

**Equality and
Human Rights
Commission**

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From safety net to springboard

**A new approach to care and support for
all based on equality and human rights**

Contents

Foreword	2
Executive summary	4
1. Introduction	9
2. From safety net to springboard – the Commission’s vision, proposals and actions	19
3. Capabilities, co-production and cost-benefits – a fresh approach to care and support	40
Appendix 1 – Summary of proposals and actions	51
Appendix 2 – List of those consulted	58

Foreword

Where, after all, do universal human rights begin? In small places, close to home...

Eleanor Roosevelt

A decent quality of life where people are able to live with dignity and respect is a basic human right. For millions today and many millions more in the future, only effective care and support has the power to translate that right from an aspiration into an everyday reality.

This fact presents us with a clear choice about our future options. We already have evidence of how a reformed approach to care and support has the potential to act as a springboard – widening opportunity, enhancing economic prosperity and promoting the well-being of individuals, families and the country as a whole. By deepening and accelerating reform and widening its reach, care and support can play a greater role in helping Britain prosper economically and help us all thrive and grow in our ageing society.

Without such reform, our approach to care and support will remain largely a safety net. The resulting ‘care crunch’ of inadequate provision and missed opportunities is likely to severely undermine Britain’s future social and economic success – exacerbating inequalities, threatening human rights and leading to tensions between generations and between social groups.

We believe the recommendations in this report represent a form of practical idealism: a contribution to building the ‘good society’, based on a fair, workable and affordable infrastructure that commands the support of everyone. The Commission will play an active role in seeking to turn our vision into reality. Addressing human rights and equality in these ‘small places, close to home’ is central to building the fairer society we seek.

**Nicola Brewer, Chief Executive,
and Baroness Jane Campbell, Commissioner,
Equality and Human Rights Commission**

February 2009

Executive summary

Introduction

The Equality and Human Rights Commission is the independent advocate for equality and human rights in Britain, set up by an Act of Parliament and launched in October 2007. We aim to promote and protect human rights, reduce inequality, eliminate discrimination and strengthen good relations between people.

This report concerns the future of care and support¹ and the role it can play in promoting human rights, equality and good relations. It has been published in order to influence thinking on the future of care and support in England and it sets out the actions the Commission itself will take to help make its vision for care and support a reality. The Government plans to publish its proposals in a Green Paper on care and support in spring 2009.

The report draws on a literature review and consultation with stakeholders.² We have examined evidence concerning the current performance of care and support in protecting and promoting human rights and equality and have assessed the implications of predicted social and economic developments and challenges in coming decades. This includes the economy, our ageing population and changing social expectations. Our understanding of what it is to be a disabled or older person, our perception of the role and position of women in society are all changing rapidly. There is also much new thinking concerning the relationship between citizens and public services and our approach to promoting human rights and equality.

The Commission's role is not to oversee the social care system itself. That role is to be carried out by the Care Quality Commission (CQC) which replaces the Commission for Social Care Inspection, the Healthcare Commission and the Mental Health Act Commission in April this year. We will aim to work alongside the CQC to ensure that our collective equality and human rights remit is effectively discharged. This report sets out a detailed programme of work through which we will engage our partners as well as making recommendations for reform to achieve the role we believe care and support can play in promoting equality and human rights. We do not make detailed recommendations about future funding – that is predominantly the role of government – but we do highlight the key principles that in our view should affect future decisions and strategic choices about long-term investment in social care.

1 Care and support helps people to be independent, active and healthy throughout their lives. It is about helping people to do day-to-day things like living in their home, working, cooking, shopping and caring for their family. The care and support system includes a wide range of services such as meals on wheels, home adaptations, housing support services, support to help disabled people live independently, benefits for disabled people, occupational therapy, day care, care homes and support for carers.

www.careandsupport.direct.gov.uk/background/

2 The consultation was carried out by Cordis Bright Consultants. Details of the methodology used can be found in the introduction, and a list of those consulted is included in the Appendix. The Consultation report can be found at

www.equalityhumanrights.com/careandsupport.

From safety net to springboard

The challenges are profound and far-reaching. The Commission's view is that without fundamentally re-designing care and support for the future, there is a grave danger that we will undermine individual opportunity, the strength of family life and our future national prosperity. It is our belief that the Government must consider modernising the basic approach to care and support to achieve three key aims: promote the capabilities and autonomy of each individual regardless of means; encourage co-production and partnership to create a sustainable infrastructure of care and support; and identify and communicate the cost-benefits of reform to society as a whole. These ideas are explained in detail in Chapter 3 of the report.

In doing so, care and support has the potential to become a springboard, not simply a safety net, focused on helping people to maximise control over their own lives, to make social and economic contributions and to stay safe and well. The benefits of this approach will accrue to society as a whole.

Care and support should be everyone's concern. It should engage individuals, families and communities, business and employers, planners, house builders and all providers of public services, from local authorities to schools, from arts and culture to sport. Success relies as much on nurturing reliable and sustainable networks of informal support as it does on reforming public support services. We all have a contribution to make and a benefit to reap.

The Commission believes our proposals will help optimise the role of care and support in promoting economic prosperity and growth in the future, including providing opportunities for job creation and supporting more individuals to enter or remain in paid employment, including in old age. Effective care and support could also help us to avoid the negative social and economic costs associated with poverty, benefit dependency and long-term unemployment, ill-health, family breakdown, abuse and institutionalisation.

The Commission in accordance with its statutory remit has developed a series of proposals and actions under seven broad principles. We want to engage and work with our stakeholders on these proposals, including the Government, local authorities and non-governmental organisations with a commitment to equality and human rights. The principles are:

1. Care and support based on clear outcomes and founded on human rights and equality.
2. Access to publicly funded care and support based on clear, fair and consistent criteria.
3. Individuals and families in control of their care and support.
4. The right balance between safety and risk to promote choice and independence.
5. Local strategic partnerships that play a central role in developing and maintaining local care and support.

