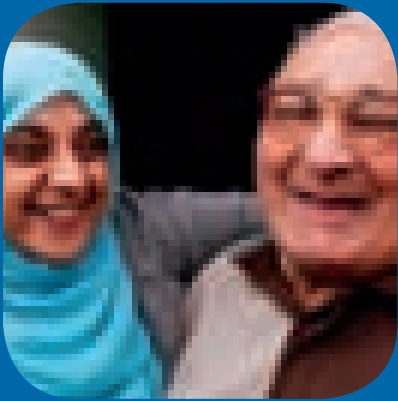


The case for change – Why England needs a new care and support system



READER INFORMATION

Policy	
HR/Workforce Management	Estates
Planning	Commissioning
Clinical	IM&T
	Finance
	Social Care/Partnership Working

Document Purpose	Consultation/discussion
Gateway Reference	9853
Title	Care and support reform – key facts
Author	HM Government
Publication Date	12 May 2008
Target Audience	PCT CEs, SHA CEs, Care Trust CEs, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, Allied Health Professionals, third sector organisations, private sector providers
Circulation List	Communications Leads
Description	This document sets out the case for an open debate about the long-term future of England's care and support system. The Government wants to engage with the public and key stakeholders about how the existing system can meet the challenges of the future.
Cross Ref	<i>Putting People First, Independent Living Strategy, Lifetime Homes, Lifetime Neighbourhoods</i>
Superseded Docs	N/A
Action Required	N/A
Timing	Consultation running May to November 2008
Contact Details	Care and Support Team Rm 543, Richmond House 79 Whitehall London SW1A 2NS careandsupport@dh.gsi.gov.uk www.careandsupport.direct.gov.uk
For Recipient's Use	

Contents

Foreword by the Prime Minister	4
Foreword by Secretaries of State	5
Executive summary	6
1. Introduction	12
2. What is care and support?	16
3. Why do we need a new care and support system?	22
4. Our vision for a 21st-century care and support system	32
5. The balance of responsibility	42
6. The different ways of allocating government funding	48
7. How we will be engaging everyone in the debate	52

Foreword by the Prime Minister



The need for care and support because of age or disability is a reality that at one time or another faces every family in this country. Thanks to better healthcare, new technologies and a more prosperous society we are all living longer. Life expectancy has increased by around 11 years, for both men and women, since 1948. Today's children have the prospect of spending a third of their lives in retirement and of seeing their own children retire. This is clearly a cause for celebration but it also presents new issues which, as a society, we must address.

For most of us, at least some part of our longer retirement will be spent needing care and support from others, whether from family members or organised services. But our system for supporting those who need care is currently ill equipped to provide a high-quality service for all who need it.

Over recent years, people's expectations have risen and they demand more from their care. Older people have shown that they can lead healthy and active lives well into retirement and that, with the right support, age need be no barrier to an active and full contribution to society. And people with even severe disabilities have shown that the services they need the most are those which empower them and enhance rather than diminish the control they have over their lives.

But too often, organised care services can seem bureaucratic and inflexible, unresponsive to these rising demands for personalisation and independence. And we must do more to ensure that family members and friends who provide care are given the support they deserve – and which reflects our dependence as a society on their willingness to contribute their time and energy.

This Government has already led the way by achieving a new consensus about the long-term future of the pension system. Now it is time to create a new care and support system that is fit for the 21st century: a system that is personalised to individual needs and gives real control to those needing care and their carers; that values the informal care on which our society depends; that gives people who would benefit from it access to care in the home; and that offers us all protection against the costs of care in old age, which can be catastrophic for some families.

This document explains the challenges facing our society and the decisions we need to make about the values of a new care and support system. This is your opportunity to engage in a debate about our future – a debate that will affect every family and shape the kind of society in which we live.

A handwritten signature in black ink that reads "Gordon Brown". The signature is written in a cursive, slightly slanted style on a white background.

Foreword by Secretaries of State

People have told us what they want from the care and support system. They want to be able to stay healthy throughout their lives, maintain their independence and wellbeing, support a family, be treated fairly and equally and have an active role in their community.

The Government, through *Putting People First*, *Lifetime Homes*, *Lifetime Neighbourhoods*, the Independent Living Strategy and the NHS Next Stage Review, has already embarked on an ambitious programme of reform so that the care and support system works better for people, is easy to access and is of high quality.

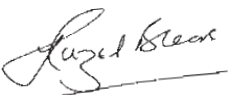
This programme of reform is already starting to make real differences to people's lives, but there is still more that can be done. We need to be prepared for the impact that the increasing expectations and demographic changes in our society will have on the care and support system. As more and more people need care and support and rightly demand more and more from the care and support they receive, the current system will not be sustainable in the long term. A new care and support system is needed to bring together the range of activities, services and relationships that underpin care and support, so that people are clear about what they are entitled to.



Secretary of State for Health



Secretary of State for Work and Pensions



Secretary of State for Communities and Local Government

We are already doing a lot to achieve our vision, but as society and the pattern of our lives are changing, we need to examine some fundamental questions. This debate is an opportunity for you to have your say about difficult issues that need to be addressed when developing a new system.

Important questions are being raised about issues that we have previously taken for granted: about our expectations as individuals and how we wish them to be fulfilled; about the balance of responsibility between individuals, families and the state; and about the levels of taxation we are prepared to pay and what we expect in return.

About a third of all men and half of all women will, upon reaching the age of 65, need long-term care and support at some point as they age. And there are many people with enduring life-long conditions who need care and support far earlier. But these issues affect all of us – whether we are in need of care and support ourselves, are a friend or family member of someone who needs care, or pay for the care system through taxation. This is your chance to shape the future.



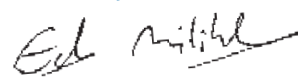
Secretary of State for Children, Schools and Families



Chief Secretary to the Treasury



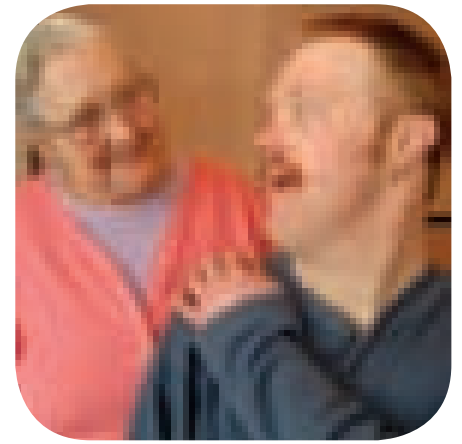
Secretary of State for Innovation, Universities and Skills



Secretary of State for the Cabinet Office

Executive summary





In a civilised society, we have a moral obligation to ensure that people in need are not left without any care or support. The existing care and support system is not sustainable, because of the impact of changing demographics and expectations in our society. We need to address these challenges now, before their effects are felt on the system and impact on people's lives.

There are a number of issues that need to be addressed before a new care and support system can be developed.

The Government believes that finding a solution to these issues will require a radical rethink of how we pay for and deliver care and support services. The long-term challenge is to create a new settlement between individuals, families and the Government that will be sustainable in the future, that offers us all protection and dignity, and that is fair.

From May to November 2008, the Government is engaging with the public and key stakeholders to explore the key issues for debate.

The Government wants to discuss several questions that are based on these key issues, which need to be addressed

before a new care and support system for England can be developed. The information will be used to inform and assess potential solutions.

What is care and support?

Care and support describes the activities, services and relationships that help people to be independent, active and healthy – as well as to be able to participate in and contribute to society – throughout their lives.

It is about helping people to do day-to-day things like:

- living in their own home
- working
- cooking
- shopping
- caring for a family.

The reasons why people might need care and support include:

- accidents
- long-term illnesses
- being disabled
- growing older.



Why do we need a new care and support system?

Society is going through huge change. People are living longer than ever before, and the proportion of older people in our society is growing. We have different social values, and we expect more choice and control over all areas of our lives, including public services.

And too often the existing system does not live up to the expectations of those who depend upon it.

We have an ageing population. In the next 20 years, the number of people over 85 in England will double¹ and the number over 100 will

quadruple. Similarly, advances in medical knowledge and practice mean that disabled people can live longer and can lead healthier lives. We expect over 1.7 million more people to have a need for care and support in 20 years' time.²

A radical rethink of the care and support system is needed to address these challenges. Otherwise, it is likely that families, including dependent children within the family, will be under pressure to provide inappropriate levels of care, and in some cases people will go without support. If we fail to get to grip with these long-term issues we will fail to provide quality of life for potentially large groups of

people, and consequently demand for NHS services will increase inappropriately.

What types of assistance might be part of a new care and support system?

This is a cross-government reform, and a range of services and types of financial assistance are being considered within the scope of the debate. These include:

- those services that are grouped together as 'social care', such as meals on wheels, domiciliary care, day care, care homes, counselling and occupational therapy, and support for carers;

- some elements of housing support services for older people and disabled people, funded through Supporting People, as well as adaptations that help people get around at home safely, such as handrails and walk-in showers, often funded through the Disabled Facilities Grant;
- support for independent living for disabled people, including the Independent Living Fund; and
- benefits that help people with the extra costs of disability in later life (although any changes that may emerge will not affect existing benefit recipients).

Our vision for a 21st-century care and support system

The Government wants a society where all are respected and included as equal members of society, and where everyone has the opportunity to fulfil their potential. Public services should enable people to feel empowered and supported in meeting their aspirations. Everyone should be able to understand their role in terms of what they contribute to society and what they are entitled to receive from the state.

