directly (for example, £x for heating, £y for bus fares and so on). The problem with the attendance criterion, as this debate demonstrates, is the potential ambiguity of the policy intention.

### **Integrating support for care costs from AA/DLAc into the care system**

The foregoing analysis of the experience of disabled people receiving disability benefits has been intended to provide an empirical base for an analysis of policy options. The Wanless review recommended integrating support for care costs from AA (and DLA) into the care system, to improve targeting of resources. What are the likely effects of such a policy reform, and who would be affected?

We consider which groups are likely to lose or gain from the structural changes implied in the proposal. Given the complexity in the existing systems of benefits and of care-charging, this is a field where the devil really is in the detail<sup>28</sup> and a proper evaluation requires proposals to be worked out much more thoroughly. A main difficulty is that the destination is itself a moving target. It is unlikely that the resources diverted to care provision would be allocated to local authorities' care budgets without accompanying reforms to the care financing or allocation systems. The Department of Health and local authorities are already changing their policies. The reallocation of AA/DLAc might be part of a more fundamental shift that would see more care offered on a more universal basis.

Nevertheless, any reform is likely to involve three major changes in the flow of resources to disabled people.

#### **1. Care, rather than cash**

This is the central objective of the proposal – money that is now going directly to disabled people to spend on the exceptional costs of living would now be spent mainly on paid-for care services. Those few who already spend most of their benefit on paid-for care will

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<sup>28</sup> Another detail, not discussed in this paper, is how the proportion of AA/DLAc entitlements to be diverted to the care system will be separated from the proportion to remain in support of extra costs.

not be much affected. Many people would presumably receive more care than they do now, and probably an increase in their overall resource allocation. Many people would receive less cash than they do now. The assumption is that the net gainers are at the more severe end of the disability scale (whose needs are, in the official phrase, "substantial or critical"), the net losers at the less severe end. The overall number of losers could exceed the overall number of gainers.<sup>29</sup>

## 2. A carer test

Local authorities take account of support from carers and family members such that having a carer may disqualify a disabled person from eligibility for care services.<sup>30</sup> Disabled people with a partner therefore tend to receive fewer services. Where other relatives are available, either to live in or to provide help on a daily routine, negotiations often arrange a small package of services to support and encourage the informal care provision. Most of the money is spent on people without close family care. This is likely to be an outcome of any reallocation of funds into the care provision system. The gainers would be disabled people without informal carers; the losers would be those with informal, and especially live-in, carers. Couples are a readily identifiable group of potential losers.<sup>31</sup>

## 3. Means testing

AA and DLAc are not means tested, though there are also provisions within the mainstream system of means tests to boost the incomes of disabled people. Local authorities apply means tests in their charging arrangements. The basic care financing model proposed by the Wanless review is said to involve no means testing for care. However, it does involve a user "co-payment" and the review acknowledged that some financial help with this co-payment might be needed for those on the lowest incomes – in other words some means testing would continue. Entitlement to care would still, therefore, be less universal than AA/DLAc. The review also suggested that financial help with other disability-related costs might be better dealt with through pension credit. It can be assumed, therefore, that a switch of resources from AA/DLAc to services would be associated with at least some increase in means testing.

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29 The Wanless report suggests transitional protection to prevent immediate losses of income at the point of reform. This would make the exchange of resources less painful for current recipients (and so for politicians) but does not deal with the underlying equity questions for following generations of claimants and clients.

30 Department of Health *Fairer Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care*, para 44. Available at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4009653](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653)

31 AA and DLAc are paid to disabled people regardless of their living arrangements and existing care arrangements. The severe disability premium is largely limited to means-test recipients who live alone, and this can be interpreted as a carer test.

The general advantages and disadvantages of means testing are well known. In principle, it concentrates public funds on those with the lowest economic resources (vertical equity), but is less effective at targeting on variations in need (horizontal equity). Means-tested benefits tend to be subject to lower rates of take-up and so may not reach all of those for whom they are intended. Means testing of state support, whether in the form of cash benefits or care services, may act as a disincentive to private provision for old age.

Other things being equal, the main group of losers under this third option would be recipients of AA/DLAc on higher incomes. As we have seen, AA and DLAc tend to go to people in the lower parts of the income distribution anyway, so there is a degree of targeting in the system without means testing.

These outcomes look likely to result in more funds dedicated to care for the most severely disabled people, who lack care at the moment, and who have no spare income to pay for services. But the costs are likely to be borne by moderately severely disabled people with a partner, especially if their income is above the means-test floor.

### **Social services, or social security?**

One way of thinking about how these three reallocations might work is to ask whether we could achieve them by changes within the benefit system, rather than by transferring money to social services departments. For example:

- A disability care benefit could be made conditional on the money being spent on paid-for care services. The working tax credit has just such a provision to support parents with the costs of childcare services.
- A disability care benefit could be restricted to single people, or to people who live alone (unless all members of a household were disabled).
- A disability care benefit could be means tested, or added into the mainstream means-test network as a premium. (One possible scenario is that the savings from increased means testing in the benefit system might be used to pay for a reduction of means testing in the care system!)

Reanalysing the Wanless plan in terms of a self-contained social security reform helps to identify the distributional issues more clearly.

There are other differences between social services and social security, besides the allocation of resources. Differences in approach and tradition have to be taken into

account too. Three particular considerations are: "discretion" versus "entitlement"; budgetary control; and independence.

### 1. Discretion versus entitlement

People are "entitled" to "claim" their social security benefits, including AA and DLA. This means that there is a published set of rules establishing eligibility; a body of decision makers adjudicating the outcome on the basis of the evidence and in the light of case law; and a right of appeal to an independent tribunal. Social services departments are moving towards more open and formal eligibility criteria but retain considerable discretion to determine what services to offer on a case-by-case basis. A social worker assesses need by applying professional judgments to all the circumstances. A client disappointed by the outcome can ask for reconsideration, but cannot argue on the basis of legal entitlements.

There are arguments in favour of both approaches, and room for discussion about which is best for assessing the need for care. Disabled people's needs may be difficult to characterise in hard and fast rules. Discretion means that eligibility can be sensitive to individual needs. But discretion can result in inconsistencies of treatment and/or the exercise of social control by the decision maker. Even though these problems may actually occur rarely, a disgruntled client can never be sure that they have not occurred on any particular occasion. It seems quite likely that the effect on individuals of a transfer of resources from the social security budget to local authorities would vary across local authorities – a "postcode lottery". We are not arguing that entitlement is intrinsically better than discretion or vice versa, but the issue needs to be addressed in the development of alternative policies.

### 2. Budgetary control

Eligibility criteria for benefits are set in advance and payments have to be made to as many people as apply and turn out to be eligible. Expenditure on benefits can be controlled in the long run, but only by changing the rules of eligibility. Local authorities are encouraged to review their eligibility criteria each year by reference to their budgets: an annual budget is allocated and decision makers are required to ration services as they go. In public finance language, social security benefits are "demand-led", whereas social care services are "cash-limited". The keepers of the purse naturally prefer controlled budgets to demand-led expenditure. But if the person assessing need is also the agent of budgetary control, there may be strong pressure to underestimate the extent of need. It would in principle be possible to separate these functions: an independent assessment of need, with budget holders deciding how much of that need should be met. This is ideal,

but politically uncomfortable, because the amount of unmet need would become explicit. Arguably this is happening anyway through individual budgets.

### 3. Independence

Recipients of disability benefits are free to spend the money on anything they choose. Historically, support for care needs from local authorities was in the form of free or subsidised services, over which the client had little choice and no control. There has been a strong trend over the past 10 years towards "direct payments" (cash paid to the disabled person who arranges and pays for their personal assistance in the open market) and, more recently, pilot schemes of "individual budgets"(resources from social care and other funding streams are combined to finance an individually tailored package of services or equivalent-cost direct payment).<sup>32</sup> These more transparent allocations of funds have been intended to give disabled people greater choice over how their needs are met, and therefore a sense of independence – but they are limited to regular expenditure on care-related services. A transfer of funds from social security to local authority budgets could work against the trend towards greater flexibility and independence.