6. Funding that balances affordability and sustainability with fairness.
7. Equality and human rights law and practice re-calibrated to respond to our ageing society.

We make a number of proposals in this report that we believe ought to be considered in the light of the Government's forthcoming Green Paper on the future of social care. The Commission believes the following to be particular priorities:

- Action to instil an equality and human rights culture across care and support, including a national rights-focused framework of outcomes and action by the Equality and Human Rights Commission in partnership with the Care Quality Commission to ensure compliance with the law.
- Identifying and rooting out ageist policy and practice – for example in inspection, charging policies or the exclusion of older people from schemes which support independent living.
- Ensuring everyone requiring care and support is empowered by information, advice and, for those who require it, independent advocacy.
- Building a detailed and robust evidence base concerning the cost-benefits of reform and of investment targeted to preventing avoidable ill-health and dependency.

The Commission's actions

The Commission itself can also make a major contribution to progress in how we focus our resources and powers in pursuit of improved equality and human rights outcomes. Our strategic approach is to work with others, particularly statutory public bodies, to extend our reach and make maximum use of our powers to change policy and practice in social care, improving key outcomes for people requiring care and support and their families. In summary the Commission will:

- Work with the Government, the statutory sector and others to develop a national outcomes framework for care and support founded upon equality and human rights principles.
- Work closely with the Care Quality Commission to build upon the innovative user-led and human rights approaches developed by its legacy Commissions, to monitor, inspect and ensure compliance across the social care sector including enforcement where necessary.
- Promote compliance with equality and human rights law, including action to empower local organisations and individuals to understand and to use the law in order to seek redress and to ensure that they have greater power and control over their lives.
- Collate and disseminate good practice concerning the promotion of human rights and equality through care and support.
- Enforce the public sector equality duties and intervene in human rights cases relating to care and support.

- Research and gather evidence to inform future activity, including research into the prevalence and nature of ageism in care and support policy and practice.
- Grant funding for pathway projects to evaluate the benefits of independent advocacy and to develop informal networks of support in local communities.
- Work with partners to commission credible and robust cost benefit analysis concerning the benefits of reform to inform the public debate about the future of social care.
- Carry out further analysis and consultation to develop the proposals in this paper and to develop detailed proposals for implementation.
- Report on progress via our own annual report and triennial ‘state of the nation report’ as well as via other publications.

Details of the Commission’s planned actions and activities are included alongside our proposals.

1. Introduction

The Equality and Human Rights Commission is the independent advocate for equality and human rights in Britain. We aim to eliminate discrimination, reduce inequality, promote and protect human rights and strengthen good relations between people.

This report concerns the future of care and support and the role it can play in promoting human rights, equality and good relations. It has been published in order to influence thinking on the future of care and support in England. Similar work, which has influenced this report, is on-going in Scotland and Wales. The Government is expected to publish its own proposals in a Green Paper in spring 2009.

Care and support – an issue for everyone

In 2007-08, 1.75 million people of working age and older people used care and support services according to the Commission for Social Care Inspection (CSCI). Local councils spent £16.5 billion in 2006 if charges are included. Of this expenditure, 59 per cent was on services for older people and 22 per cent on adults aged 18-64 with learning difficulties. This represented a 1.2 per cent real terms increase in expenditure compared to annual rises in 2004-05 and 2005-06 of 4 per cent and 8 per cent respectively.

Private expenditure on care and support is considerable – estimated to be £5.9 billion in charges and top up expenditure alone.³ Skills for Care has estimated the social care workforce in England in 2007-08 to be 1.5 million workers.

The number of people aged 65 and over with care and support needs is estimated to rise by 87 per cent between 2001 and 2051 as our society ages.⁴ The number of people over 60 with learning disabilities will increase by 37 per cent in the 20 years between 2001 and 2021.

The 2001 national census estimated there are 5.2 million partners, relatives or friends providing support for people without payment, of which 1.7 million care for 20 hours or more a week. By 2041, nearly 1.3 million disabled older people are projected to be requiring informal care – an increase of around 90 per cent.⁵

Care and support is a dynamic issue which is set to touch everyone's lives at some point and potentially at multiple stages throughout life – whether it concerns our grandparents, our parents, our partners, our colleagues or the people we manage at work, our neighbours, our children or ourselves.

It has a direct bearing on the choices we are able to make and the opportunities we have to lead the lives we wish to lead. It can determine our health and well-being and the quality of family relationships. It will have an increasing economic influence, both in terms of levels of private and public expenditure required to

3 CSCI (2009) The State of Social Care 2007-08.

4 Hancock et al (2007).

10 5 Pickard et al (2008a).

sustain care and support and on the ability of individuals – those requiring support or those providing it informally – to participate in paid employment.

Crucially, how we approach care and support will be an increasingly important factor in whether people enjoy their most fundamental human rights – a decent quality of life, lived with dignity and respect. It will also have a major role to play in future patterns of inequality and levels of social cohesion, especially concerning the relations between different generations.

The role of care and support in promoting human rights, equality and good relations

The promotion and enforcement of equality, human rights and good relations encapsulates the three fundamental duties of the Commission, as set out in the Equality Act 2006.⁶

Promoting and protecting human rights

All public authorities have duties to promote human rights.⁷ At its most basic, care and support offers protection of people’s right to life by ensuring their most fundamental physiological needs, such as eating, taking medication, getting up in the morning and going to bed at night are met. But for those who require it, and those with whom they share their lives, the availability and organisation of care and support also determines whether they enjoy a number of other important human rights including:

Article 3: The right to live free from inhuman and degrading treatment – for example to intervene to prevent an older person from being subject to abuse, exploitation or violence by those supposed to care for them or others.

Article 4: The right to liberty and security – for example to support a person’s right to choose to stay living in their own home rather than move into an institution if that is what the person wishes, or to move from one local authority area to another whilst maintaining their package of care and support.

Article 8: The right to respect for privacy and family life – for example to provide support to enable people to maintain ordinary family relationships, such as supporting disabled parents and therefore protecting children from becoming their primary carers.