The Government has listened to what people want from care and support and has used this information to develop key principles that will underpin the vision for a new care and support system.

A new system must:

- promote independence, choice and control for everyone who uses the care and support system;
- ensure that everyone can receive the high-quality care and support they need, and that everyone gets some support from the Government, but that funding is targeted at those most in need; and
- be affordable for government, individuals and families in the long term.

The Government is already working towards this vision. The existing transformation programme is changing care and support so that there is better information, high-quality services, more focus on prevention and more personalised care and support.

The questions for debate

A number of issues need to be addressed before a new care and support system can be developed.

The Government wants to discuss several questions that are based on the key principles for a new system. The information will be used to develop and assess potential solutions.

¹ Government Actuary Department projections, 2007.

² Personal Social Services Research Unit (PSSRU) projections. This estimate is for personal social services only – not the entire care and support system.

There are three main questions open for debate.

1. What more do we need to do to make our vision of independence, choice and control a reality?

The Government has a clear vision for care and support that promotes independence, choice and control. This vision is set out in more detail in Chapter 4. We are already working towards this vision and have set out a three-year transformation programme. However, we would welcome your views on how we can go further to ensure that this vision becomes a reality in the long term.

2. What should the balance of responsibility be between the family, the individual and the Government?

The demographic and social changes highlight a number of fundamental questions about the balance of responsibility between individuals, families and the Government. There needs to be an open and honest debate about what the appropriate balance of responsibility is if England is to have a sustainable care and support system for the future.

When thinking about the balance of responsibility we also have to think about what role the Government should play in supporting individuals and families in saving and in helping protect them from the risk of high costs. Should the Government do more to ensure that people prepare for the costs of their own care, for instance by making some

sort of saving for these costs compulsory? By funding care and support centrally, the Government bears some of the risk of high costs. What role do people want the Government to play?

3. Should the system be the same for everybody or should we consider varying the ways we allocate government funding according to certain principles?

- **Should there be one system for everyone or different systems depending on the type of need for care and support that somebody has?**
- **Which is more important to us: local flexibility or national consistency?**
- **What should the balance be between targeting government resources at those who are least able to pay and having a system that supports those who plan and save?**

People will receive different levels of support depending on the level of care and support they need. However, there are other ways of targeting resources, and we want to establish clear, fair rules, based on shared values, about who is eligible for financial help from taxation.

We want to explore whether or not it is fair to protect financial support for people who have been disabled at a younger age, and expect people who have more predictable care costs to have made some provision to continue to look after themselves in later life.

Currently, many decisions about services are made at a local level, and a lot of money is also raised at local level. However, this does lead to variations between localities. Should there be an equal system for everybody, regardless of where they live, or should local people be able to decide local priorities for care and support? Should funds be raised locally, or should there be a national system?

There will always be a need to make sure that the poorest people in society are supported, but means testing can be perceived as penalising people who have worked hard and made sensible financial decisions at earlier points of their life. We want people to identify what they think the right balance is.

How to get involved in the debate

Every adult in the country will be affected by a new system. We want the people who will be affected by change to be the same people who are informing change.

People will be able to give their views and find out more information at www.careandsupport.direct.gov.uk or they can email careandsupport@dh.gsi.gov.uk or write to the Care and Support Team, Room 543, Richmond House, 79 Whitehall, London SW1A 2NS.

Between May and November 2008, there will be a series of events where the key issues will be discussed in further detail. These include a stakeholder event in every

government region and a number of citizen events. At the end of the six months, there will be a final event bringing both stakeholders and citizens together to provide a further opportunity for a broad spectrum of views to be heard.

The Government is using media channels and working in partnership with stakeholders at a national and regional level to encourage as many people as possible to take part.

Additional research will ensure that seldom heard groups have the opportunity to provide us with their views.



1

Introduction



This document sets out the case for an open debate about the long-term future of England's care and support system. The Government wants to engage the public and key stakeholders in discussion about how the existing system can meet the challenges of the future. If we don't address these issues now, there is a risk that the demands on families will become too heavy and people will go without the services they need to live their lives fully and stay well.

This engagement process will take place between May and November 2008, and the findings will be used to inform a Green Paper on the reform options.

Care and support describes the activities, services and relationships that help us to be independent, active and healthy – as well as to be able to participate in and contribute to society – throughout our lives.

In a civilised society, we have a moral obligation to ensure that people in need are not left without any care or support.

The Government, in partnership with local government, the NHS and the social care sector, has already developed an extensive transformation programme for the next three years to improve the care and support system, which is set out in *Putting People First*.³ This, in combination with the Independent Living Strategy, *Lifetime Homes, Lifetime Neighbourhoods*⁴ and *Our NHS Our Future: NHS Next Stage Review*,⁵ will improve the quality of the care and support system in the medium term. However, a radical rethink of how we deliver and pay for care and support services is needed if England is to have a care and support system that is fit for the 21st century.



³ *Putting People First: A shared vision and commitment to the transformation of adult social care*, HM Government, 2007.

⁴ *Lifetime Homes, Lifetime Neighbourhoods: A National Strategy for Housing in an Ageing Society*, Communities and Local Government (CLG), 2008.

⁵ *Our NHS Our Future: NHS Next Stage Review – interim report*, Department of Health (DH), 2007.



The need for change

The existing care and support system is not sustainable, because of the massive challenge that changing demographics represent for our society. In 20 years' time, the cost of disability benefits could increase by almost 50%.⁶ We expect a £6 billion 'funding gap' in social care,⁷ just to deliver the same level of support that people experience now, if expenditure on social care rises at the same pace as anticipated economic growth.

People also have changing expectations about the quality and type of services they experience, with ever increasing numbers wanting to stay in their own home and avoid institutionalisation.

The existing system does not always live up to people's expectations. Too often, our existing system also underfunds the kind of preventative home-based domiciliary care necessary to

keep people active and healthy. The current system has a tendency to create an over-reliance on residential care or even healthcare options, when the preference of many people would be earlier interventions to help them stay in their home and help them stay active.

The current system of social care is criticised for penalising those who save for their old age, whereas the current benefits system gives the same amount to everybody, regardless of their financial means. People say they do not like means testing, and yet they also say that money should be targeted at those who need it the most. We need to discuss how to balance these conflicting arguments.

The key issues

This debate aims to find an affordable, fair and sustainable way of delivering and funding a first-class care and support system in the future.

For this to be achieved these three main questions need to be debated:

- 1. What more do we need to do to make our vision of independence, choice and control a reality?**
- 2. What should the balance of responsibility be between the family, the individual and the Government?**
- 3. Should the system be the same for everybody or should we consider varying the ways we allocate government funding according to certain principles?**



- **Should there be one system for everyone or different systems depending on the type of need for care and support that somebody has?**
- **Which is more important to us: local flexibility or national consistency?**
- **What should the balance be between targeting government resources at those who are least able to pay and having a system that supports those who plan and save?**

How people can get involved

These are issues that affect everybody, whether they are in need of care now or are likely to need care in the future. About a third of all men and half of all women will, upon reaching the age of 65, need long-term care and support at some point as they age.⁶

Over the next six months, key stakeholders and the general public are being asked for their views. Further details about the engagement process are outlined in Chapter 7.

⁶ Disability Benefits long-term projections, Department for Work and Pensions (DWP) Forecasting Division, November 2007.

⁷ PSSRU projections.

⁸ *Caring for the very old: Public and private solutions*, H Glennerster, 1996.

2

What is care and support?



Care and support describes the activities, services and relationships that help people to be independent, active and healthy – as well as to be able to participate in and contribute to society – throughout their lives.

The care and support system aims to promote independence and wellbeing, and should be based on people being able to get personalised services that are tailored to their specific needs.

Care and support is absolutely central to the strength of a society. It encompasses many things, from basic human rights (such as being safe in your home and having enough to eat and drink) and personal care (such as being able to get out of bed, dress and go to the toilet when you want and in privacy), to having and being in control of your private life and meeting personal aspirations such as learning new skills or working. It's about being able to have a family life and participate in the community and being able to meet or speak with friends when and where you choose. It's about basic human dignity and freedom from degrading treatment.

What is the purpose of a care and support system?

We all need to do day-to-day things like working, cooking, shopping or caring for a family. Many of us don't need support to carry out these tasks – we do them ourselves as part of everyday life.

But there are events or barriers that mean that people need care and support to carry out these activities – these could be long-term illness, impairment, surgery, abuse or difficulties in older age.

A lot of care and support is provided without payment as part of family relationships, friendships or contributions from the local community. The 2001 Census suggests that there are 5.2 million carers in England and Wales – one in 10 of the population.⁹ The voluntary sector plays a crucial role, providing not just services, but also information, advocacy and support. It is estimated that over one million people work within local councils and the private and voluntary sector to deliver 'formal' social care services in England.¹⁰ This means that there are huge numbers of people across the country who are involved in providing and using care and support services.



⁹ Office for National Statistics (ONS), Census 2001.

¹⁰ DH estimates, 2008.

HOW MANY RECIPIENTS AND PROVIDERS OF INFORMAL CARE ARE THERE IN ENGLAND?