### Discussion

Our intention in this paper has been to analyse the likely impact of the proposed reforms of cash and care, not to recommend that they should or should not be adopted. One theme of our analysis has been the acute scarcity of systematic research on the current interactions between cash and care. Another has been lack of clarity about how the proposed reforms would work.

Nevertheless, we can identify some probable consequences in broad terms. The Wanless and other similar proposals would probably deliver more care to severely disabled people, especially those living alone. We have shown that many disabled people, especially those living alone, do not at present have access to care. So these outcomes would be in line with the policy objectives.

There are some differences between social care allocation procedures and social security benefit adjudications that also need to be taken into account. A transfer of resources to local authorities would imply a trend from entitlement to discretion, and from demand-led to cash-limited cost control. Given the move towards direct payments and individual

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<sup>32</sup> Individual Budgets Evaluation Network *Individual Budgets Evaluation: A Summary of Early Findings* (University of York, 2007)

budgets, it is harder to say what the effect would be on the degree of independence enjoyed by disabled people. Transferring resources from benefits to social care may speed up the move within social care towards greater choice. But if the aim is greater control, the logic might be for more money to be delivered through the benefit system and less through social care. The pros and cons of these aspects of the relationship between the state and its citizens cannot be quantified, but they should not be ignored.

We have emphasised that the precise effect of transferring AA/DLAc resources to local authorities will depend on the future policies and practices of social services departments, after the proposed reforms. In the past, they have been associated with the six characteristics listed on the left of figure 2. The direction of travel (arrow 1) is already away from those characteristics, towards the six characteristics hitherto associated with AA/DLAc. New proposals outlined by Wanless and other commentators are likely to move social services further in the same direction (arrow 2). The question is whether AA and DLAc's resources should be moved in the opposite direction (arrow 3), to the position in the middle of the spectrum, eventually adopted by social services.

**Figure 2: Stylised representation of policy differences between AA/DLAc and social services departments**

Social services		AA/DLAc
Provision of formal care		Cash for extra costs
Informal carer test		Independent of family
Means tested	1 2	Contingent on need
Discretion	▶▶ ?◀?	Entitlement
Cash limited		Demand-led
Controlled by social workers		Controlled by disabled person

A major reform needs to be evaluated on the basis of its costs as well as its benefits. It is likely that the proposal will lead to a loss of cash income for a large proportion of disabled people claiming AA or DLAc. We have shown that most of them have modest incomes. Standard of living indicators suggest that the present benefits do little more than compensate disabled people and their families for the extra costs associated with disability. A reduction in cash incomes is likely to lead to an increase in deprivation.

Some of those proposing the reform have not addressed these adverse outcomes. They have implicitly assumed that much of the £9 billion spent on AA/DLAc is going to people

who do not need it, a windfall of free money available to the exchequer to be spent on other purposes. They need to show that the value to be derived from the injection of funds into the care system is substantially greater than the existing value of the same funds in the disability benefit system. One way of putting this question is: who should pay for the increase of much-needed care to be provided to some disabled people by local authorities? Should it be taxpayers in the middle and upper ends of the income distribution (including most of the active participants in this debate)? Or should it be other disabled people?

### Acknowledgments

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### Outline of attendance allowance and disability living allowance

Attendance allowance (AA) is paid to over-65s at rate of £64.50 per week if they need *both* help throughout the day *and* supervision during the night; they receive £43.15 per week if they meet *either* the day *or* the night condition, but not both. The same rules govern access to the care component of the disability living allowance (DLA) for under-65s; but here there is a third rate of £17.10 per week for people who need help only part of the day, or who cannot cook a meal. DLA also has a mobility component for under-65s who cannot walk, or need assistance when walking outdoors, but DLAm is largely left out of the current analysis.

People who receive either element of DLA before their 65th birthday continue to receive it, rather than AA, after 65.

All these benefits are based solely on the identified needs of disabled people, and are

neither means tested themselves, nor treated as income in means test calculations. But recipients of the main means-tested benefits (income support, pension credit, housing benefit and council tax benefit) can add the severe disability premium of £48.45 per week to their needs assessment if they are receiving AA or the middle/higher rate of DLAC, live alone (or live with another disabled person) and have no one getting carer's allowance for their care.

AA/DLA and the severe disability premium can be taken into account in local authority means tests for home care but only if part is disregarded to allow for disability-related expenditure. A 2003 survey found that most local authorities did take these benefits into account but there was considerable variation in how disability-related expenditure was allowed for.<sup>33</sup> AA/DLA and the severe disability premium are taken into account in determining whether a care home resident is entitled to local authority help with fees. If a resident is so entitled, AA/DLA and severe disability premium cease to be payable and the local authority contribution is accordingly larger. Different procedures apply in Scotland, which has introduced a version of "free" personal care.

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33 Thompson, P and Mathew, D *Fair Enough? Research on the Implementation of the Department of Health Guidance "Fairer Charging Policies for Home Care & Other Non-residential Social Services"* (Age Concern, 2004)

## Chapter 9

# Information, advice and advocacy – power to all the people

Stephen Burke, Chief Executive of Counsel & Care

## **Information, advice and advocacy – power to all the people**

Information, advice and advocacy are the glue of a care system that functions well and delivers choice and control to older people, their families and carers. The present provision of information, advice and advocacy services is at best patchy. This chapter sets out how better provision of these services could empower all of the people as part of a new universal entitlement.

### **A new world?**

When I'm 70 in 2030, I expect I will still be working. But I also expect a new world will exist to help plan, choose and pay for care for my family and myself. Of course, all that I need to know will be available electronically and there will be a national service run by charities that can answer any question I have. But I will also have my own independent care adviser whom I can call and go and see when I want to talk through major life decisions. The adviser will help arrange everything for me – dealing with the care provider, the money and the authorities. Not everyone will pay their adviser; for some, the independent service will be commissioned by their local area partnership. But everyone will be able to get the advice and support they need to get the care they need, even though there will be many more older people than now. It's not long until 2030 ...

### **Starting in 2007**

Choice and control are central to the present government's public service reform agenda. This is driven by a belief in the potential of people power and personalisation as a key force for improving the delivery of public services to ensure that the needs of individuals and their communities are met.

Nowhere is the need for a rebalancing of the power relationship in favour of the individual clearer than in the field of social care. As the 2007 spending review indicates, there are major challenges ahead in defining the responsibilities of the individual versus the state in terms of paying for care.

We are embarking on a big debate about creating a universal entitlement to care and support for every older person. Whatever the outcome, a fundamental building block for a long-term care settlement will be information, advice and advocacy. This should equip people to understand their rights and responsibilities, plan ahead and engage successfully with care provision. It should support and empower them to challenge what is unacceptable and protect against abuse.

The widespread support for direct payments and individual budgets has reinforced the principles of choice and control. Clearly, the best way to deliver care that supports older people's well-being and enables them to live their lives as they want is to give individuals the power to decide what works for them. But the government has acknowledged that with the new emphasis on individual choice and control comes an increased need to provide support to those who find exercising this choice a challenge.

Care for older people is one key area, but the need for support across the spectrum – from information to advice to advocacy – is universal across different forms of social care; whether it is a child with learning difficulties, a younger adult with mental health problems or an older person with physical disabilities, the danger of social exclusion but also the possibility of empowerment are substantial.

Without an acknowledgement of the need for support services including information, advice and advocacy, choice and control will remain the preserve of the privileged few, and the most vulnerable social care users will continue to be “done to” – remaining isolated, disadvantaged and without a voice.

Support for decision making through information, advice and advocacy is therefore the missing link that can ensure that the choice and control agenda really does deliver power to *all* of the people.