Article 9: The right to freedom of thought, conscience and religion – for example to support people with religious observance such as prayer, diet or the opportunity to participate in religious festivals.

6 Equality Act 2006, section 8.

7 Through the Human Rights Act. In addition, the UN Conventions on the Rights of Persons with Disabilities, on the Rights of the Child and on the Elimination of Discrimination Against Women give specific responsibilities to governments.

Article 10: The right to freedom of expression – for example accessing communication support or independent advocacy.

Article 12: The right to marry and found a family – for example having support to live independently with a partner.

These rights – and the intentions behind them – are at the core of what good care and support should mean at a day to day level. Whilst they may sometimes appear abstract, they are really about such mundane things as eating a meal when you are hungry rather than when a service wants to provide it; having a bath in privacy and comfort; being able to play with your children or go to church or to the pub in the same way as everyone else.

The Commission also promotes and monitors Britain's implementation of international human rights treaties, which will include the United Nations Convention on the Rights of People with Disabilities which is expected to be ratified by the Government by spring 2009. Article 19 of the Convention concerns disabled people's rights to 'live independently and be included in the community' and requires governments to take 'effective and appropriate measures to facilitate the full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community'.⁸

Promoting equality

All public authorities, including central and local government and their partners, have duties to promote disability, gender and race equality. The Government is committed to extending this to age, sexual orientation and religion or belief in the Equality Bill, which is expected to receive Royal Assent by the end of 2009. The Government also intends to introduce new protection from age discrimination in the provision of goods and services, including in relation to health and social care.

In relation to care and support, equality can be understood in three ways: equality of access to care and support; equality of outcomes from care and support; and the contribution care and support can make to people's equality of opportunity to participate and contribute fully in society.

The majority of people requiring care and support will be considered disabled for the purposes of the Disability Discrimination Act (DDA) 1995. The DDA requires public authorities (and agents acting on their behalf) to promote disabled people's participation in public life. Care and support is central to achieving this objective. As one participant in our consultation told us:

...no other public service [other than social care] has the potential to support people to achieve equal citizenship and the ability to participate in society...

Promoting good relations

The Equality Bill is expected to introduce a new duty on the public sector to

promote good relations between groups covering all seven ‘strands’ of equality – age, disability, gender, transgender, race, religion or belief and sexual orientation.

If we are to succeed in creating a sustainable approach to care and support, considerable attention needs to be paid to good relations and social cohesion.

We will need to cultivate a cohesive society that has at its heart an ethos of caring about and for one another; a society that engenders and facilitates the giving and receiving of informal care and support; which maintains a commitment to pooling risk through a modern active welfare state in a way which is seen to be mutually beneficial; and which helps maintain and promote positive intergenerational relations.

Choosing the future

There are many positive developments in relation to care and support, aimed at providing those eligible for services with greater dignity and more personalised support, with greater choice and control, with wider opportunities to participate in society and to maintain health and well-being. The CSCI report on the state of social care in England 2007-08 has found that for people who are entitled to receive services, the service that they receive is in general better than it has ever been.

The Government has initiated a major debate about the future of social care aimed at developing a new settlement between individuals, families and the state that is ‘fair, sustainable and unambiguous about the respective responsibilities’ of each, and is allocating £520 million into a programme to transform social care set out in Putting People First.

The Welfare Reform Bill, before Parliament at the time of writing this report, proposes a ‘right to control’ for disabled people, expanding the reach of personalisation into areas such as employment support. The Health Bill, also before Parliament, aims to pave the way for the Government to pilot greater personalisation for people with long-term health conditions in the NHS. The Department for Children, Families and Schools is also piloting ‘personal budgets’ for families with disabled children and for young disabled people as they approach adulthood. The emphasis placed on human rights and equal citizenship in the new Valuing People Now strategy for people with a learning disability is welcome. Initiatives such as ‘Lifetime Homes, Lifetime Neighbourhoods’ aimed to modernise housing and wider infrastructure to meet the demands of our ageing society will help people maintain independence as they get older.

Fully realised, these reforms have real potential to help deliver the equality and human rights objectives of the Commission. The challenge however is that the number of people who are left to finance or secure their own care through informal channels is growing markedly, and not everyone receives the support they require to make effective decisions about how to secure and organise care and support to meet their needs and aspirations.

That is why the Commission believes we are at a fork in the road. We must now choose between two futures. As a country we can harness the full potential of care and support by deepening and accelerating reforms already embarked upon, aiming to create a future in which care and support acts as a springboard, enabling

each of us to reach our full potential and to make a contribution, at home, at work and in our communities. This way, care and support can play its full role in helping the country to develop its economy and to prepare fully for the demographic change of the coming decades. In doing so, care and support will begin to accumulate the levels of public and political support necessary to put its future on a sustainable footing.

Or we can fail to realise the potential of care and support and be at risk of extensive social and economic costs as a result – poorer health, economic inactivity, widening gender inequalities, damaged family relationships and intergenerational tensions. As a marginal public service, acting only as a safety net and not seen as contributing valuable social or economic outcomes, the potential of publicly funded care and support will be a missed opportunity at a time when public services should be playing as full a role as possible in helping re-build our economy and prepare our society for the challenges to come.

Real lives – the difference an equality and human rights approach can make to care and support

The following five stories illustrate the difference an approach to care and support, based on equality and human rights, has the potential to make. Some of the examples may appear too every day, surely a matter of common sense, but it is remarkable how often we can get these things wrong when we do not employ a framework based on dignity and respect for all. Getting the ‘small stuff’ wrong often leads to more substantial problems in the future. As Eleanor Roosevelt said, this starts in small places, close to home.