- Informal care is considered to be the most important source of care for dependent older people in the UK¹¹
- An estimated 1.7 million disabled older people receive some level of informal care¹²
- An estimated 0.9 million younger people with physical sensory impairments or learning disabilities receive some level of informal care¹³
- Some 5.2 million people provided some care in England and Wales in 2001 – this was 10% of the 2001 population. Of these, around 1.25 million are providing more than 50 hours of care a week¹⁴

“ I’m 100% reliant, if you like. Without them I wouldn’t be able to get up in the morning. I wouldn’t get dressed, I wouldn’t have a bath, I wouldn’t be able to look after Oscar, which actually for me is the most important thing. It means I can have a normal life, which sounds a bit odd, but it means I do go shopping and I do get the housework done, and I am in charge of all those kind of little things that people take for granted.”

– Person receiving care and support services

The care and support system aims to promote independence and wellbeing, and should be based on people being able to get personalised services that are tailored to their specific needs. The system should help people to:

- participate in and contribute to society (eg to work, gain an education or care for their family);
- stay well or get back to full health quickly after accidents or surgery (eg through accessing advice on diet or being taught to walk again after an accident);
- undertake practical tasks (eg to go shopping, work in the garden or do the cooking);
- undertake personal care (eg get out of bed and wash and dress themselves); and
- be safe at home (eg move around safely and be safe from abuse or neglect).

WHO USES CARE AND SUPPORT, AND WHY?

A range of different people use care and support services.

- **David** – a 72-year-old man with severe rheumatoid arthritis wants to plan his future and not create additional demands on his family
- **Rufus** – a 27-year-old with bipolar disorder wants support to get back into work and stay in work
- **Patricia** – a 42-year-old mother of three with multiple sclerosis wants support to continue being able to look after her family
- **Preeti** – a 31-year-old with profound learning disabilities has a family who want support to remain her primary carers
- **Ethel** – an 85-year-old woman with dementia wants support to stay healthy and safe in her own home

What types of assistance might be part of a new care and support system?

Society is going through huge change. We are wealthier and live longer, and our lives have been transformed by technology. We have different values, beliefs and expectations. These changes are explored in detail in Chapter 3, as they have a huge impact on any future care and support system. A new care and support system provides the opportunity to create a system that truly reflects the needs of the 21st century.

This is a cross-government reform, and a range of services and types of financial assistance are being considered within the scope of the debate. These include:

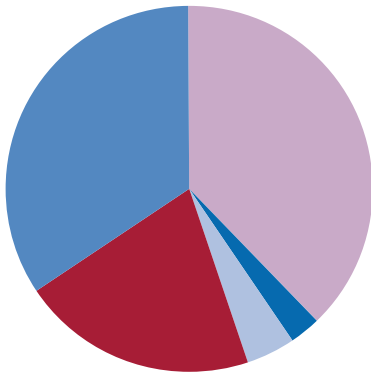
- those services that are grouped together as 'social care', such as meals on wheels, domiciliary care, day care, care homes, counselling and occupational therapy, and support for carers;
- some elements of housing support services for older people and disabled people funded through Supporting People as well as adaptations that help people get around at home safely, such as handrails and walk-in showers, often funded through the Disabled Facilities Grant;

¹¹ *Long term care for older people in the UK: structure and challenges*, A Comas-Herrera et al, 2005.

¹² *Informal care for younger adults in England: current provision and issues in future supply, England 2005–2041*, PSSRU, 2007.

¹³ *Informal care for younger adults in England: current provision and issues in future supply, England 2005–2041*, PSSRU, 2007.

¹⁴ ONS Census, 2001.



- Older people with support needs
- Older people with mental health needs
- Frail older people
- Adults with learning disabilities
- Adults with physical or sensory disability

Number of older people and disabled people using services funded through the Supporting People programme¹⁵

- support for independent living for disabled people, including the Independent Living Fund; and
- benefits that help people with the extra costs of disability in later life (although any changes that may emerge will not affect existing benefit recipients).

There are many forms that a new system could take. Some services could be integrated to provide a single seamless service; others may just need to work together more effectively.

At this early stage, keeping the scope of the debate broad will enable the Government, stakeholders and the public to think widely about all possible solutions to the challenges we face as a society.

We also need to think about the care and support system in the context of the whole of the UK and consider what impact different solutions for the English care and support system may have on how care and support works in the devolved administrations. Social care is a devolved

matter but benefits are reserved, meaning that any changes to disability benefits would affect the whole of the UK.

Governments throughout the world are struggling with the same issues, and no-one has found an easy solution. Building a new consensus about the funding of care and support is one of the main public policy challenges of our time.

WHAT IS DISABILITY?

Disability should be distinguished from impairment and ill health.

For the purposes of this document, disability is defined as:

- disadvantage experienced by an individual ...
- ... resulting from barriers to independent living or educational, employment or other opportunities ...
- ... that impact on people with impairments and/or ill health.

(Improving the Life Chances of Disabled People, Cabinet Office, 2005)



HOW MANY STATE-FUNDED CARE AND SUPPORT USERS ARE THERE IN ENGLAND?

- Approximately 1.26 million people receive local authority-funded social care. Of these, approximately one million receive community-based care and 259,000 receive residential care¹⁶
- Roughly, two thirds of users are over 65, with physical disability or sensory impairment being the main cause of use¹⁷
- Over 1.2 million people receive Attendance Allowance in England¹⁸
- About 30,000 Disabled Facilities Grants are paid per annum¹⁹
- There are currently around 21,000 people receiving Independent Living Fund support²⁰
- Nearly 465,000 people receive Carer's Allowance²¹
- Around 45,000 disabled people receive housing support services, funded through the Supporting People programme²²

¹⁵ Supporting People client record data, CLG, April–December 2007.

¹⁶ *The state of social care in England 2005–06*, Commission for Social Care Inspection (CSCI), 2006.

¹⁷ *The state of social care in England 2005–06*, CSCI, 2006.

¹⁸ DWP estimates, 2007.

¹⁹ CLG estimates, 2007.

²⁰ DWP estimates, 2008.

²¹ DWP estimates, 2007.

²² CLG estimates, 2006/07.

3

Why do we need a new care and support system?





Society is going through huge changes. People are living longer than ever before, and the ratio of older people to younger people is increasing dramatically. We have different social values, and we expect more choice and control over all areas of our lives, including public services. Furthermore, the current system has not always been able to keep pace with rising expectations and the increasing need for care.

A radical rethink of the care and support system is needed to address the challenges and meet the opportunities of the 21st century. Otherwise, we risk the demands on families becoming too heavy and people going without the services they need to live their lives fully and stay well.

How are demographics changing?

We have an ageing population. In the next 20 years, the number of people over 85 in England will double and the number over 100 will quadruple.²³ Life expectancy has risen since 1981 by 6.1 years for men and nearly 4.5 years for women.²⁴ The ratio of people aged 65+ to those aged 20–64 years is projected to increase from 27% to 48% by 2050.²⁵

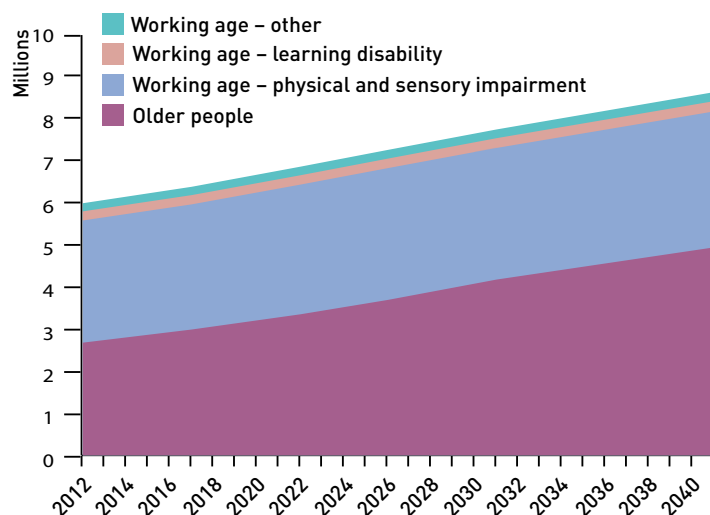
“ Over the past 30 years, disabled people have used ‘Social Model’ principles in our campaigns for comprehensive civil rights, anti-discrimination legislation and independent living. In only 30 years disabled people have gone from being passive recipients of welfare and charity, to citizens with powerful rights to non-discrimination and equality. ”

– Baroness Jane Campbell,
Chair of the Equality and Human Rights Commission’s
Disability Committee

²³ Government Actuary Department, 2007.

²⁴ DH, 2007.

²⁵ *Pensions: Challenges and Choices*, Pensions Commission, 2004, citing Government Actuary Department, 2002 projections.



Projected number of adults aged 18+ with a care need, England, 2007-40 (PSSRU projections)

Similarly, advances in medical knowledge and practice mean that disabled people can live longer and healthier lives, and more people with profound and multiple learning disabilities are living into adulthood. Research from the United States found that the average age at death of people with Down's syndrome increased from 25 years in 1983 to 49 in 1997.²⁶

Today's successes do not come without consequences for the future, and an ageing population will lead to a huge increase in demand for care and support services. Although living longer means a higher number of active years, as reflected in the changes being made to the pension age, it can also mean more years with support needs – the average man now spends nine years living with long-term limiting illness, compared with six years in 1981.²⁷ We expect over 1.7 million more people to have a need for care and support in 20 years' time.²⁸

How are expectations changing?