### **Complex and confusing**

At present we have a complex and bewildering social care system. It is not transparent, it is inconsistent and it is widely perceived as unfair. It causes great confusion – many people do not know what their rights and entitlements are, they get lost in the care maze and they don't get the help they are entitled to.

Counsel & Care's national care advice service picks up the pieces for thousands of older people and their families and carers every year. They either can't find their way around the system or have been blocked at various points along the way from getting what they need and are entitled to. Many of the calls received by Counsel & Care originate from local advice agencies that don't have in-depth knowledge of the community care system. People have often tried half a dozen or more different local services before finding Counsel & Care, when they regularly tell us that they wished they had known about us earlier.

The top 10 issues that people contact Counsel & Care about reflect both these difficulties getting advice and the range of issues concerning older people and their families in getting the care and support they need:

- information – particularly about the assessment process;
- care home funding – third-party top-ups;
- charitable assistance – household items;
- mental health – dementia;
- self-funders – care home and help at home;
- carers' issues – conflict of interests;
- formal complaints – local authorities and providers;
- community support at home – eligibility issues;
- housing – housing problems; and
- health – hospital discharge.

### **Case study**

Mrs D contacted Counsel & Care because her mother was in a care home and the council was looking at the possibility of moving her, as no third-party top-up would be available. Her mother's capital was about to drop to below the upper capital limit, but the council stated that if no third-party top-up was available, it would not pay any of the fees and would look at moving her mother to a cheaper care home. It was asking Mrs D to transfer her mother's remaining capital into her current account so that her mother's money could be used to pay her own top-up.

Because the council continued to be difficult to deal with, it was agreed with Mrs D that Counsel & Care would advocate and start by drafting and then sending a letter to the monitoring officer at the council. A complaint was sent to the complaints officer and investigated by a team leader not involved with the case. The outcome was that Mrs D's mother did not have to move from the care home.

These calls require advice and explanation about how the system works, older people's and their carers' entitlements, and strategies to help them get the support they need. Counsel & Care also gets thousands of calls and web hits from people wanting basic information, factsheets and guides across the spectrum of care, whether people are living in their own home or a care home.

In 2005 the Office of Fair Trading's report on care homes called on the government to establish a one-stop-shop providing information and advice for older people and their families about choosing and paying for care homes. This was reiterated by the Commission for Social Care Inspection's 2007 report, *A Fair Contract*.

A number of national organisations have taken the initiative and are setting up a national one-stop-shop providing advice on care for older people. This is due to be launched in 2008 by a partnership involving Counsel & Care, Elderly Accommodation Counsel, Help the Aged and the Nursing Home Fees Agency. This one-stop care advice service will provide one telephone number and one website address as a gateway to information and advice about all aspects of care for older people.

At a local level a number of different pilot projects are beginning to join up provision of services for older people. These include LinkAge Plus, following on from the government's *A Sure Start to Later Life* report, and the Partnerships for Older People projects. Advice, information and advocacy are some of the important services that can be accessed from the single accessible gateway being established by LinkAge Plus.

A recent consultation by the Older People's Advocacy Alliance showed that older people's expectations of advocacy were exceeded by the outcomes. The two areas where positive outcomes were experienced were the tangible gains that older people felt had been achieved as a result of using advocacy services, and the feelings and emotions of the older people using the services. The gains and the preventative benefits for older people are immense as advocacy services allow them to achieve material satisfaction alongside maintenance of their well-being and peace of mind.

However, there are many older people who will choose to be their own advocates, as people become better informed. The "baby boomer" generation, now just entering their 60s, will no doubt lead the way here. Older people advocating for other older people would be a welcome move forward, as it would encourage those better able to express themselves to help those who cannot, and promote cohesion between different groups of older people.

One of the goals of the *Our Health, Our Care, Our Say* 2006 white paper is "more choice and a stronger voice for individuals and communities". One of the ways that this could be successfully implemented, according to the Department of Health, is by seeing that those using services and their carers have more say over where, how and by whom services are

delivered, and with this, access to information that will enable them to make choices.

A Joseph Rowntree Foundation paper published in 2005 called for independent information, advice and advocacy for older people to be placed higher up the policy agenda, and for the introduction of national minimum standards for independent advocacy. Counsel & Care supports this. Indeed, recent comments by the Care Services Minister indicate that calls such as that made by the Joseph Rowntree Foundation are being listened to. However, it can be taken further. The Older People's Advocacy Alliance, as the national umbrella body for advocacy providers, must be provided with additional funding and support to ensure that it has a basis for continued growth into a stronger network that will ensure that the quality of advocacy services is universalised and maintained across the UK. Advocacy can only be effective, however, if services for older people are in place to advocate for.

Finally, while a range of initiatives are taking place nationally and locally to improve care advice, there is an urgent need to join these up with developments in the provision of other types of advice for older people, their carers and families. One vehicle for doing this is the Thoresen review of generic financial advice. The Pensions Service also has a critical role to play with other partner agencies.

### **The future?**

In an ideal world, in 2030 there will be a national body providing an information and advice resource, available on the internet (comprising downloads, forums, blogs, chat-rooms, newsletters and whatever else will be available by then) and by telephone and mail. The national body would work closely with local groups in every local area. The local groups would have the facility to offer services such as advocacy, befriending, help claiming benefits, support for carers, casework, debt advice, good neighbour schemes, mediation, social activities, nutrition and health advice, complementary therapies, counselling, training and education, gardening and handyman schemes, and so on.

These exist in some areas now, but in the ideal world there would be much more consistency in the quality and provision of service. The local groups would have closer contact with the national body, with improved access to resources and continuing personal and professional development. These services would be consistent across the country, with, of course, on-going funding and investment in adapting services to meet the needs of individuals living in that local area. The national body would be responsible for policy and national campaign work, based on feedback from local areas and evidence

from enquirers to the national advice line. Proper funding for local groups must be a statutory requirement, again to ensure consistency of support across the country. There must be recognition of how important home visits and face-to-face work are for vulnerable older people.

Of course, in an ideal world you wouldn't need advice agencies and then we would all be redundant!

Counsel & Care has called for all older people, their families and carers to have access to an independent care adviser, as well as independent advocacy in every neighbourhood, using the Sure Start for Older People approach. Direct payments and individual budgets would provide a mechanism for service users to commission appropriate advocacy services for themselves. This should be the responsibility of every local strategic partnership, to prioritise and facilitate delivery through their local area agreement.

Independent advice and advocacy will be the key to ensuring that older people are able to take advantage of the government's drive to enhance their choice and independence. This will be particularly important for socially excluded older people, who may feel less able to articulate their choices or who may find negotiating with figures of authority intimidating. Ensuring that all older people can access services, no matter what their socioeconomic background, should be paramount in the rollout of the choice agenda to guard against deepening the inequalities that already exist between groups of older people within society.

### **Privilege or people power**

Without a more consistent approach to the provision of information, advice and advocacy services, the attempt to deliver "people power" within public services will fail and choice and control will remain the preserve of the privileged. Almost by definition, social care users are among some of the most vulnerable in our society, and yet the system upon which they rely is one of the most complex and difficult to navigate. Information and advice about social care services are hard to come by – primarily as a result of the patchwork of providers, funders and legal authorities.

The relationship between a social care user and his or her provider is not a simple, two-way thing – in between there can be social workers, family members, financial assessors, health workers and many others. It is easy to see how the voice of the individual can be drowned out, and how someone can become lost trying to navigate the system.

These challenges are compounded in the case of the self-funder, who is left to navigate the system without any professional input, often at a time of major change and considerable personal upheaval.

This is where advocates can play such a vital role, yet advocacy services are patchy on the ground and, where they do exist, they are often underfunded and struggling to survive. The failure to join up services on the provider side means that many advocacy cases have their roots in the interface between health and social care, but a lack of investment in advocacy services has led to poor service design and professional dominance.