Tea without sugar

Placing my mum who had severe dementia into a care home was one of the most difficult decisions of my life. I was desperate to make sure the staff treated her as the person I knew – my mum. I remember the day I moved her in, telling the manager all the things my mum liked and disliked. She especially disliked sugar in her tea. The first time I visited the staff were serving afternoon tea. I noticed they put two sugars in every cup. I said to the member of staff ‘my mum doesn’t take sugar’ to which she replied ‘it doesn’t matter – she won’t know anyway’.⁹

The absence of dignity and respect in the above example is in stark contrast with an example from The State of Social Care in England 2007-08 report by CSCI. The preferences of a woman in a care home were sensitively noted so that her care was exactly as she wanted:

I wear a light night dress. I like a cup of tea before bed and when in bed please close the door. I would prefer to be washed and dressed by a female carer.¹⁰

9 Source: Alzheimer’s Society.

Coming out

When Richard decided he wanted to talk to someone about being gay he realised there was nobody to turn to. Coping with a learning disability and living in supported accommodation, the conversations he had with his support worker only ever revolved around cooking, money and personal hygiene. He had no idea how to broach a discussion about his sexuality, but eventually built up the confidence to do it.

I said to my support worker and my key worker, 'I'm gay and this is how I feel'. At that point, you could almost hear a pin drop. Then they started talking about cooking and my health again.

Later, his support worker asked him if this was a phase he was going through. What happened next shocked him. He was assigned a social worker and a psychiatrist even though, as he says, 'I had never had a mental health issue in my life', and was given a risk assessment.

I asked for literature on being gay, where to meet people, how to have safe sex. It didn't happen. I was stuck in a place where I couldn't express how I felt and I couldn't talk to staff about how I felt. I was just seen as a risk to myself and the organisation.

Things are different now. Richard lives in his own flat with an in-control budget. When he wants, he spends some of it on visiting a nightclub or with a dating agency, meeting people of his own sexual orientation. As he says: 'I'm in control now.'¹¹

'Til death do us part

Burma veteran Richard Driscoll from Cheltenham Gloucestershire was unable to walk unaided and relied on his wife of 65 years to help him get around, while Beryl Driscoll was blind and was accustomed to using her husband as her eyes. But they were forced to spend seven months apart when a place in a care home was found for Mr Driscoll after he fell ill but social services would not pay for his wife to stay with him. She had to be looked after by other relatives and the couple, both 89, were able to meet only twice a week. Mrs Driscoll said:

We have never been separated in all our years together and for it to happen now, when we need each other so much, is so upsetting. I am lost without him – we were a partnership. It has been such a struggle without him. He was my eyes. Since I went blind 16 years ago he has done everything for me. I am so depressed. I just want to be with Richard but I am told I don't fit the criteria. I think it is very cruel.¹²

Mr and Mrs Driscoll were re-united after her needs were re-assessed and she was deemed eligible for support within a residential care home. Nevertheless, this was not a product of respect for the couple's human rights, which arguably would have

11 Caring Business, 27 September 2007, 'I couldn't tell anyone how I felt: A resident's tale by Richard Blake'.

12 The Guardian, 1 February 2006, 'Council splits up couple for the first time in 65 years'.

never seen them split apart in the first place, but of the pressure on the local authority of widespread national media coverage.

Respect for the right to private and family life would prioritise keeping couples and families together.

On the terraces

Gavin Croft spent £375 of the care money he received from Oldham Council on a season ticket for Rochdale Football Club, for a fellow fan to accompany him to home matches and commentate on the action on the pitch. Gavin, who has multiple sclerosis and whose vision is impaired, recruited his companion from a supporter's internet site.

Gavin's wife said that allowing her husband to spend his care money in this way gave her a much needed break. She said:

It's been great. It gives me the only time I get off all week and I don't have to watch football in the wet and cold.

Back on track

'Lee', who has a learning disability, had recently lost his father, faced losing his job, his home and shared custody of his son. He had got into a lot of debt and fallen behind with his rent so he faced eviction. He was frequently absent from work and when he did attend was often under the influence of alcohol. His health was deteriorating and he did not understand the letters he received from his landlord or officials. Under these pressures he began to drink heavily and expressed suicidal feelings.

Lee was referred to Breakthrough UK's advocacy project. The advocate focused on building a rapport and discussing the different ways in which he could address the problems he was encountering. She helped him to understand the significance of the correspondence being sent to him and what he was required to do, explaining everything in plain English and accompanying him to court hearings and to meetings with his solicitor. With her support, Lee started attending bereavement counselling, completed and maintained an alcohol detoxification programme, attended sessions with a debt counsellor and put in place payment plans to deal with bills and creditors. It emerged that Lee's employer was completely unaware of the problems he was dealing with outside work, or the extent of his emotional stress. With Lee's permission the advocate explained all this to his employer which helped Lee to keep his job. Two years after contacting Breakthrough, Lee continues to work full time. His employer says that without the support provided by the advocacy project, Lee would definitely have lost his job.¹³

13 Hurstfield et al (2007) 'The costs and benefits of independent living', Department for Work and Pensions.

The challenge ahead

In coming to its recommendations, the Commission has considered the implications of demographic, social and economic changes of both the immediate future and the coming decades. It has explored the changing roles and expectations of older and disabled people and of women who continue to provide the majority of paid and unpaid care and support.

It has identified the need to create a sustainable role for informal care and support, averting what we have termed the ‘care crunch’. This term describes the consequences of over-reliance on informal or privately funded care that places a sometimes intolerable physical and financial burden on families having to balance work with bringing up children and supporting older parents and relatives.

The Commission believes the central challenges for reform in the next decade are:

- Transforming the purpose of care and support from being not only a ‘safety net’ but also a ‘springboard’.
- Helping people to stay safe and secure.
- Building public and political engagement and support concerning the value of a reformed approach.
- Creating a care and support offer for everyone, especially information, advice, brokerage and advocacy.
- Sustaining a committed, capable workforce.
- Achieving a sustainable role for informal care and support.
- Extending choice, control and respect for diversity.
- Optimising the social and economic participation of those requiring support and their families.
- Overcoming ageist policy and practice.
- Agreeing a fair and sustainable approach to funding care and support.
- Harnessing the role of wider policy, services and infrastructure.
- Promoting positive intergenerational relations.