Society has experienced huge social changes in terms of what we value and want from public services. Many of the generation of people born after the Second World War and in their late 50s now – sometimes referred to as the 'baby boomer' generation – are known for demanding choice, control and change in all areas of their lives.

It is likely that the children of the baby boomers will in turn have even greater involvement in designing their own care and support. The care and support system needs to reflect these demands.

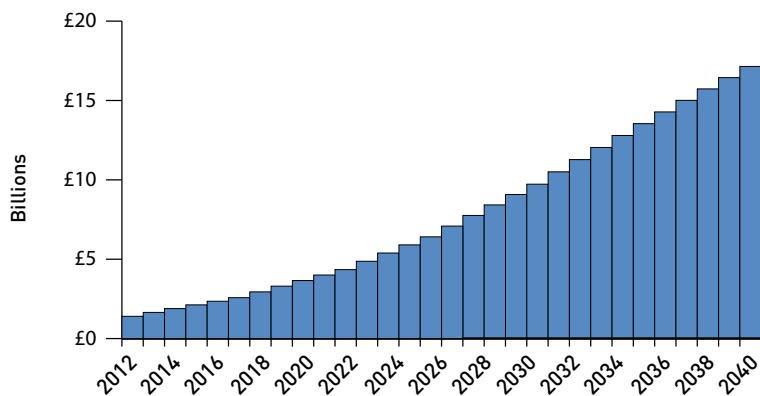
In addition, the Disabled People's Movement has driven massive changes in the way we think about equality and disabled people, and emphasised the need to ensure that people can take control of their own lives.

The new care and support system needs to reflect these demands. We need to build upon the current transformation programme, outlined in Chapter 4, to ensure that a new care and support system promotes independent living and gives people the personalised services that they want and expect.

What effect will demographic change and rising expectations have on care and support?

The existing system cannot cope with these pressures – it is not financially sustainable. In 20 years' time, the cost of disability benefits could increase by almost 50%²⁹ and we expect a £6 billion 'funding gap' in social care.³⁰

We need to find a fair and sustainable way to fund care and support in the future. If we don't, it is likely that



The funding gap in social care is projected to be £6 billion in 2027 using 2005 eligibility criteria (DH estimates based on PSSRU projections)

families, including dependent children within the family, will be under pressure to provide inappropriate levels of care, and in some cases people will go without support and become ill. If we fail to get to grip with these long-term issues we will fail to provide quality of life for potentially large groups of people, and consequently demand for NHS services will increase inappropriately.

Given the demands on resources, it will be essential that reform solutions can achieve maximum value for money. Already since 2004, this Government has achieved efficiency savings of £513 million in social care alone,³¹ and we want to build on these achievements. However, we will not be able to meet the rising costs just from cost-effectiveness savings,³² and we need to consider the options for bringing more funding into care and support.

The other main challenges

In the long term, the main challenges for care and support are demographic change and changing expectations, but designing a new system creates the opportunity to address other more immediate issues.

Lack of transparency in the system

There are several problems with the current system that make it less effective and more difficult for people to use. Currently, people are unclear about their responsibilities and those of government and there is little information about how best to save and prepare for the costs of care and support.³³ This can limit people's ability to choose between different options and control what happens to them.

²⁶ Centre for Disease Control and Prevention, Atlanta, USA, 2002.

²⁷ ONS Census 2001, 1981.

²⁸ PSSRU projections.

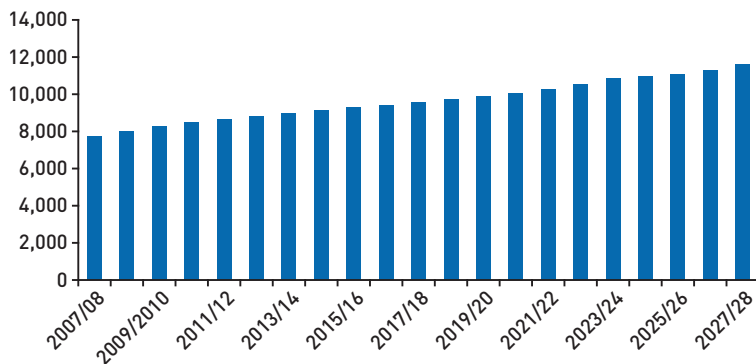
²⁹ DWP Forecasting Division, November 2007.

³⁰ DH estimates based on PSSRU projections, 2008.

³¹ DH Benefits Tracker, 2007.

³² *Expenditure on Social Care for Older People to 2026: Projected Financial Implications of the Wanless Report*, King's Fund, 2006.

³³ *The future of care funding: Time for a change*, Caring Choices, 2008.



The cost of disability benefits for the over-65s (£ million) in England, Scotland and Wales, from 2007 at 2007/08 prices (DWP Forecasting Division projections)

People also underestimate the likelihood that they will have a need for care or support in the future. About a third of all men and half of all women will, upon reaching the age of 65, need long-term care and support at some time as they age.³⁴ This is a significant proportion, meaning that, realistically, everybody should be planning for the future.

Because individuals have often not understood or expected the high costs of care, there are people with moderate and substantial needs who have to rely on their family for care and support or go without vital services. In the long term, these people are more likely to need more intensive care more quickly, which goes against the aim of supporting people to stay well for as long as possible. It may also place that family under significant or intolerable strain and lead to family breakdown.

Unfairness in the system

Similarly, people are unclear about the different roles that central and local government play in contributing to the costs of care and support, and about local variations in how much funding is provided for care and support. People do not understand the rules on when money from taxation is used to pay for care and support, which contributes to a sense of unfairness.³⁵

People find the current means testing system unfair. Although there will always be a need to make sure that the poorest people in society are supported, the current system does not provide an incentive for people to prepare for their care costs. One of the key questions in this debate is how to support those who are most in financial need at the same time as encouraging people to prepare for the costs of care while feeling supported in doing so.

The national guidelines on fair access to care services (FACS) define four levels of need for social care. Local authorities can then decide which levels will be eligible for care, but there is some allowance for local flexibility in interpretation, and different local authorities fund different levels. This means that some local authorities will fund people with moderate needs, whereas others will fund only those with critical needs.

Having different levels of eligibility criteria in different local authorities does not necessarily mean that people's needs aren't being met. There is a range of ways in which local authorities support people with low or moderate care needs, including housing or leisure programmes.

However, we want to ensure that this variation does not result in people being denied the care they need.



“ Most European baby boomers have witnessed the legalization of divorce and abortion, the arrival of the contraceptive pill, the boom in consumerism, and other changes that have come to be associated with, if not the result of, the baby boomer generation. ”

– Jim Ogg Young Foundation,
The Economic and Social Research Council
Social Science Week,
March 2006



³⁴ *Caring for the very old: Public and private solutions*, H Glennerster, 1996.

³⁵ *The future of care funding: Time for a change*, Caring Choices, 2008.

“ It’s important to look after each other – after all no one knows what could happen ... and we have a reputation for that in this country. ”

– service user, ‘People who use social care services’ understanding of social care and language used in relation to social care services: qualitative research’, Research Works Ltd and COI (2007)

We have therefore asked the Commission for Social Care Inspection (CSCI) to undertake a review of the criteria for FACS, their application by councils and their impact on people.

One of the key questions in this debate is how much we value local accountability. A more national system of eligibility would have huge implications on the degree to which services can respond to local needs. For there to be local flexibility in delivering services, there must inevitably be variation between localities.

How can the care and support system respond?

There have also been a number of changes in society that create opportunities that the new care and support system can take advantage of.

Changing attitudes

There has been a real change in attitudes to ageing and later life. Many people who

are retiring now are among the wealthiest pensioners in history,³⁶ and people look forward to an active retirement, having more time to spend with their family, care for grandchildren or meet personal aspirations such as travelling or other hobbies.

There has also been a change in attitude towards care and support in later life and who is responsible for undertaking or paying for that support. One survey found that only 28% of people now expect their children to look after them in older age.³⁷ A recent poll suggested that nearly three quarters of people are not worried about selling their home to pay for care, and only one in five children are worried about parents spending their inheritance.³⁸

There is a clear consensus about the need to establish clear and fair rules about what people are expected to contribute for others and what they are entitled to themselves. People do not want to live in

a country where people in difficult circumstances are left to go without support, and they are proud to live in a country where provision for people in need is seen as a part of everyday community life.³⁹

Economic change

There have been massive changes in the opportunities for accumulating wealth. Unemployment has fallen in every region of England, and record numbers of people are in work – over 2.8 million more people are in employment now than in 1997.⁴⁰

Between 1997 and 2007, annual house price inflation was between 5.6% and 17%.⁴¹ This has been particularly beneficial for older people. Overall, the generation of people retiring now are wealthier than any previous generation. In 2005, an average 70-year-old saw their household illiquid assets increase to around £215,000, from £88,000 a decade before.⁴² In 2004, people



“ It’s protective and supportive of your fellow man, I should know I paid taxes all my life – I suppose you could see it as protecting yourself if you’re particularly selfish! ”

– service user, ‘People who use social care services’ understanding of social care and language used in relation to social care services: qualitative research’, Research Works Ltd and COI (2007)

³⁶ *A national care fund for long term care*, International Longevity Centre, 2008.

³⁷ Survey by MORI on behalf of Independent Age, 2007.

³⁸ Survey by GfK NOP on behalf of the Local Government Association, 2008.

³⁹ ‘People who use social care services’ understanding of social care and language used in relation to social care services: qualitative research’, Research Works Ltd and COI (2007).