Advocacy service providers are those that go beyond the neutral provision of information or advice, but instead actively involve themselves in the interests and circumstances of the person they are working for, seeking to understand the needs and wishes of the individual, to articulate those needs and wishes and ensure they are delivered.

From the individual's perspective, an advocacy service *feels* different – advocates may be objective, or dispassionate, but they are not neutral; they are on your side, working for you to make the world work better for you.

Throughout our lives, and in different situations, many of us find ourselves in need of support, ranging from simple information through to advice and even advocacy. Sometimes our friends or family may "advocate" for us, or a service provider may go the extra mile – taking on our case and making sure we get the best result. But the independent advocacy services that really support people power within the public service improvement agenda are something more than this: they are formally independent of the services they are helping us to understand, secure or use; they are well-trained, expert and sometimes paid.

As we move towards a more self-directed model of social care, advocacy will become more important. If the most excluded – those with mental health problems, poor literacy, low confidence or simply those who are just too ill and tired to face dealing with bureaucracy – are to be part of the people power revolution, then they must have their voices amplified by advocates. The 2007 spending review recognised that individual budgets, for example, will not succeed without investment in local information and advocacy services.

The alternative is the continued move to a two-tier, two-speed social care world – in which those who are wealthy, articulate or supported by family or friends benefit from

choice, and others are left behind.

Information and advice are the glue of a care system that functions well and delivers choice and control to older people, their families and carers. A universal entitlement to care must include access to good information, advice and advocacy.

*With thanks to colleagues at Counsel & Care, Help the Aged and the Older People's Advocacy Alliance.*



## Chapter 10

# Achieving successful reform – lessons from overseas

Professor Caroline Glendinning, Professor of Social Policy in the  
Social Policy Research Unit at the University of York

## Achieving successful reform – lessons from overseas

This chapter highlights some of the lessons that can be drawn from other countries' approaches to social care reform. Given the pressures of demographic ageing across all advanced welfare states, the chapter focuses primarily on lessons to be learned about social care arrangements for older people. Inevitably, the chapter is selective; rather than giving a comprehensive overview of how other countries have tackled these challenges, specific examples are selected to illustrate a number of key points.

The policies and practices of other countries cannot always be easily transferred and applied to the UK. Policies on social care are often complex and reflect the financial and organisational structures, values and cultural traditions of individual countries. In many countries, including the UK, social care is the responsibility of regional and local governments, resulting in variations *within* countries in the level and mix of social care services.

Reforms can therefore address a wide range of objectives that reflect local circumstances and priorities – capping global expenditure; reducing reliance on costly institutional care; stimulating new types of services; increasing equity; redistributing responsibilities between local and central government; increasing choice for users; supporting informal and family carers. Nevertheless, as the chapter will show, reforms to social care can sometimes involve bold innovations; major changes to established arrangements; and challenges to traditional values and assumptions. Moreover, comparisons with other countries can help identify some of the weaknesses and strengths of current arrangements in the UK.

Underpinning the chapter is the assumption that there are major shortcomings within the UK in the levels of resources available for social care; in the coherence and comprehensiveness of current arrangements; in equity between people with similar levels of need; and in the ways that costs and responsibilities are shared between the state, the family and the individual.<sup>1</sup> Moreover, the Wanless review<sup>2</sup> has shown that care costs will rise substantially over coming decades and that current arrangements are not sustainable. Faced with these pressures, what can we learn from other countries?

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1 Joseph Rowntree Foundation *Paying for Long-term Care: Moving Forward* (2006)

2 Wanless, D *Securing Good Care for Older People: Taking a Long-term View* (King's Fund, 2006)

1. A strong policy lead from central government is vital for effective and sustainable reform, even in federal/devolved systems.

In the UK, responsibility for raising revenue for social care rest largely with the Westminster government (although Scotland has limited tax-raising powers, it has not so far used them). However, responsibility for allocating resources and providing services is devolved to the governments of Scotland, Wales and Northern Ireland. A major inequity now exists between Scotland and the other countries of the UK because of Scotland's decision to fund free personal care for older people.

Other countries show how a strong central government lead is key to both ensuring economic and political sustainability and safeguarding equity. In Australia, a federal country in which individual states and territories have considerable powers, the commonwealth government nevertheless plays the major role in funding and planning aged care services. During the 1980s and 1990s, responsibilities for all aged care policies were centralised within a single commonwealth government department. This enabled the government to use centralised planning, supply-side mechanisms and direct financing to control the supply of expensive institutional facilities; improve the range and co-ordination of community-based services; and remove inequities between states and sectors in levels of funding and access to care services.

Mechanisms included direct subsidies for nursing and care home places; shared funding of community-based services with state governments; and direct financing of the voluntary and local government providers of home meals services. As a result of this commonwealth government-led redistribution of resources, expenditure on the most dependent older people increased by 18% in real terms between 1985/86 and 1993/94.

In Germany, also a federal state, until 1994 responsibilities for funding social care for older people were split between health insurance funds and the regional and local governments that administered means-tested social assistance for older people lacking the resources to pay for their care. Again, the central government took the lead in introducing a new care insurance scheme covering the whole country. In contrast, in Italy the *indennità di accompagnamento* care allowance has developed separately from social services and the healthcare system, resulting in a complex, fragmented set of arrangements.<sup>3</sup>

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3 Da Roit, B, Le Bihan, B, and Österle, A "Long-term Care Policies in Italy, Austria and France: Variations in Cash-for-care Schemes" in *Social Policy & Administration* vol 41, no 6 (2007)

A strong central government lead is therefore important in reducing fragmentation and improving the efficient use of resources. Central government leadership is necessary to manage different stakeholder interests. In Germany these included trade unions, employers and sickness insurance companies; in both Germany and Austria, local and regional governments were also key stakeholders in reform. A strong central government role also helps in improving equity through the introduction of nationally uniform, comprehensive assessment processes providing equitable gatekeeping to care services or to specific levels of funding according to assessed levels of impairment or need. Such gatekeeping mechanisms can be powerful ways of containing costs and also make it easier to estimate future demand and expenditure. Germany, Austria, Japan and the Netherlands all operate more or less uniform assessment mechanisms across the country.

Strong central government leadership does not necessarily mean that arrangements are centrally administered. The French *allocation personnalisée d'autonomie* is a nationally funded scheme, using a single national assessment that guarantees access to the same level of services across the whole country, but is nevertheless administered locally by the *departments*.<sup>4</sup>

2. A single funding stream is easier for users to understand and access, and easier for central government to manage fiscally to ensure financial sustainability.

This is particularly the case when funding for social care involves different levels of government (central and local) and where boundaries with healthcare funding are unclear. In the UK, resources for social care are embedded within the budgets of several government departments and services, including the Department for Work & Pensions (attendance allowance, disability living allowance and carer's allowance), the NHS (continuing healthcare, which includes all care-related costs, and nursing care for people outside hospital), local authority adult social care services and other government and local authority departments (such as Supporting People). Accessing these different funding streams involves multiple assessments using different eligibility criteria, including combinations of disability, illness and incapacity-related criteria; the availability of informal care; and tests of income and assets.<sup>5</sup> It is not clear how well these funding streams are targeted.<sup>6</sup>

4 Ibid

5 Glendinning, C "Improving Equity and Sustainability in UK Funding for Long-term Care: Lessons from Germany" in *Social Policy & Society* vol 6, no 3 (2007)

6 Wanless, op cit

To some extent the problem of multiple funding streams has been recognised in the piloting of individual budgets.<sup>7</sup> However, other countries have taken far more radical approaches. As early as the 1960s, Australia disentangled funding for long-term care from acute healthcare, as did the Netherlands with its Exceptional Medical Expenses Act (AWBZ). The introduction of care insurance in both Germany and Japan was also prompted by the fragmentation of funding streams and the inappropriate use of expensive medical services. Moreover, single funding streams are not exclusive to social insurance approaches – in Austria the fragmented and highly variable responsibilities of regional governments for social care were replaced in 1993 by a national, tax-funded care allowance (this also involved renegotiating responsibilities between central government and the provinces that are embedded in the Austrian constitution).