The background evidence and analysis leading to the Commission having identified these challenges is available on the Commission’s website at www.equalityhumanrights.com/careandsupport.

Our proposals primarily relate to England – the provision of social care services is devolved – but we believe that much of our analysis and many of our recommendations have wider resonance.

How this report was produced

This report was written by the Commission. It is based on extensive research, consultation and review of current thinking by government, policy-makers, campaigners and users of services.

The Commission asked Cordis Bright consultants to develop and to road-test a vision and set of principles for the reform of care and support.

Cordis Bright's methodology comprised:

- A literature review examining a model of the care and support system which places a commitment to equality and human rights at its core.
- Interviews with 53 stakeholders covering government, care and support providers, advocacy and representative organisations, academic institutions, think tanks and social care practitioners (a list of consultees can be found in the Appendix).
- Roundtable discussions to test interim findings and gain input into the draft vision and principles.
- Follow-up discussions with additional stakeholders.

The report also draws on work carried out by Sophie Moullin from the Institute for Public Policy Research exploring the role and purpose of care and support and on the cost-benefits of a reformed system. It has also taken information gathered during a stakeholder roundtable looking at the role of information, advice, brokerage and advocacy, and a roundtable with the then Minister for Care Services Ivan Lewis, exploring the relationship between care and support and the promotion of equality and human rights which was part of the formal Department of Health consultation.

Acknowledgements

The Commission wishes to thank Cordis Bright consultants, Sophie Moullin and Agnes Fletcher who helped write the final report and all who took part in the consultations, roundtable discussions and who commented on drafts.

2. From safety net to springboard – the Commission’s vision, proposals and actions

This chapter sets out the Commission’s vision, proposals and actions aimed at building an active and sustainable infrastructure of care and support, and our underpinning rationale.

Our vision

The Commission’s vision is of an infrastructure of care and support which acts as a springboard by promoting and sustaining the capabilities¹⁴ of individuals and their families to maximise control over their own lives, to participate and contribute socially and economically, and through doing so improve their well-being and prosperity and that of the wider community and economy.

Proposals and actions

2.1 Care and support based on clear outcomes and founded on human rights and equality

Proposal 2.1.1

A national framework of guaranteed outcomes, based upon human rights principles, should be developed for care and support.

Actions for the Commission

The Commission will contribute towards the development of a national framework of human rights focused care and support outcomes that should be developed and agreed across government, the statutory and third sectors.

The Commission will negotiate a memorandum of understanding enabling it to work alongside the new regulator for health and social care, the Care Quality Commission (CQC) to develop a robust human rights approach, promoting and measuring achievement of the agreed outcomes across the range of public and private provision. This should include CQC working with the Commission, other inspectorates and regulatory bodies on ‘themed inspections’, for example in relation to personal safety or health and well-being.

Rationale

As one respondent to our consultation said:

...the fundamental problem with social care is that it is predicated on need rather than rights...

14 ‘Capabilities’ is an approach to human rights and equality developed by the economist Amartya Sen and promoted in the Equalities Review (2007). It is explained in detail in Chapter 3 of the report.

The Commission believes the time has come to break fully from the culture of paternalism that helped shape the post-War settlement of 1948 and to create a system designed for the likely challenges and aspirations of England in the 21st century. A national framework of rights-focused outcomes, similar in purpose to those for Children's Services and the Children's Commissioner set out in the Children Act 2004, will aid the transformation of care and support from a system that has been historically based on a passive definition of individual need to one based on an active conception of rights and duties in which people are enabled to be full and equal citizens.

At present the provision of care and support is patchy with sharp differences across localities and between different groups, fuelling the risk of greater inequality over the long-term. The ability to collect and analyse comparable data about outcomes for individuals across the mixed economy of social care provision is essential to maintaining effective regulatory oversight, and to closing the gap between those who receive local authority provision and those who do not.

The outcomes should work as a framework across needs assessment, in determining eligibility, in relation to personalisation, workforce training, inspection and strategy development, and be shared by health, social services and the full range of agencies involved in Local Strategic Partnerships and subject to Comprehensive Area Assessments. They should apply equally to those requiring or receiving publicly funded services, those paying for services themselves and to those providing unpaid care and support.

The Commission proposes that the most suitable approach to outcomes is provided by a 'capabilities approach' building on the Equalities Measurement Framework that the Commission will shortly finalise with the Government Equalities Office (GEO). This approach and its benefits for care and support is explained in detail in Chapter 3.

The Commission welcomes the creation of the CQC as a streamlined regulatory authority, and we look forward to working closely together to achieve our shared objectives. CQC has a central role to play in promoting and measuring achievement of these outcomes in what is increasingly likely to be a complex mixed economy of provision and consumption of care and support, including from increasingly diverse and atypical providers. The Equality and Human Rights Commission will work with the CQC to support it in delivery of its duties to promote human rights and equality.

2.2 Access to publicly funded care and support based on clear, fair and consistent criteria

Proposal 2.2.1

The Commission proposes that everyone should be entitled to a self-directed assessment of their needs, irrespective of their income or of the funding available to local authorities to provide support, based on a clear framework of universal outcomes consistently applied across local authorities and other public authorities as appropriate.

Proposal 2.2.2

The Commission believes that equality and human rights outcomes are most likely to be achieved where people receiving care and support are able to move from one local authority area to another in the confidence that they will continue to receive an equivalent level and quality of support in their new place of residence, at least for an agreed transitional period. A ‘portability’ duty might be placed on local authorities to co-operate with one another to ensure effective transition, so enabling people requiring care and support and their families to enjoy equal freedom of movement.

Actions for the Commission

The Commission will consult on its proposal for a ‘portability’ duty to explore the implications of this approach with local authorities.

Rationale

While the Commission believes that care and support have often been underfunded and are still in need of significant investment, we also recognise that scarce resources will always need to be allocated on the basis of greatest need.

The Commission is particularly concerned about the life chances of disabled people and their ability to participate in employment or education which, for example, is critically affected by the availability of care and support. We are also concerned about older people who may face discrimination in the provision of services, and about the impact of narrowing eligibility for publicly funded support on gender equality, given women continue to provide the overwhelming majority of unpaid care to relatives.