⁴⁰ *Transforming Britain’s labour market: Ten years of the new deal*, DWP, 2008.

⁴¹ Housing Live Tables, Table 502, ‘Annual house price inflation in the UK from 1970’, CLG, 2008.

⁴² *A National Care Fund for Long-Term Care*, International Longevity Centre, 2008.



WHAT IS TELECARE?

Telecare is the name given to a number of electronic technologies that can be provided in the home, including movement sensors, fall alarms and gas monitors.

Greater use of telecare can bring substantial benefits, including assisting people to remain in their own homes, reducing inappropriate admissions to hospitals, facilitating discharge from hospital and providing advance warning of deterioration in a person's condition.

The Audit Commission estimates that 'telecare supported home care could replace the need for hospital admission in 5 per cent to 15 per cent of patients aged 70 years and over. The average length of stay in hospital could be reduced by between 20 per cent and 60 per cent.' (Audit Commission, *Older People, Independence and Wellbeing*, 2004)

aged over 60 owned about £932 billion in equity on their homes.⁴³

That said, there are still groups of people who have been unable to access these opportunities and to increase their wealth. There are still pockets of the country where employment opportunities are scarce, and not everyone has been able to benefit from the growth in the housing market.

We need to consider what the impact of these changes is on the way we pay for care and support in the future.

Technological change

We have seen tremendous growth in technologies that can help people live safely at home. In the 1970s, stair lifts and bath rails were cutting-edge technology. Today, pressure pads can be fitted in the floor that trigger an alarm

if someone falls; sensors indicate when a fridge hasn't been opened for 24 hours; and motion detectors sound an alarm if someone hasn't moved for a long time.

More and more organisations are now providing new technologies that help people in their everyday lives. The number of providers in the care and support market has expanded rapidly in the last two decades, providing choice for people who want to buy a range of care products.

This technology potentially has a large impact on the number of people who can fulfil their wish of being able to stay in their own home, with the appropriate support. We need to encourage innovative ways of caring and supporting people, so that solutions to people's needs are more personalised.

What do these changes mean for care and support?

These demographic, social, technological and economic changes need to be taken into account when developing a care and support system for the 21st century. The vision for this system is explored further in Chapter 4.



“ I am a bit unsure really. You are never sure what you pay for and what is provided. ”

– member of the public, ‘General public’s understanding of social care and language used in relation to social care services: qualitative research’, Research Works Ltd and COI (2007)



⁴³ *Lifetime Homes, Lifetime Neighbourhoods: A National Strategy for Housing in an Ageing Society*, CLG, 2008, citing S Wilcox, 2007.

4

Our vision for a 21st-century care and support system





The Government wants a society where everyone is respected and included as an equal member of society, and where everyone has the opportunity to fulfil their potential. Disabled people and older people contribute a great deal to society, and should be treated with the dignity they deserve. Public services should enable people to feel empowered and supported in meeting their aspirations. Everyone should be able to understand their role in terms of what they contribute to society and what they are entitled to from government.

The vision for a new care and support system

In relation to care and support, the Government wants to help people to:⁴⁴

- participate in and contribute to society (eg to work, gain an education, or care for their family);
- stay well or get back to full health quickly after accidents or surgery (eg through accessing advice on diet or being taught to walk again after an accident);

“ What I want social care to provide is the means to live my life, as opposed to just surviving and relying on the routine services they provide. ”

– member of the public, ‘People who use social care services’ understanding of social care and language used in relation to social care services: qualitative research’, Research Works Ltd and COI (2007)

⁴⁴ *Putting People First: A shared vision and commitment to the transformation of adult social care*, HM Government, 2007.



“ Ultimately, every locality should seek to have a single community-based support system focused on the health and wellbeing of citizens. Binding together local government, primary care, community-based health provision, public health, social care and the wider issues of housing, employment benefits advice and education/training. ”

– *Putting People First*

- undertake practical tasks (eg to go shopping, work in the garden or do the cooking);
- undertake personal care (eg get out of bed and wash and dress themselves); and
- be safe at home (eg move around safely and be safe from abuse or neglect).

The key principles underpinning the vision

People have told us what they want from care and support, and the Government has used this to develop key principles that will underpin the vision for a new care and support system. People want an integrated system in every community that supports them to live independently as active citizens and ensures that they have maximum control over their own lives. The system should be of high quality, easy to access, fair, sustainable and efficient.

Promoting independence, choice and control for everyone who uses care and support services

Being independent means different things to different people. It can mean fulfilling your aspirations or deciding how and where you want to live. It can also mean being able to determine which care and support services you use and getting support to help you plan for your care needs.

Research shows that if people can get the right support at the right time, they can retain their independence for longer, and the need for intensive care later on can be prevented.⁴⁵ Therefore, there needs to be a focus on prevention so that people can avoid or delay the onset of more intensive needs. A new care system should help people to be independent for as long as possible by focusing on prevention and early intervention.

Services should be of high quality, easy to access, and personalised towards an individual's particular needs. If there is to be independence, choice and control, people need to have appropriate information to support their choices. This applies to people who care for family members as well as people who need care and support themselves.

Currently, accessing information on housing, finance, and care and support services can mean going to different places and talking to many different people. There are examples of good information provision – for example, the voluntary sector plays a key role in this area – but more still needs to be done to make sure that people can access information and advice more quickly and clearly.

“ Disabled people (including older disabled people), have challenged the meaning of ‘independence’. ‘Independent living’ does not mean doing things for yourself, or living on your own. Instead, it means:

- having choice and control over the assistance and/or equipment needed to go about your daily life;
- having equal access to housing, transport and mobility, health, employment and education and training opportunities. ”

– Independent Living Strategy, Office for Disability Issues (ODI), 2008

People also need what they receive to be personalised towards their particular needs. Some people may want services, others may need some extra financial assistance. Some people may need support and advocacy to develop a package which is best for them, others may simply want more information so that they can plan independently, or with their family. The care and support system should be flexible so that it can adapt to these different needs and wishes.



Ensure that everyone can receive the high-quality care and support they need, and that everyone gets some support from the Government, but that funding is targeted at those most in need

Any future system must ensure both that the poor are not disadvantaged, and that people who have worked hard and made sensible financial decisions throughout their lives are rewarded appropriately.

“ I don’t know where I would start if I needed some services tonight. ”

– member of the public, ‘People who use social care services’ understanding of social care and language used in relation to social care services: qualitative research’, Research Works Ltd and COI (2007)

⁴⁵ Partnerships for Older People Projects Interim Report, 2007.



A new system should be clear about how taxpayers' contributions are allocated to people in different circumstances. Everyone should know what type of support they are entitled to in terms of how much funding they will receive from the Government and what other services will be provided for free.

Taxpayers' money is not an unlimited resource. The Government believes that it should be targeted to help the people who have the greatest care and support needs while rewarding those who prepare for their own care needs.

But a new system should also help everyone to meet their care and support needs, regardless of the particular balance of contributions by the Government and the individual.

The system must be affordable for government, individuals and families in the long term

There are three main ways of funding care and support: money from people in need of care and support, contributions from their families, and money from all taxpayers via the Government.

Government funding can only come from the taxes paid predominantly by the working population. In a world where there are fewer people working and paying taxes, and more and more people are retired, using taxes to support the retired population can only go so far.

The Government will not shirk its financial responsibilities for care and support. Local government provides the main source of funding for social care, and overall government funding for local authorities increased by 39% in real terms

from 1997/98 to 2007/08;⁴⁶ funding for Attendance Allowance – a benefit paid to help cover the costs of disability in later life – has increased by 37% in real terms over the same period.⁴⁷

However, while this investment has alleviated short-term pressures and ensured improvements in service quality, this type of solution is unsustainable in the long term. The care and support system has to be able to meet the challenges of demographic change and rising expectations described in Chapter 3.

Recent research^{48,49} suggests that people are happy to accept responsibility for contributing towards the costs of care and support – their own or other people's – particularly in later life, if they are clear about what they are paying for, why they are paying for it and what the Government will pay for. There needs to be agreement about the balance

THE TRANSFORMATION PROGRAMME

The Government has already developed a transformation programme that will remain the key driver of change in the short to medium term. This includes:

- *Putting People First* (HM Government, 2007)

This is a cross-government commitment (in partnership with local government, the NHS and the social care sector) to the transformation of adult social care and sets out a shared vision of outcomes for the system, which stresses the need for improved information and advocacy, more control and personalisation, and ensuring that prevention becomes the norm.

- *Lifetime Homes, Lifetime Neighbourhoods* (CLG, 2008)

This is a cross-government strategy for housing and communities, connecting housing, health and care. We will build all homes to Lifetime Homes standards by 2013 within our new vision of Lifetime Neighbourhoods. For older people today, actions include better home adaptations, repairs, advice and information.

- *Independent Living Strategy* (ODI, 2008)

This is a five-year plan that seeks to realise the Government's aim that all disabled people (including older disabled people) should be able to live autonomous lives, and to have the same choice, freedom, dignity and control over their lives as non-disabled people.

- *Our NHS, Our Future: NHS Next Stage Review – interim report* (DH, 2007)

This sets out a process of unprecedented engagement so that patients, the public and all kinds of providers of care work together to shape pathways of care that are more personalised towards the patient.