A single funding stream for social care is easier for central government to control; offers health budgets some protection from the pressures of demographic ageing; and helps secure political legitimacy for collective funding of non-health care services.

**3. In most countries, access to social care is based on universal principles – it is equally available to poorer and better-off people.**

In the UK, access to publicly funded residential care involves a test of assets – only those with capital under £21,000 can access it – a barrier widely believed to be unfair as it treats differently people with similar levels of disability. Under US Medicaid, those with assets above a prescribed level are not eligible for publicly funded care, a similar wealth eligibility criterion. In Australia, too, an assets test determines access to public funding for institutional care. However, in Australia, a 1997 proposal to charge a substantial "accommodation bond" lump sum entry payment to nursing homes was dropped after strong opposition, illustrating the political limitations to the use of user assets to fund long-term care. The alternative, means-tested accommodation charge that was introduced in 1998 has helped many short-term residents avoid having to sell the family home.

In most other countries, however, access to publicly funded social care is based on universal principles – it is the level of impairment, incapacity or support needed that determines access, not the level of income or assets. While co-payments, based on income levels, may subsequently also be required, an individual's financial situation is not a criterion that determines initial eligibility for social care. Countries as diverse as Austria,

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<sup>7</sup> Cabinet Office/Prime Minister's Strategy Unit *Improving the Life Chances of Disabled People* (2005)

Germany, Japan and the Netherlands all provide social care according to universalist principles that avoid means testing as a condition of access.

Problems associated with means-tested access to social care have been major drivers for reform in several countries. In Germany, older people who had exhausted the very limited care benefits available under sickness insurance had no option but to spend down their resources until they became eligible for means-tested social assistance. This was widely felt to be highly stigmatising, with the consequence that many older people did not apply for the funding they would have been entitled to.<sup>8</sup> With the 1994 introduction of long-term care insurance, numbers of older people dependent on means-tested social assistance towards the costs of institutional care halved. Other benefits of a universal approach to entitlement to social care include an affirmation of the citizenship rights of service users; and avoidance of the problems of poor quality often associated with programmes exclusively for poor people.

The experiences of other countries also show it is quite feasible to combine universal access with a progressive system of co-payments based on income levels. Entitlement to the French *allocation personnalisée d'autonomie* is based on a national assessment of dependency, but is combined with co-payments where, above a fixed income threshold, users contribute according to their income level.<sup>9</sup> User charges for home nursing services are rare, probably because of the links with healthcare. Charges are more often levied for home care and care services in care homes, using a mixture of local or national criteria, and are almost always levied on the hotel services in care homes, on the basis that individuals are normally responsible for their housing and living expenses.

#### 4. Good-quality care is delivered by integrated professional teams.

The boundaries between health and social care services in the UK have long been recognised as risking the delivery of fragmented services. While there has been progress in developing integrated services, the risk of fragmentation still remains, particularly for people with complex needs.

In Denmark, local municipalities are responsible for funding (from local taxation) and providing community nursing and social care within a national legal framework. In most

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8 Brodsky, J, Habib, J and Mizrahi, I *Long-term Care Laws in Five Developed Countries: A Review* (Brookdale Institute/World Health Organization, 2000)

9 Da Roit et al, op cit

municipalities these services are delivered by integrated professional teams. As well as home help and nursing services, these teams provide round-the-clock care for severely disabled people and six-monthly "preventive" visits to all older people to identify potential problems and service needs. Significantly, the integrated teams also provide support to people living in specialist adapted housing and nursing homes – a level of integration that provides continuity when people move from home to nursing home or back and has also reduced expensive nursing home and hospital use.

Although for the past decade Denmark has encouraged the growth of private service providers, these remain restricted to offering domestic help only. One reason for the slow development of a private market is that it threatens the continuity of care offered by the integrated municipal teams.<sup>10</sup>

5. Many countries are introducing cash payments or vouchers instead of care services in kind, but the aims underpinning these developments are different and evidence on the outcomes is mixed.

Introducing cash payments often has several aims: increasing choice for social care users; compensating for gaps in services; stimulating the creation of new jobs or providers in social care; increasing efficiency and reducing costs by promoting competition between providers; and shifting care preferences and service use from institutional to domiciliary sectors.<sup>11</sup> In countries with less developed welfare services, cash payments are more likely to be aimed at stimulating the development of services and care-related jobs and, where this fails, to support family care giving. In countries with more extensive service provision, cash payments may aim to increase choice and personalisation for users.

Sometimes the use of these payments is tightly controlled, in order to stimulate the supply of specific services and/or in specific sectors. This was the intention behind introducing vouchers for nursing homes in Valencia.<sup>12</sup> Similarly, the French *allocation personnalisée d'autonomie* aimed to stimulate service sector employment; it finances a specific care package, determined by a team of professionals, and can only be used to

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10 Stuart, M and Weinrich, M "Home is Where the Help Is: Community-based Care in Denmark" in *Journal of Aging & Social Policy* vol 12, no 4 (2001)

11 Timonen, V, Convery, J and Cahill, S "Care Revolutions in the Making? A Comparison of Cash-for-care Programmes in Four European Countries" in *Ageing & Society* vol 26, no 3 (2006)

12 Tortosa, MA and Granell, R "Nursing Home Vouchers in Spain: The Valencian Experience" in *Ageing & Society* vol 22, no 6 (2002)

pay for these services.<sup>13</sup> Finnish home care services vouchers aimed to compensate for reductions in municipal home help services and stimulate job creation in the private and non-profit sectors. In Ireland, home care grants were introduced to shift care preferences from institutional to community-based care and stem the spiralling costs of nursing home care.<sup>14</sup>

In other countries, promoting user choice is an explicit aim of cash payments, alongside increasing the supply and diversity of care. The Netherlands introduced a cash “personal budget” option as an alternative to services funded through AWBZ; here the aim was to stimulate alternative sources of care to circumvent long waiting lists for services. There has been a modest increase in the number of home care agencies, while older personal budget holders prefer to employ close relatives (including spouses).

In some countries, cash payments aim to support family care. German long-term care insurance offers a choice between a cash benefit and services in kind; the cash option has consistently been more popular, despite the fact that it is of much lower value. The cash benefit is widely believed to be passed on, partly or wholly, to an informal carer – where that person is co-resident, it becomes part of the household budget. The Austrian care allowance has similar objectives and is valued positively by informal carers.

Evidence on whether cash payments achieve their objectives is mixed. Evidence from Germany and the Netherlands indicates modest increases in the numbers of home care provider organisations, although the stability of providers and quality of services can be problematic. In the Netherlands and Flanders,<sup>15</sup> personal budgets have encouraged some new recruitment into the social care workforce, for example from the long-term unemployed or newly retired people. However, there is also evidence from Austria and Italy of the growth of extensive grey labour markets of immigrant care workers from central and eastern Europe, employed by families using care allowances.<sup>16</sup> In the absence of formal service provision, families to some extent free themselves from the direct provision of informal care by buying care in the grey market place.