Allocating resources fairly requires a transparent system of eligibility criteria, tied to clear outcomes and a universal entitlement to assessment, divorced from the allocation of public funding. Local authorities must be mindful of their duties to promote equality in the way they determine eligibility criteria for services. A High Court judgement in late 2007 found that Harrow Council in London was in breach of its duty under the Disability Discrimination Act to have due regard to the need to eliminate discrimination against disabled people and to promote equality of opportunity in taking a decision to restrict eligibility only to those with needs deemed to be ‘critical’.¹⁵

The Commission believes a ‘capabilities’ approach provides the fairest, most practical and beneficial way to determine needs. Those requiring support, and their families where appropriate, must be fully engaged in determining their own needs.

The Commission welcomes a number of the recommendations made by the Commission for Social Care Inspection in its review of the Fair Access to Care Services Criteria.¹⁶ In particular:

- Setting ‘eligibility criteria’ for access to support in a broader context that is more consistent with Putting People First and offers some level of assistance and advice to everyone seeking care and support.
- Revising eligibility criteria, based on ‘priorities for intervention’, and reinforcing the need for local authorities to make a clear distinction between the assessment of individual needs and any subsequent allocation of public funding so that everyone requiring an assessment gets one (and such assessments represent a true picture of their needs, not one which is coloured by the financial considerations of the local authority carrying the assessment out).

The Commission recognises the potential for conflict between family members concerning care and support arrangements and encourages local authorities to investigate the potential of ‘mediated family conferences’ based on the model of ‘Family/Whanau agreements in New Zealand,¹⁷ using the capabilities framework.

Freedom of movement is severely restricted for people requiring care and support because they are unable to move from one local authority area to another with the guarantee that – despite their needs remaining the same – they will be allocated an equivalent care and support package. This post-code lottery of provision seriously undermines the opportunities of working age disabled people and their families to move to take up employment opportunities which may only be sustainable if their existing package of care and support can be maintained. Equally, it can act to prevent older people moving to be nearer the informal support of their relatives if the effect is to lose what formal support they currently enjoy.

In addition to promoting human rights, co-operation between local authorities to facilitate freedom of movement through the ‘portability’ of care and support packages is likely then to help increase the economic participation of those requiring care and support and their families, as well as optimising the role of informal networks of support by enabling people to move to be near them. The Commission will carry out further development of this proposal in consultation with local authorities and others.

16 ‘Cutting the cake fairly’ (2007) CSCI review of eligibility criteria for social care.

17 See <http://www.cyf.govt.nz/2223.htm>.

2.3 Individuals and families in control of their care and support needs

Proposal 2.3.1

Everyone seeking care and support should be given access to accurate, accessible and tailored information and advice and where appropriate brokerage and advocacy, including in relation to human rights, non-discrimination and equality.

Proposal 2.3.2

Primary legislation should introduce a ‘right to control’ via individual budgets for all adults assessed as requiring care or support, including carers. The legislation should specify the circumstances in which the right might be challenged. Such legislation should include regulation-making powers, allowing the Government to include, replace or withdraw funding streams and services from the legal provision as necessary over time.

Proposal 2.3.3

Local authorities should make provision, including working in partnership with other agencies or via a budget-holding lead professional to ensure that independent advocacy is made available to those who require it, in particular people with learning disabilities, mental health conditions, dementia or who are on the autistic spectrum.

Proposal 2.3.4

Local authorities should work closely with users and providers to help shape opportunities for reconfiguring existing services and developing new ones over time, so that the shape of local care and support markets eventually presents a more suitable range of options for commissioning.

Proposal 2.3.5

The National Skills Academy for Social Care should build on the commitment of Skills for Care, the General Social Care Council and the Social Care Institute for Excellence and play a central role in the transformation of care and support from a service-led to user-led culture.

Actions for the Commission

The Commission has a role to play both in providing high quality advice and guidance through our own helpline service, as well as contributing towards capacity building at the local level through our grants programme.¹⁸ We will support local organisation’s including user-led organisations which have an important role to play in delivering credible advice, information and guidance.

The Commission will produce and disseminate good practice guidance for local organisations and individuals concerning ways they can use equality and human rights legislation to influence policy and practice.

The Commission will conduct research concerning the availability and quality of independent advocacy across England, including making available grant funding for the piloting and evaluation of a series of independent advocacy projects targeting individuals, families and communities who may otherwise not experience the full benefits of personalisation.

The Commission will work through others in helping to tackle low pay in the social care sector which has a disproportionate impact on women and ethnic minority workers, many of whom work part-time. We will also seek to raise productivity and efficiency through improved training and development as well as developing the supply of skilled and motivated social care workers for the future.

Rationale

The Commission believes the reform of care and support must herald a fundamental shift where people requiring care and support cease to be treated as objects of others' care and instead are empowered wherever possible to tailor support in ways which allow them to take command over their own lives, increasing their degree of choice and control. The Commission recognises that people will be differently placed and will have different preferences concerning the degree of control they assume, but believes the goal of maximising choice and control can be universally applied and is critical to promoting dignity and respect. This principle is perhaps no more important than in respect of people whose mental capacity is declining due to dementia, who should be engaged at an early a stage as possible in discussing their care and support plans.

The success of self-directed support relies on the acknowledgement that whilst services may be fragmented, people's lives are not. For example, for a disabled person to go to work they may require services, resources and support ordinarily provided or funded by the NHS, social services or Jobcentre Plus. It is the cumulative effects of these services, support and resources which make work possible – the impact being more than the sum of the parts. For that reason, self-directed support, individual budgets and personalisation need to be rolled out across public services, not confined to care and support. The risk otherwise is that a lack of choice and control in one area will cancel the benefits of increased choice and control in another. For example, the Commission is planning to intervene in a case involving a man who has lost his direct payments having moved from social care to NHS Continuing Care.