- *Independence and Opportunity: Our Strategy for Supporting People* (CLG 2007)

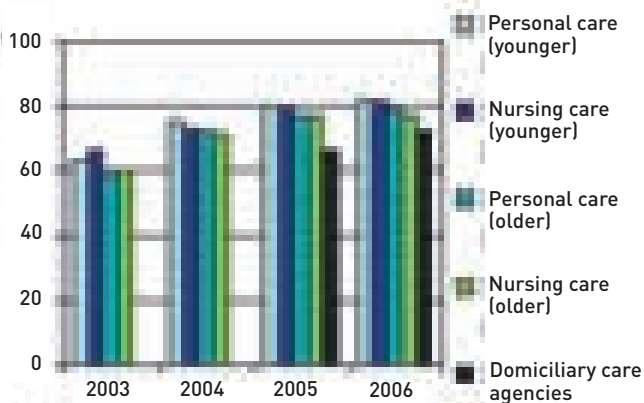
This strategy identifies how best to move forward with Supporting People. The strategy sets out the Government's aims to improve service user choice and control, keeping service users at the heart of the programme and of the local delivery of the service.

⁴⁶ Comprehensive Spending Review, HM Treasury, 2007.

⁴⁷ DLA/AA quarterly statistics, DWP, February 2007.

⁴⁸ *The future of care funding: Time for a change*, Caring Choices, 2008.

⁴⁹ Survey by GfK NOP on behalf of the Local Government Association, 2008.



Percentage of care that met national minimum standards⁵⁰

of responsibility between individuals, families and government.

How the Government is working towards this vision

The Government has developed an extensive transformation programme, and people are already benefiting from having real choice and control over the support they need. Service quality in social care has improved year on year, and many more disabled people are now able to access work compared with 10 years ago.

Better information

Improving information is a key part of the transformation programme. Without information, people cannot feel they have a proper say over their choices, or have control over their care.

The Government has already signalled in *Putting People*

First and Lifetime Homes, Lifetime Neighbourhoods its commitment to develop better information and advocacy for care and support.

Better quality

There have been year-on-year improvements in the quality of social care services.

Local Area Agreements are also allowing local agencies to work together and allocate funding to partners where this will have a greater impact on shared outcomes. This locally agreed approach will be supported by commissioning which incentivises and stimulates quality provision.

In April this year, the Government created a new agency, the Pension, Disability and Carers Service, to deliver a more integrated and seamless service for people claiming benefits. This merger of The Pension Service and the Disability and Carers Service will provide the platform for

higher-quality services that will be easier to navigate and will support future demographic changes.

More focus on prevention

Putting People First has also committed to a greater focus on prevention. The benefits of such an approach have already been demonstrated in ongoing Partnerships for Older People Projects.

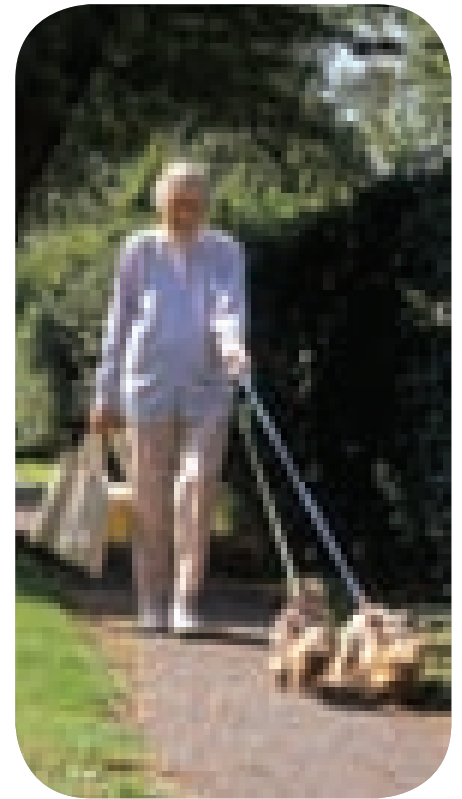
There is also evidence of the effectiveness of early intervention on housing adaptations. Older people's falls alone cost the NHS around three quarters of a billion pounds a year,⁵¹ as well as often precipitating a permanent move to a care home. However, by making minor home safety modifications, studies show that many of these falls can be prevented and there is growing evidence that adaptations can deliver economic benefits and better outcomes for older and disabled people.⁵²

PARTNERSHIPS FOR OLDER PEOPLE PROJECTS (POPPS) PILOTS

POPPs pilots are looking at many different ways of improving the health and wellbeing of older people by focusing on early intervention and prevention. The pilots are delivering a diverse range of interventions and service delivery models, including:

- improving access to low-level care services for older people such as help with daily living skills (eg shopping, gardening and housing repairs) but also improving access to specialist services for older people with chronic or complex conditions such as dementia, long-term conditions etc;
- proactive case-finding to identify older people most at risk of hospitalisation and of losing their independence;
- using technology such as telecare to support older people to live safely and securely at home; and
- providing new services to promote social inclusion for older people and increased participation in local communities facilitated by improved access to universal services such as leisure, transport, education and employment opportunities.

These pilots are being fully evaluated, but early indications suggest that they are having a significant effect on reducing avoidable emergency admissions to hospital and have the potential to generate savings for the NHS. Older people feel more integrated into the community and their needs are incorporated more effectively into the wider priorities of the local area.



⁵⁰ *The State of Social Care in England 2005–06*, CSCI, 2006.

⁵¹ *Lifetime Homes, Lifetime Neighbourhoods*, CLG, 2008, citing Parrot, 2000 (actual figure £726 million).

⁵² *Better Outcomes, Lower Costs*, F Heywood and L Turner, Office for Disability Issues, 2007.

WHAT IS A PERSONAL BUDGET?

A personal budget is where a notional cash pot is established for someone with care and support needs and the person controls how the money is spent on services. *Putting People First* made a commitment to use this model for all adults who are eligible for social care. Currently, we are also piloting individual budgets – an approach that includes social care funding with other housing and employment support in the same pot.

More personalised care and support

The lives of some have already been transformed by having a combined care package and choice and control over the support they need. Personal budgets allow people to play an active part in shaping their care package so that they can receive the type of care and support that is most valuable to them.

Personal budgets give people a more integrated service with a clear contact for advice on a number of types of support. Many local authorities are working hard to make personal budgets available to people in their area. However, this vision is still some way from being a reality for all people, and the Government is committed to extending such self-determination for everyone. This will be at the heart of a new care and support system.

Person-centred planning and self-directed support will become mainstream, with a greater emphasis on self-assessment, and everyone who is eligible for social care will receive their support through flexible personal budgets.

The NHS Next Stage Review is also challenging frontline staff to review the services they provide and organise them around the needs of patients, building on evidence of what ways of organising services works best.

Question for debate

As well as addressing the financial challenges which demographic change and rising expectations put on the care and support system, this debate is also about hearing the public's views on how we can go further to make sure we make this vision of independence, choice and control a reality.



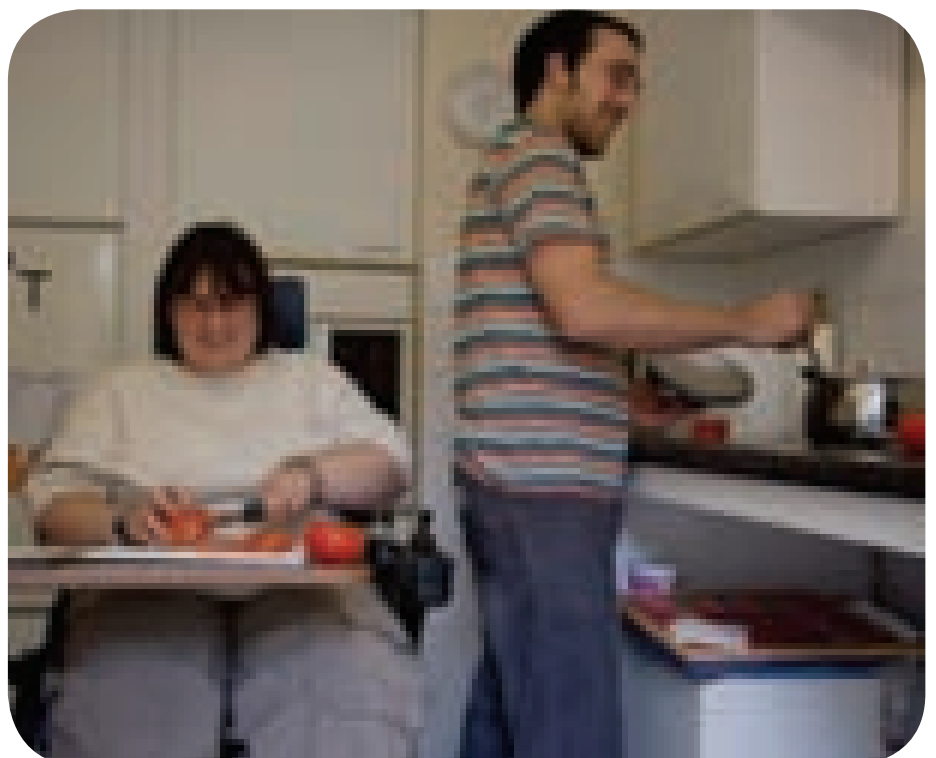
JAY'S STORY

An individual budget enables Jay to live on her own in her new flat. She is proud of her new home and likes to do all the chores herself. Jay has help from staff with cooking and budgeting and she has learned new skills like ironing. Jay has learned how to travel independently into town. She regularly visits her parents and enjoys playing bingo. Jay values her independence and her new home has improved her quality of life. However, being busy is very important to Jay, so she is trying to get a job now.