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13 Da Roit et al, op cit

14 Timonen et al, op cit

15 Breda, J, Schoenmaekers, D, van Landeghem, C, Claessens, D and Geerts, J “When Informal Care Becomes a Paid Job” in Glendinning, C and Kemp, PA (eds) *Cash & Care: Policy Challenges in the Welfare State* (Policy Press, 2006)

16 Kremer, M “Developments in Austrian Care Arrangements: Women Between Free Choice and Informal Care” in Glendinning and Kemp, op cit; Da Roit et al, op cit

How cash payments are used, including the regulation of relationships between care workers and their employer care allowance recipients, is critically important,<sup>17</sup> both in safeguarding the quality of care provided and in offering social protection to care workers. The lack of control over how care allowances in Austria and Italy are used has led to the widespread employment of immigrant care workers outside labour and social security regulations and lacking job security, social insurance coverage or health and safety protection. The grey labour market also undermines measures to develop quality care standards. In contrast, in the Netherlands and Flanders, even though cash allowances can be used to employ close relatives, including spouses, above a specified number of hours this must comply with minimum labour market contract rights. Similarly, the French *allocation personnalisée d'autonomie* must be spent on a specified care package and this has enhanced the numbers, quality and professionalisation of care workers.<sup>18</sup>

Evidence on how far cash payments allow social care users to exercise greater choice and control is also mixed. Where desired options are available – for example, care providers or employees who can provide the help in the desired manner and time – then satisfaction is high.<sup>19</sup> On the other hand, choices for relatives and families may be reduced. Where relatives are employed with formal contracts, they invariably provide much more care than they are paid for and can find it difficult to negotiate time off and holidays.<sup>20</sup>

Cash payments are seen as a lower-cost alternative to formal services. This assumption is built into German long-term care insurance, where the cash payment is at a significantly lower value than services in kind, and into the Dutch personal budget, which automatically reduces by 25% the value of the support a user is assessed as needing, on the grounds that informal and non-statutory service providers incur fewer overhead costs. One reason why cash payments are lower-cost, therefore, is that they transfer some costs to families.

**6. Support and social rights for informal/family carers are integral to an overall strategy for social care.**

Family care is the dominant form of support for older people throughout the world. It is often treated as a "free" resource. However, the hidden costs of unsupported informal care

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17 Ungerson, C and Yeandle, S *Cash for Care in Developed Welfare States* (Palgrave Macmillan, 2007)

18 Da Roit et al, op cit

19 Kremer, M "Consumers in Charge of Care: The Dutch Personal Budget and Its Impact on the Market, Professionals and the Family" in *European Societies* vol 8, no 3 (2006); Pijl, M and Ramakers, C "Contracting One's Family Members: The Dutch Care Allowance" in Ungerson and Yeandle, op cit

20 Breda et al, op cit; Pijl and Ramakers, op cit

can be substantial and have indirect implications for wider economic competitiveness (if carers cannot take paid work) and public spending on services like healthcare (if they develop health problems as a result of unsupported caring). There is uncertainty in the UK and elsewhere about the future availability of informal care, and this uncertainty affects projections of the overall future cost of social care.

Internationally, two broad approaches can be identified. Incentives can be provided to encourage and sustain family care, together with protection and compensation for caregivers. German long-term care insurance reflects the belief that time spent caring deserves recognition.<sup>21</sup> The cash benefit option therefore includes a carer's right to four weeks' break each year by funding substitute professional services (this is also available if the carer is ill); carers' retirement and accident insurance contributions are also paid; and carers may receive advice, support and training from care insurance funds and retraining if they return to paid employment after care giving.

A second approach, in countries like Denmark, Japan and, to some extent Scotland, is to substitute formal services for informal care. Japan's long-term care insurance scheme, introduced in 2000, was designed to reduce reliance on family care by making community-based services more accessible to older people. Following extensive debate, it was decided that care insurance benefits would take the form of services in kind rather than cash payments, as the latter would inhibit demand for formal services and prolong the provision of oppressive and sometimes poor-quality care by daughters-in-law. Significantly, evidence from Denmark and Scotland shows that increased service provision does not necessarily reduce the overall volume of informal care provided to older people.<sup>22</sup>

**7. Usually, reforms to long-term care are consistent with existing structures and with cultural traditions about the responsibilities of families and the state. However, major changes and divergences are also possible.**

Successive UK governments have adopted incremental and piecemeal approaches to reform. This has contributed to the inequity between Scotland and the rest of the UK; to a complex range of funding streams and eligibility criteria; and to widespread perceptions

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21 Morel, N "From Subsidiarity to 'Free Choice': Child- and Elder-care Policy Reforms in France, Belgium, Germany and the Netherlands" in *Social Policy & Administration* vol 41, no 6 (2007)

22 Bowes, A and Bell, D "Free Personal Care for Older People in Scotland: Issues and Implications" in *Social Policy & Society* vol 6, no 3 (2007)

of unfairness.<sup>23</sup> Public support for a stronger state role in relation to older people's social care remains high.<sup>24</sup>

The introduction of Japan's long-term care insurance shows how system-wide change can be accomplished, even in the face of strong institutional and cultural traditions. Here public-sector provision was given a much stronger role in financing long-term care than it enjoys in other sectors of the economy. Moreover the scheme aimed to reduce the centuries-long reliance on daughters-in-law as the main providers of care for older people.

Both incremental and system-wide approaches to reform are possible. However, given the range of different policy domains on which long-term care reforms can touch, an overarching vision and strategy are essential, whether these are implemented gradually or through wholesale radical reform.

### **Conclusions**

Reform processes are complex; there are no easy solutions and numerous trade-offs are likely to be required. However, the experiences of other countries offer many examples of universal, equitable, politically popular and economically sustainable approaches to funding, organising and delivering social care.

### **Acknowledgments**

This chapter draws heavily on background work carried out for the Joseph Rowntree Foundation and published as Glendinning, C, Davies, B, Pickard, L and Comas-Herrera, A *Funding Long-term Care for Older People: Lessons from Other Countries* (Joseph Rowntree Foundation, 2004). The views expressed are the author's alone.

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23 Robinson, J (ed) *Towards a New Social Compact for Care in Old Age* (King's Fund, 2001); Brookes, R, Regan, S and Robinson, P *A New Contract for Retirement* (Institute for Public Policy Research, 2002)

24 Deeming, C and Keen, J "A Fair Deal for Care in Old Age? Public Attitudes Towards the Funding of Long-term Care" in *Policy & Politics* vol 31, no 4 (2003)



## Chapter 11

# The case for reform

Lord Bruce-Lockhart, Former Chairman of the Local Government Association and Former Leader of Kent County Council

## The case for reform

I would like to address three questions. First, is there clarity and consensus about demographic change? Second, what kind of care services do we need for the decade ahead? Third, what is the funding requirement to respond to demographic change and change in service demand?

It has been said that you can judge a society by the way it treats and cares for its elderly. That was never more so than it is today. I was pleased to see that the Treasury's 2007 comprehensive spending review set out just five factors of change and that one of them was, rightly, the challenge of demographic and social change.

People over 85 require the most urgent attention and the most intensive care. According to the government's actuaries, in 2005 there were 1.2 million over-85s and by 2050 there will be 4 million. For the first time, there are more people in England over 60 than under 16. In the comprehensive spending review challenges report, the then Chancellor focused only on the next 10 years, reporting a forecast 38% increase in the number of over-65s. There is clear recognition of a dramatic demographic change but, I am afraid, a failure to act on it.

In considering a changing service, we need to respond not only to the demographic change in numbers. Help the Aged, Age Concern, the King's Fund, numerous charities and local authorities are also reporting a sharp increase in mental, learning and physical disability in old age. We must respond to this too. At the same time, the adult social care budgets of local authorities are also responsible for the age group 16 to 65. In this group, we see that medical advances, coupled with better health and social care, mean that children with the most severe learning and physical disabilities are often living into middle age. Indeed, the director of social services in my own county of Kent reports that this financial demand is now even greater than the escalating demand from changing demography. Those vulnerable younger people require and deserve intensive, high-quality care.

In 1991, the government introduced a bill on community care that allowed elderly people to receive care in their own homes for their first time. That radical reform brought new independence to the elderly and has been, and must be, built on so that independence is the central principle of a changing service. In November 2006, the Commission for Social Care Inspection reported improvements in social care by local authorities. It is clear that

community health and social care services must be designed around the needs and wishes of elderly people. Social care services must be personalised, offer choice, focus on early intervention and prevention, bring a higher quality of life for elderly people, deliver care with kindness and compassion, and give time. They must also value and care for the many carers who do invaluable work. At the same time, we need greater innovation and stronger partnerships between social care and the health service and stronger collaboration with, and a stronger role for, the voluntary sector.