The Commission strongly supports the proposed 'right to control' in the Welfare Reform Bill and would welcome the early incorporation of relevant and appropriate services and support currently relating to or provided by the NHS, the Department for Communities and Local Government, the Department for Work and Pensions, the Department for Innovation, Universities and Skills and the Department for Children, Schools and Families.

Personalising services in this way provides a powerful means of addressing and overcoming disadvantage and inequality faced by people who might otherwise have critical aspects of their identity, characteristics or lifestyle overlooked, such as their ethnicity, sexuality or gender. For example, as Dame Denise Platt, Chair of CSCI recently observed:

Black and minority ethnic people should feel that their individual needs are being met, rather than providers making assumptions about their cultural requirements. People can only make these choices if they are given the opportunity to direct their own care.

Doing so requires significant changes in the structures, cultures and attitudes underpinning existing systems. Such change cannot happen overnight and as much attention must be paid to the process of transforming care and support as to the outcome if new patterns of inequality and disadvantage are to be avoided.

Where individuals and families are concerned, these new and negative patterns may emerge from the different capacities of individuals and families to navigate markets to secure their needs or through exploitation. There is a considerable risk of this to publicly and self-funded individuals alike if an effective infrastructure of advice, information, brokerage and advocacy is not in place.

Robust policies must also be available to avoid individuals and families finding themselves in vulnerable situations. High quality advocacy should be made available to assist people who may otherwise not benefit from personalisation in self-directed assessment and planning individual budgets. For independent advocacy to be effective, its provision must be clearly separated from the provision of assessment, information, advice and brokerage. The Government should put in place incentives such as additional funding to encourage public bodies, including local authorities and health authorities, to work together more effectively to meet the needs of local populations as identified in the 'Joint Strategic Needs Assessment'.

This builds on the cross-government concordat with local government, the NHS and CSCI set out in Putting People First, with the aim of ensuring a strategic balance of investment between preventative services and the provision of intensive support for those with complex needs.

The business models of many service providers are based on the certainty provided by block-purchasing by local authorities, often through long-term contracts. Without such certainty, some providers may not survive, leaving individuals with few if any options to choose from. In the immediate term at least, local authorities will continue to manage the local provider market for care and support. Efforts must be made to ensure commissioning decisions reflect the genuine aspirations of those requiring services. This will be achieved by working closely with users and providers to help shape opportunities for reconfiguring existing services and developing new ones over time, so that the shape of local care and support markets eventually presents a more suitable range of options for commissioning. There is also no

inherent reason – given the will – why existing tools like block contracting cannot be used to commission personalised care and support.¹⁹

Individuals are also likely to require support concerning the options which might be available to them to satisfy their needs and requirements and confidence in taking on such responsibility. Peer support, including that provided through user-led organisations, will be a vital element in the successful rollout of self-directed support.

The care and support workforce will need to undergo a significant attitudinal, cultural and professional skills transformation. This should not be a block to reform and need not be a threat to the workforce. The choices and aspirations of individuals need to drive change, but it requires the active engagement and support of organisations such as the forthcoming National Skills Academy for Social Care.

Furthermore, the creation of a sustainable workforce in care and support demands that attention is paid to pay and conditions. Numbers employed in adult social care in councils fell from an estimated 228,000 in 2006-07 to 221,000 in 2007-08, whilst the number employed in the independent sector increased from an estimated 988,000 to 1,070,000.²⁰ In the Commission's consultation, stakeholders perceived that employees of independent sector social care agencies had poorer terms and conditions of employment than in many other industries. In addition to the prime concern for the rights of these individuals – who are overwhelmingly women, part time workers and from ethnic minority communities – stakeholders noted that this contributes to difficulties in recruiting staff. This perception may be confirmed by the high level of vacancies notified to JobCentres for care workers which exceeded 80,000 in the second half of 2007 and has remained at these levels since the start of 2008.

2.4 The right balance between safety and risk to promote choice and independence

Proposal 2.4.1

Local adult safeguarding boards should be placed on a statutory footing and the police and local partners should be placed under a statutory duty to participate and contribute, including in the sharing of information.

19 For example see:

Zarb, G. (1994) 'The Haringey On-call Support Service', in Unell, J. *Kings Fund Major Grant Programme Community Care Projects*, London: Kings Fund.

Zarb, G. (1993) 'Starting from Scratch: The Experience of Developing an Independent Service in Haringey', London: PSI.

20 CSCI (2009) *The State of Social Care 2007-08*.

Proposal 2.4.2

Local authorities should routinely offer to facilitate and pay for Protection of Vulnerable Adults and Criminal Records Bureau checks and through their information, advice and guidance function make clear the risks to individuals of not doing so. The Commission does not believe such checks should be made compulsory in legislation.

Actions by the Commission

The Commission, through its grants programme and local partnerships, will develop approaches to building ‘circles of safety’ as an element of personalised support.

The Commission has commissioned research into disabled people’s experiences of targeted violence, harassment and abuse and will publish its proposals and actions to improve disabled people’s safety and security in late spring 2009.

Rationale

Safety and security are core freedoms, without which people cannot exert choice and control over their own lives or participate fully. But risk is also a normal part of everyday life. Promoting greater independence inevitably involves transferring responsibility for identifying and choosing how to address risks to individuals. The challenge for reform is establishing an effective balance between risk taking and personal safety. The Commission shares the view expressed by Action on Elder Abuse that: ‘It is crucial that the Government integrates the safeguarding of adults into their new policy of personalisation’.