– story based on a service user in the Coventry City Council Individual Budget pilot

This debate will build on the current transformation programme set out in *Putting People First*, and is focused on developing long-term solutions for care and support that deliver what people want well into the future.

What more do we need to do to ensure that this vision of independence, choice and control becomes a reality?



5

The balance of responsibility



Care and support is currently paid for by families, individuals and the Government. The demographic and social changes outlined in Chapter 3 highlight a number of fundamental questions about the balance of responsibility between these three groups. There needs to be an open and honest debate about what the appropriate balance of responsibility is if England is to achieve a care and support system that fulfils the vision outlined in Chapter 4.

Recent research^{53,54} suggests that people are happy to accept responsibility for contributing towards the costs of care and support – whether their own or other people’s – particularly later in life, as long as they are clear about what they are paying for, and why, and what the Government will pay for.

The long-term challenge is to create a new settlement between individuals, families and the Government that will be sustainable in the future.

Who pays for care and support at the moment?

There are three main sources of contributions to care and support.

The family

Families often contribute towards the costs of care and support for a loved one. The Office of Fair Trading’s report into care homes for older people in the UK found that a third of people receiving local authority funding also relied on top-ups from third parties.⁵⁵ Although there is limited evidence, it is widely agreed that families make significant financial contributions to help their loved ones, in all care settings.

Family and friends also provide care and support themselves, and are a vital part of the care and support system. The 2001 Census suggests that there are 5.2 million carers in England and Wales – one in 10 of the population.



⁵³ Survey by GfK NOP on behalf of the Local Government Association, 2008.

⁵⁴ *The future of care funding: Time for a change*, Caring Choices, 2008.

⁵⁵ *Care Homes for Older People in the UK*, Office of Fair Trading, 2005.



HOW IS A PERSON'S HOME TAKEN INTO ACCOUNT?

Under the current social care system, if a person requires care in their own home, the value of their home is not taken into account when assessment is made of whether they are able to pay for this care themselves or not.

If a person needs to move into a care home, then unless there is a spouse, partner or other qualifying person who continues to live in that home, the value of that home will be taken into account. However, the Government has introduced deferred payments so that people who need residential care can avoid having to sell their house against their wishes.

Caring can be an immensely rewarding activity, and many people say they do not want to give up caring for their loved ones. However, without support, carers often find they have to give up other activities in order to provide care and support to their loved one. We are considering, through the Carers' Strategy, how much and what kind of support carers need themselves, to enable them to maintain a balance between the provision of care and a healthy life outside caring.

The individual

Many people with care and support needs have historically paid for their own care and support, because they feel able to support themselves sufficiently, because they have decided to go to a private agency, or because their local authority has assessed their finances and has decided that they are able to contribute financially towards their care.

They may also get services provided by the voluntary sector.

Many people can face very high costs if they need care, because they often do not understand how the current system operates and so do not plan ahead for their care. People are used to saving for the future in terms of pensions and making sure they have an inheritance to pass on to their children, but often they are not aware of the fact that they need to cover the costs of their care as well.

Relying on people to cover their own costs in this way, without any protection or preparation, can have a massive effect on people's income and quality of life. If people were to save for these costs earlier, then they would be able to manage these potentially high costs of care. If people were to prepare for costs through insurance, they would protect themselves against the risk of high costs.

However, for those who do look to insure themselves against this risk, there are currently few products on offer.

One of the key principles of the new care and support system is that it is affordable to the individual, as well as to the family and the Government. We therefore need to look at what role the Government should play in supporting people's financial contributions. Should the Government encourage the private insurance market? Should the Government create a compulsory form of saving for people? These are all questions that need to be addressed.

The Government

Some aspects of care and support, such as disability benefits and some elements of housing support services for older people and disabled people, are provided directly by the state and funded by taxation.

HOW MUCH DOES THE GOVERNMENT SPEND ON CARE AND SUPPORT?

Total state expenditure on care and support in England in 2006/07 was an estimated £20 billion. This is equivalent to over 2% of GDP⁵⁶ and 4% of total government expenditure.⁵⁷ This expenditure includes:

- **social care** – £13 billion state expenditure in England, comprising £7 billion on over-65s and £6 billion on people aged 16–64⁵⁸
- **disability-related benefits** – £3.4 billion expenditure in England on Attendance Allowance⁵⁹
- **carer benefits** – £1 billion expenditure in England on Carer's Allowance⁶⁰
- **other support** – approximately £2 billion expenditure in England on the main 'other' care and support funding streams (£1.6 billion on Supporting People, including £300 million spent on over-65s, £200 million on the Independent Living Fund and £121 million on Disabled Facilities Grants).⁶¹

The Government, through the local authorities, uses national taxation and money raised through council tax to pay for social care services for people with low incomes and assets.

In practice this means around 68% of people in care homes⁶² are funded (partly or in full) by taxation, and 73% of expenditure on care and support services at home⁶³ is also funded by taxation.

Having care and support funded through taxation has the advantage that by sharing the costs among all taxpayers, fewer people are faced with the burden of having to fund their total care and support costs. However, at the moment, the ratio of working people to retired people is dropping.

How should we pay for care and support in the future?

We need to find a way to pay for care and support that will be sustainable in the future as demand for services increases.

We think the principle of sharing costs between the family, the individual and government is right. However, we must avoid overstressing families and individuals, and believe that it is worth exploring how every adult could contribute in a way that insures them against very high costs of care and support.

We want to examine the potential sources of funding with the public and stakeholders, and debate the appropriate levels of contributions from each source.

There are three potential sources of contributions to care and support.

The family

Traditionally, care and support has been provided as part of highly valued family relationships⁶⁴ and brings fulfilment to the carer.⁶⁵

However, we know that providing excessive levels of care can have a negative

⁵⁶ Blue Book, ONS, 2007.

⁵⁷ Total Managed Expenditure, National Statistics budgeting tables, ONS, 2008.

⁵⁸ Expenditure for England only, given in *Personal social services expenditure and unit costs 2006/07*, Information Centre for Health and Social Care, 2008.

⁵⁹ DWP estimates.

⁶⁰ DWP estimates.

⁶¹ DWP and CLG estimates.

⁶² *Care of Elderly People – UK Market Report*, Laing and Buisson, 2005.

⁶³ *Domiciliary Care – UK Market Report*, Laing and Buisson, 2007.

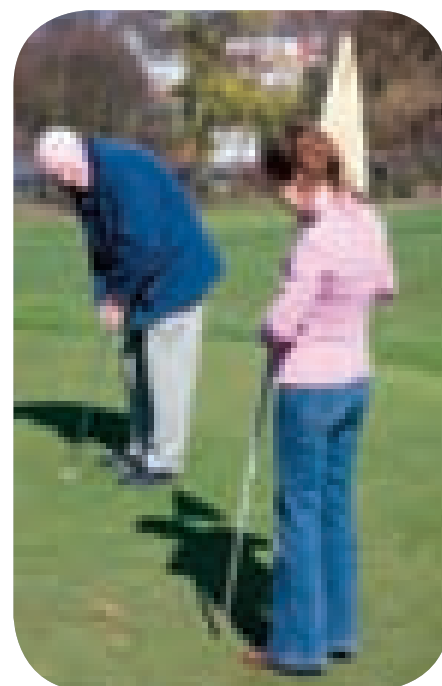
⁶⁴ What things are important in people's lives? A Bowling, *Social Science and Medicine*, 41(10), 1995.

⁶⁵ Development of the carer experience scale for economic evaluation (presentation), H Al Janabi, 2007.

THE COST OF RESIDENTIAL CARE

- Around a quarter of us will need residential or nursing care at some point in our lives.
- Residential care costs £23,000 per year on average (including nursing care and boarding and lodging costs).
- The average length of stay in a care home is about two years for a man and three years for a woman, although some will remain in a care home for much longer and therefore the costs would be significantly higher.

(Bebbington et al, *Lifetime risk of entering residential or nursing home care in England*, PSSRU, 1997)



impact on the carer's health, and can prevent opportunities to work⁶⁶ or to be promoted at work.⁶⁷ It must also be remembered that caring can impact on the wider family, and that some carers are young carers, who might be particularly affected by excessive levels of care.

We are considering through the Carers' Strategy how much and what kind of support carers themselves need to enable them to maintain a balance between the provision of care and a healthy life outside caring.

How much informal care is it appropriate for families and friends to undertake? How do we take account of the fact that different families and friends will have different capacities to provide support and different competing demands on their time?

The individual

Overall, older people are wealthier now than ever before. An average 70-year-old in 2005 saw their household illiquid assets increase to around £215,000, from £88,000 a decade before.⁶⁸

However, this conceals stark inequalities among older people: 32% of older people do not own their own home.⁶⁹ Many younger people who need care and support services also have relatively low incomes and savings because of the lack of opportunity to work and save.

Where people cannot afford their care, government will always have a responsibility to step in and ensure that people get the support they need to live their lives.

To have the full range of choices available to them,

people need to have made appropriate financial provision for care and support. Older people could contribute in various ways, either through pensions, private savings or housing equity, or through private insurance, which also covers them against the risk of potentially high costs, and the Government can do a number of different things to facilitate this, ranging from improving information to help people anticipate future costs, to encouraging the growth of private insurance, or even to making insurance for care and support compulsory.