The Wanless commission pointed to the need for a funding increase of some £20 billion for the care of the elderly over the next 25 years, an increase of almost £1 billion a year, and we are awaiting a response from the government. However, the situation for elderly people and the facts from the government, local authorities and many charities and voluntary groups are entirely clear. The Treasury forecast that in the next decade the number of people aged over 85 would increase by 3.8% a year. The Local Government Association showed a 6% increase in the number of weeks of care commissioned by local authorities last year alone – yet to pay for that increase, half the social services authorities had an increase in government grants of 2% or less this year. While the NHS has had a 90% increase in funding in real terms during the past decade, local government services including social care have had an increase of just 14%.

In 2006, social service directors reported that they started the year with a black hole from 2005/06 when they spent 13% – or £1.8 billion – more on adult social care than the government had estimated for funding purposes. On top of that, there are numerous other factors, including cost pressures, the reduction in grants under the Supporting People programme and the new and additional costs from direct payments, to which an Audit Commission report drew attention. As a result of the new demand, the absence of any new funding or action from the government, and because council-tax payers cannot pay more, half the social services authorities in the country are reporting that they are raising eligibility criteria and so rationing care for the elderly. In a civilised society, this is unacceptable.

When we consider funding, the relationship between local authorities and the health service is the central issue. On the one hand, local authorities have been working in close partnership with the health authorities. A number of social services departments, working with their health authorities, set themselves a target of reducing by 20% hospital admissions for people older than 75. Most of those 10 authorities achieved that target, but through additional cost to the local authority. However, it brought financial

benefit to the health authority and real benefit to elderly people.

That is encouraging but, on the other hand, because of the current cost pressures within the NHS, many local authorities are reporting cost shunting by the health service. In my own local authority, the East Kent Hospitals NHS Trust closed 180 beds last year, which has resulted in earlier discharges and the need for higher and more intensive levels of social care. It also brought reductions in primary care services, which the health service would not wish for. However, cuts are being made in respect of district nursing, community matrons, community physiotherapists and the NHS equipment provided to residential homes.

I am pleased to say that this issue is recognised across the board, not least in my own party. David Cameron has identified "the artificial and damaging barrier between the NHS and social care services". Organisations that break down that barrier do so against the odds. To give an example from my local authority, in the case of NHS continuing care, it is estimated that 24% of those in nursing homes in Kent have care needs that should be the responsibility of the NHS. We urge the government to develop a test of eligibility with clear criteria that are understood by all, so that we can resolve that issue.

The white paper on health, published in 2006, calls for "a shift in the gravity of spending. We want our hospitals to excel at the services only they can provide, while more services and support are brought closer to where people need it most." It is right that services and support should be brought to community social care and community health care but where are the action and funding to support that?

None of these issues is easy but we urgently need solutions. It is clear that local authorities and private and voluntary providers of care services for the elderly must rise to the challenges of changing need and increasing demand. However, it is also vital that we have a resolution to the immediate funding crisis in the provision of care services for the elderly and for vulnerable adults. We need a clear statement from the government about how funding will be provided to enable us to rise to the demographic and social challenges of the next decade that are so important for any civilised society.

*Lord Bruce-Lockhart was chairman of the Local Government Association until 2007. This chapter is based on a speech given in the House of Lords in December 2006, opening a debate on adult social care.*

## Chapter 12

# The prospects for reform

Sir Derek Wanless, Lead Author of *Securing Good Care for Older People*

## The prospects for reform

*Securing Good Care for Older People*<sup>1</sup> set out to estimate how much it might cost to provide social care for older people in England 20 years ahead. There were many uncertainties to tackle. How many older people will there be? Will care needs change as health services develop, particularly for those with dementias but also for those with chronic long-term conditions? Will the real cost of the resources, especially the people, likely to be necessary to meet those needs change? How much informal care might be available?

These are difficult aspects to model, but it soon became clear that there were much deeper issues; issues that will greatly influence the prospects for successful reform of social care for older people. Because, although reform of the present unloved system is inevitable, it is by no means certain that the reforms that happen will resolve the many problems, nor that they will successfully avoid unintended but potentially very damaging consequences. To a considerable extent that is because of the seriousness but also the range of the problems.

Briefly, a system has been allowed to develop on which considerable sums are spent, providing either direct care or allowances through the benefit system, but with little information available about how far the spending goes towards achieving the government's desired aims for older people of promoting choice, independence and prevention. Spending on care home placements has grown faster than that on home care, although older people prefer to receive care in their own homes. Resources have been directed towards those with the most intensive needs, leaving without help substantial numbers of people with lesser but still significant needs.

The funding system creates widespread dissatisfaction. It shocks many just when they are most vulnerable, in part because people and their families didn't know what to expect. The means testing in the present system and the penalising of those with savings are commonly perceived to be unfair. In social care the postcode lottery is alive and well, with large inequitable differences in local authority charging. Distinguishing needs at the boundary between healthcare (free at the point of delivery) and social care (means tested) also creates considerable anger and distress among older people and their families. Budgets for public-sector spending on providing care have not kept pace with need, and social care for the elderly has come to mean whatever a particular year's Budget will stretch to.

1 Wanless, D *Securing Good Care for Older People* (King's Fund, 2006)

The benefit system is another issue that prospective reformers of social care need to consider. Again, information about what is being achieved is sketchy. Two social security benefits that can be spent on the needs of those requiring care are attendance allowance and disability living allowance (care component). They are the main sources of non-means-tested funding for older people with disabilities. The interplay between provision of care, its funding and provision of benefits is complex. It is poorly understood and little analysed: not a good basis for reform in a sensitive policy area.

### **What the report aimed to do**

*Securing Good Care for Older People* sought to tackle these issues by creating a measure of value, similar to the quality-adjusted life year used by the National Institute for Health & Clinical Excellence, and using it to assess the levels of support that might be considered justifiable in particular circumstances. There is much scope for academic, economic and political debate about how such tools might be used, but the development of such tools is a likely prerequisite for the success of any major policy changes.

That report began by estimating, on the basis of defined assumptions, the likely cost, 20 years ahead, of providing the current levels of care support with the present funding methodology. This projected a rise in total costs from £10 billion to £24 billion. In a sense this is the first serious barrier to reform: the financial consequences of changing demographics are likely to be very significant, even before beginning to create enhancements to the system or to tackle the flaws in the present system.

Yet more money will need to be found, from one source or another, if unmet need is to be met and the resources developed to do all the work. The report's range of spending 20 years out rose to over £31 billion on the widest definition used for social care, despite making it clear that the report's scenarios had made only tentative steps towards tackling the well-being agenda. Areas such as improved social participation, self-esteem through occupation and a sense of control over one's life are all well-being outcomes where there is limited evidence about cost effectiveness, and therefore they were not included as aspects of spending.

A further block to immediate reform is the ability of the system, even with additional funding, to actually deliver. The report took the view that additional funding should not be forthcoming without a commitment to the reconfiguration of services capable of demonstrating value for money and fairness. Examples were felt to include an increase in the size of community-based care packages for all those needing care, particularly the

middle dependency group; an improvement in carer support services; and the tailoring of care-with-housing services for those with significant cognitive impairment.

So the backdrop to deliberations about reform should include consideration of the ability to deliver, of the availability of finance and the fairness of the system that provides it, and of the affordability and sustainability of such a system into the long-term future. People and their families need to know what the care service is likely to provide and what it is likely to cost them. Then, at the very least, they will have the ability to think ahead with some confidence that the services required will be there.