When is it appropriate for people with care and support needs to contribute to the costs, and what are acceptable levels of contribution? What role do people want the Government to play in supporting people to save for these contributions?

When Japan reformed its care and support system, it aimed to promote formal, organised services so that carers, particularly daughters, did not shoulder so much responsibility for care. In contrast, when Germany reformed its system it offered a cash payment that people could take, to support their informal carers instead of using formal services. How much care do we think it is appropriate to expect family and friends to undertake?

In the US, many states are encouraging people to take out private long-term care insurance. This protects people from potentially high care costs, and also improves the choices they have and allows them to plan for the future. However, relatively few people in the US have decided to purchase such insurance.



The Government

If every adult makes a contribution towards care and support, then the risk of high costs hitting each household are reduced. A fundamental question which needs to be addressed when considering the balance of responsibility is about how we want to spread the risk of the costs of care. The advantage of paying for care and support centrally is that it spreads this risk.

However, there are questions about what constitutes an appropriate level of contribution from every adult. The number of working age people compared with the number of people over 65 has already decreased from 5.7:1 in 1948 to 3.7:1 in 2006.⁷⁰

In addition, many younger people are already struggling to meet their own aspirations.⁷¹

We need to consider the level of contributions towards care and support that could be made by every adult in society.

Question for debate

We want to examine the potential sources of funding with the public and stakeholders, and debate the appropriate levels of contributions and balance of contributions from each source. We also want to examine the different ways in which government could help people to insure against the costs of care and support, and what role we see the Government playing in terms of bearing the risk of high costs of care.

What should the balance of responsibility be between the family, the individual and the Government?

⁶⁶ Family Resources Survey 2005/2006, DWP, 2007.

⁶⁷ The opportunity costs of informal care: does gender matter?, F Carmicheal and S A Charles, *Journal of Health Economics*, 22(5), 2003.

⁶⁸ *A National Care Fund for Long-Term Care*, International Longevity Centre, 2008.

⁶⁹ *Lifetime Homes, Lifetime Neighbourhoods: A National Strategy for Housing in an Ageing Society*, CLG, 2008.

⁷⁰ *Pensions: Challenges and Choices*, Pensions Commission, 2004, citing official population estimates for 1948 and 2006. Working age people are defined as those aged between 20 and 64 years.

⁷¹ *A National Care Fund for Long-Term Care*, International Longevity Centre, 2008.

6

The different ways of allocating government funding





The development of any new system will mean making difficult choices about how to balance different priorities. There are no right answers, and different countries have different approaches.

The Government wants to work with the public and a wide range of experts to debate issues arising from the key principles for a new system. They will use this information to develop and assess potential solutions.

What are the trade-offs?

People will receive different levels of support depending on their level of care need. However, there are other ways of targeting resources and we want to establish clear, fair rules about who is eligible for financial help from taxation, based on shared values.

Should there be one system for everyone or different systems depending on the type of need for care and support that somebody has?

The Government will avoid any unjustifiable or unfair discrimination based on age. At this point, we wish to explore whether it is fair or not to protect financial support for people who have been disabled at a younger age, and expect people who have more predictable care needs in older age to have made some provision to continue to look after themselves in later life.

Such a policy would have to be based upon firm evidence that people who are disabled at a young age face several additional challenges compared with people who need help only in older age. We already have evidence that younger disabled adults face higher care costs for longer periods of time and have less opportunity to save or prepare for the costs of their care.

Currently, people receive benefits and certain housing support based on need, and a person's wealth is not taken into account. In social care, people undergo financial means tests so that money is targeted towards those least able to pay and with the highest needs. Means testing can be perceived as penalising people who have worked hard and made sensible financial decisions at earlier points in their life. We want people to identify what they think the right balance is.



We could either have the same system for everybody, regardless of the type of care and support need they have, or we could ask people to take more responsibility to pay for care and support in older age.

We need to think about to what degree we believe it is right to distinguish between different kinds of care and support needs.

Which is more important to us: local flexibility or national consistency?

A key component within the current system is the role and work of local authorities. Local authorities work with local people to find out their priorities for local services and spend money accordingly. Local authorities also raise a lot of the funds for social care through council tax. As a consequence, local services and offers of financial support can differ for people with the same types of needs

in different areas. Some stakeholders and members of the public are dissatisfied with this system, and have campaigned for greater national consistency of the type of services offered and who is entitled to them. If there were greater national consistency, local people could lose their right to have their say about how locally raised money is spent on care.

The issue about national consistency is also linked to the question of local funding and the use of local taxation (the council tax) to fund social care. It could be argued that local taxation should no longer be used to fund social care, but this would in turn have wider implications for local government finance.

Should there be an equal system for everybody, regardless of where they live, or should local people be able to decide local priorities for

care and support? Should funds be raised locally and spent locally, or should there be a more national system?

What should the balance be between targeting government resources at those who are least able to pay and having a system that supports those who plan and save?

Means testing can penalise people who have worked hard and made sensible financial decisions at earlier points in their life. However, with no means testing, support is poorly targeted at those who need it most.

There will always be a need to make sure that the poorest people in society are supported, but we need to consider to what degree we want to target care and support based on an individual's financial means.



At one extreme, government money could be purely targeted towards those people with the least financial means. At the other extreme, everybody could get exactly the same level of care and support, regardless of their wealth. There are clearly many options between these two extremes, and we need to think about which is best for our society.

Question for debate

We have demonstrated that there are a number of issues which require careful thought and to which there is no easy answer.

There are pros and cons to each side of every trade-off. We want to work with the public and stakeholders to establish how we want to resolve these issues, before working to develop a new care and support system for the future.

Should the system be the same for everybody or should we consider varying the way we allocate government funding according to certain principles?

7

How we will be engaging everyone in the debate





Awareness of the issues surrounding the long-term future of care and support is already increasing, and the time is right to develop the solutions that will secure the future of care and support.

The Government welcomes the progress made in the last few years, aided by key contributions from organisations such as the King's Fund,⁷² the Joseph Rowntree Foundation,⁷³ the Caring Choices coalition⁷⁴ and others. In addition, the Government has already led a public debate about the implications for pensions provision of the ageing population, and is implementing fundamental changes to the pensions system to meet these challenges. Earlier this year, the BBC devoted a month to the challenge of long-term care.

Why should you get involved?

A new care and support system will affect every adult in the country, whether they use the system themselves, are taxpayers, or have family members who need support. The purpose of this debate is to ensure that everyone can have their say, so the people who will be affected by the change are able to inform the change.

The Government will use this information to develop and assess possible solutions to create a better system. People will have the opportunity to debate and comment again when the options are set out in a Green Paper.

The engagement process is also an opportunity to develop a partnership approach between government and stakeholders so that we continue to find solutions to the challenges we face together.

⁷² *Securing good care for older people: taking a long term view* (Wanless social care review), King's Fund, 2006.

⁷³ *Paying for long-term care: Moving forward*, Joseph Rowntree Foundation, 2006.

⁷⁴ *The future of care funding: Time for a change*, Caring Choices, 2008.



How will the Government be engaging with people?

All information about the debate can be found at www.careandsupport.direct.gov.uk. This site explains the questions that people will be asked and provides regular updates about how the debate is progressing. Alternatively, people can email careandsupport@dh.gsi.gov.uk or write to the Care and Support Team, Room 543, Richmond House, 79 Whitehall, London SW1A 2NS.

Over the next six months, the Government will be running a series of public events where the key issues will be discussed in detail. These include a stakeholder event in every government region and a number of citizen events. At the end of the six months, there will be a final event bringing stakeholders and

citizens together to provide a further opportunity for a broad spectrum of views to be heard.

We are using media channels and working in partnership with stakeholders at a national and regional level to encourage as many people as possible to take part.

Care and support affects groups of people whose views may not readily be heard via these routes. Additional research will be undertaken to ensure that they have the opportunity to give their views.

With acknowledgements to:

Libby Welsh/Alamy, Ian Shaw/Alamy, Ariel Skelley/
Alamy, John Birdsall, Janine Wiedel Photography/
Photofusion – front cover

Paula Solloway/Alamy – p7

John Birdsall – p13, p15, p17, p23, p35, p36, p46, p47

Janine Wiedel Photography/Alamy – p14, p21

Stewart Cohen & Pam Ostraw/Alamy – p27

Paula Baldesare/Alamy – p29

Lauren Shear/Science Photolibrary – p31

Libby Welsh/Photofusion – p39

Urike Preuss/Photofusion – p40

Eric Farrelly/Alamy – p43

Ron Chapple/Alamy – p44

Angela Hampton/Alamy – p49

Joanne O'Brien/Photofusion – p53

And special thanks to DWP, NHS and ODI

© Crown copyright 2008
286897 2p 3k June 08 (CWP) 288429
Produced by COI and the Department of Health

If you require further copies of this title visit
www.orderline.dh.gov.uk and quote:

286897/*The case for change – Why England needs
a new care and support system* or write to:

DH Publications Orderline
PO Box 777
London SE1 6XH
Email: dh@prolog.uk.com

Tel: 08701 555 455
Fax: 01623 724 524
Textphone: 08700 102 870 (8am to 6pm, Monday to Friday)

www.dh.gov.uk/publications



50% recycled
This is printed on
50% recycled paper