Tinkering with the existing framework will not achieve that. The huge financial risk to individuals at present of needing extended and expensive social care needs to be pooled across the population, one way or another.

There are many potential methods of funding, and the report considered their pros and cons. The criteria used were fairness, economic efficiency, user choice, physical resource development, clarity and sustainability/acceptability. The detailed assessment leaves considerable room for debate; much of it political, some of it about practicalities and economics. Different methods of distributing costs between the individual and the state would change the amount of care consumed and the equity of the service.

### **The preferred system**

The report concluded that, unsurprisingly, there is no single system that stands out in all respects above all others. Relative strengths and weaknesses required to be balanced and needed judgment. Yet a preferred system did emerge: the partnership model, a hybrid characterised by combining a state-financed entitlement to a guaranteed level of care with a variable component made up of contributions from individuals matched at a given rate by contributions from the state. The guaranteed level of care could be fixed nationally or locally on the basis of assessed need; it becomes an explicit entitlement. The remaining matching element would be determined locally.

Such a partnership model has many potential variations. The variant chosen in the report involved a guaranteed level of care at two-thirds of the benchmark care level (which was defined as the "economically justifiable" level), after which matching was fixed at 50% – that is, pound for pound – up to the benchmark level. The state was assumed to make no further contributions after that benchmark level was reached.

The strengths of the partnership model were perceived to be its universal and inclusive nature, providing a guaranteed minimum level of care, clarity about what is offered, limited (but still a modest level of) means testing, an incentive for people to save for their old age (consistent with emerging philosophies about pensions), good value for money and a reasonable prospect of sustainability. The weaknesses were its additional costs relative to a means-tested system such as that operated at present, that it couldn't avoid working to a limited extent with the benefit system, and that some of the benefits go to the better-off. It was considered that these were modest problems when balanced against the alternatives, which often had similar weaknesses.

The report concluded that the partnership model was the preferred option but that the decisions about its appropriateness would ultimately depend on value-based choices about the relative importance of containing public-sector costs, maximising equal access to care and balancing outcomes for different income groups. The report sought to contribute to a much-needed debate and recognised that a radical and comprehensive solution would take time to work out. Ideally, the ideas in the report and the information it provided would help consensus to emerge, which would lead to sufficiently widely accepted change that people could plan for their futures, while the real resources to deliver services could become available.

An important secondary hope was that, in the short term, further squeezing of spending rises below the level of increases in needs would be avoided. In short, short-term action – probably only possible through the existing system – would be needed to avoid further deterioration in the coverage of services while long-term solutions and the development of adequate real resources emerged.

### **The will is there**

Reform requires political will. The immediate reaction to the report from all major political parties was promising, with more than polite interest. There seemed to be a recognition that this neglected issue had the potential to rise up the agenda, never becoming the scale of electoral issue that, for example, health will always be, because of the universality of coverage of health, but nevertheless capable of becoming a serious enough subject to matter.

Its complexity too created a wariness that this would not be an easy issue to tackle well. There would be winners and losers in radical change, particularly if the related benefit system were, as it should be, tackled alongside the system of funding of care. The losers

are likely to be much more vocal than the winners and there must be considerable doubt about how much extra money will be available to ease the introduction of a radically revised system.

There is wide-ranging interest in the issue. It is vital that momentum generated by recent studies is kept up. Many organisations are involved in different aspects of the long-term care system, and 15 of them from many different perspectives (see footnote 2) got together under the banner of "Caring Choices: Who Will Pay for Long-term Care?" in a nationwide initiative to help shape future policy on long-term care for older people.<sup>2</sup> Caring Choices is seeking to raise awareness of the challenges facing the future of long-term care funding. The collaboration has been holding a series of events to gather opinions from older people and individuals involved in the care system from around England. They have kept up the pressure on politicians to tackle the issue by reinforcing the messages of the recent reviews.

These issues are not new, and social care has lagged behind healthcare and pensions in terms of attention and reform. But there is a sense emerging that financial responsibility will need to lie jointly with individuals and the state if needs are to be met and high-quality services and choice made available.

The opportunity for the government to give a medium-term response to recent lobbying came with the pre-Budget report and comprehensive spending review in October 2007. That response was framed at a difficult and tight time for the state's short-term finances.

The bad news in the document lay in the financial settlement for adult social care. Despite the evidence of growing unmet need, likely increases in demand, and resource and quality pressures in the provision of care services, resources for local authorities are to have an annual average growth rate of 1% in real terms (this figure covers all adults). The message that the present system needed to be supported while long-term reforms were worked out and implemented had had only modest influence.

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2 Caring Choices was set up as a wide-ranging collaboration of organisations representing all aspects of the long-term care system: the King's Fund, the Joseph Rowntree Foundation, Help the Aged and Age Concern, in partnership with the Alzheimer's Society, the Association of British Insurers, the Association of Directors of Adult Social Services, Carers UK, Counsel & Care, the English Community Care Association, Independent Age, the Local Government Association, the Royal College of Nursing, the NHS Confederation and the Social Care Institute for Excellence; and also working with Age Concern Scotland, the Elders Council of Newcastle, Help the Aged Scotland, the Leeds Older People's Forum and the Race Equality Foundation.

There was recognition of the need to find out what works in the extra resource made available to the Department of Health's social care funding, which directly supports new policy initiatives. It will increase by £190 million to £1.5 billion by 2010/11. It is aimed, amongst other things, at enabling further expansion of care tailored to the individual, including individual budgets, with a thorough evaluation promised to be completed in 2008.

How much this can help older people and their families will need particular attention. The aims for the extra money also include continued investment in prevention, seeking to enable service users to retain their independence and improve their quality of life, in advocacy and information services, and in investment in the social care workforce.

### **Government commitment to change**

The good news in the document, well hidden away but widely welcomed, was a signal from the government of major reform of social care and the present means-tested system. The government committed to consulting "on reform of the public support and care system focusing particularly on older people, to ensure a sustainable system that targets resources effectively, is affordable and promotes independence, well-being and control for those in need".<sup>3</sup>

A period of consultation will lead to a green paper. The recognition that the existing systems are unlikely to be able to target state resources most effectively or meet people's aspirations for their quality of life and the acknowledgment of the need for a rethink of the way the state supports people in need must be an encouraging step.

The belief of the government that there are real opportunities for reform within a system that shares the cost between the individual and the state and that provides both universal and progressive elements is a powerful boost to those arguing for such change. So is the government's recognition that change in this area is so crucial to many people's lives that it should be taken forward with a broadly based consensus.

In getting this far the government has moved a long way, but the detail is not yet revealed. In this complex area, the devil will without doubt be in the detail. In accepting that there are real opportunities for exploring some form of universal entitlement coupled with a contribution from the individual, it will, for example, be impossible to ignore the

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<sup>3</sup> HM Treasury 2007 *Pre-Budget Report Et Comprehensive Spending Review* (October 2007)

relationship between any proposals made and the benefits available to the poorest.

There is no certainty that change will follow, although it seems very likely. It is a huge advance that the government is prepared to give consideration to a system based on universal entitlement coupled with individual contributions.

We may well have reached a tipping point now that the government and all major opposition parties have acknowledged the serious shortcomings of the delivery and funding systems for social care; systems that are going to become more relevant to more people and their families in coming years and that are already failing many worthy of help. Political leaders have taken the first steps towards radical reform; they ought to see that they have everything to gain from tackling these issues now, as they will not go away.

Proponents of reform must use the evidence increasingly becoming available to make their case effectively. The green paper, when it comes, must show continued determination to reform; meanwhile, opposition parties must get their manifestos ready. Cautious optimism is perhaps a fair way to describe the prospects for reform in this long-neglected area, but there is a good deal of detail still to be finalised and consensus to be built.

## **The Smith Institute**

The Smith Institute is an independent think tank that has been set up to look at issues which flow from the changing relationship between social values and economic imperatives.

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