People requiring and/or receiving care and support can find themselves in extremely vulnerable situations where their safety and right to live with dignity and respect can easily be compromised. For example, it is estimated that 342,000 people aged over 66 had experienced some form of neglect or abuse – including financial abuse – in 2006-07.²¹ Anecdotal evidence points to the practice amongst some religious communities of the forced marriage of disabled adults, as a means of securing care and support in lieu of public service support.²² A report by Women’s Aid finds that disabled women are twice as likely to experience domestic violence than non-disabled women, are more likely to experience abuse over a longer period of time and to sustain more serious injuries as a result of the violence. This is often at the hands of a

21 Briefing Paper: The UK Study of Abuse and Neglect of Older People 2007, Action on Elder Abuse, August 2007.

22 For example see: Independent, 27 July 2007, ‘Disabled youngsters forced into marriage to provide passports’.

partner who is also an informal carer.²³ A recent thematic inspection of care homes for older people showed that inadequate staff training, written documentation such as safeguarding policy and procedures and recruitment processes were common shortfalls, alongside problems with the provision of information to people on their rights to be safe and how to report any concerns.²⁴

Increased autonomy through measures such as individual budgets should result in many older and disabled people having greater control over who provides support for them, empowering them to prevent or address negligence or abuse. Research by Skills for Care shows that people assuming greater control via direct payments experience less abuse. One in 10 employers of personal assistants said they had suffered abuse from personal assistants, compared to almost twice the number (18 per cent) who had been mistreated by local authority commissioned staff.

For some older and disabled people who need support to have the confidence to challenge negligence or abuse, or for those people who have difficulty in communicating, individual budgets could result in increased risk of exploitation, negligence and abuse unless adequate safeguards are effectively implemented.

These risks are particularly acute for older or disabled people who may use individual budgets to pay relatives or other informal carers such as neighbours and friends, who exist beyond regulatory and inspection regimes and are not subject to any standards. It is clear that in cases such as the murders of Steven Hoskin or Brent Martin, who both had a learning disability, that financial exploitation preceded the physical abuse which led eventually to their deaths.

Safeguarding human rights must be a priority in any eligibility framework and local authorities should not be distracted from acting decisively to protect people from serious breaches of their human rights, including threat to life or risk of inhuman or degrading treatment such as elder abuse and neglect, domestic violence, targeted crime or forced marriage.

Furthermore, evidence of such behaviours must be treated first and foremost as a matter for the police. This is why the Commission proposes leadership by the police of local adult safeguarding boards and a statutory obligation on other agencies to co-operate including in the sharing of information.

Independent advocacy has a central role in play in promoting people's safety and security without compromising their personal autonomy through supporting decision-making and communication, removing the undue interference of others and in enabling individuals to recognise the strengths and weakness, opportunities and threats of different options available to them.

23 Women's Aid (2008) Disabled women and domestic violence – Making the links.

24 CSCI (2009) The State of Social Care 2007-08.

Having the support to participate and engage in employment or the wider community can provide access to the social networks which make us all safer than we would otherwise be, and make it harder for criminals to target otherwise lonely and isolated individuals.

Promoting safety and security requires a multi-pronged approach, engaging and involving agencies including the police and criminal justice agencies, local strategic partnership, social housing providers and inspectorates. It also requires a long-term effort to address prejudice and hostility targeted towards disabled and older people and their families. The Commission has commissioned research to improve our understanding of the extent and nature of disabled people's experiences of targeted violence, harassment and abuse and will publish the research and set out our proposals later in 2009.

2.5 Local strategic partnerships that play a central role in developing and maintaining local care and support

Proposal 2.5.1

Local Strategic Partnerships and their constituent members should uniformly assume an explicit role to help shape, manage and sustain the local care and support infrastructure with success measured through Comprehensive Area Assessment.

Proposal 2.5.2

The Voluntary and Community Sector (VCS) requires sustained support from central and local government to promote and facilitate the voluntary giving of care and support. The Commission would welcome a new performance indicator for the Local Area Agreements and Comprehensive Area Assessment concerning performance on encouraging volunteering.

Proposal 2.5.3

More local authorities should facilitate the development of care and support 'time banks'²⁵ to encourage the voluntary giving of low-level support such as cleaning, shopping, gardening and basic home repairs and maintenance.

Actions by the Commission

As part of the Commission's good relations remit, we will work with local partners on approaches to improving networks of informal support, including via the Commission's grants programme.

The Commission strongly supports the development of the Lifetime Neighbourhoods agenda by the Department for Communities and Local Government and will work with the department and partners to develop a

forward-looking agenda which ensures policy and practice on housing, planning, transport, the built environment and social cohesion are based upon a proper understanding of the implications of an ageing population.

Rationale

Publicly funded care and support services play a critical role in directly responding to our society's need for care and support. But they are only part of a much wider and more complex network of contributors. Their effectiveness in delivering desired outcomes rests on our ability to transform all levels of society to adapt to our ageing and changing society. New structures for local governance and 'place shaping', including Local Strategic Partnerships, Local Area Agreements and Comprehensive Area Assessment, have a central role to play in developing and shaping and sustaining local care and support infrastructure.

Our housing and wider infrastructure plays a central role both in shaping care and support needs and the social and economic costs of meeting them. For example, there are 300,000 people living in unsuitable housing who require accessible or adapted accommodation in England today, many of whom will have avoidable support needs as a result. 'Bed-blocking' is a costly consequence of this situation, incurring significant avoidable costs to the NHS. Access to local shops and amenities such as GP surgeries and banking facilities can play a significant part in determining the ability of people with care and support needs to stay living in their own home. The programme of modernising housing and infrastructure, including transport and travel planning, new towns and regeneration projects must account for its changing demography and make the fullest contribution to supporting independence and well-being. Planning for an ageing society is not just about the needs of a population growing older, it is also about the impact this will have on younger generations including the families and other informal networks that will support them.

Sustaining a commitment to care and support in an ageing society requires that serious attention is given to strengthening bonding and bridging social capital. Many older people report loneliness and isolation,²⁶ and evidence shows that isolation creates the opportunity for people with learning disabilities to be targeted and subject to exploitation and hostility.²⁷

The Voluntary and Community Sector (VCS), and in particular user-led organisations, have a central role to play not just as a direct provider of care and support services, but also in helping to build a strong network of voluntary support, including peer support, and in relation to developing the bonding and

26 For example, a survey by Age Concern England in 2005 found that one in five people over 65 were alone for more than 12 hours a day.

27 EHRC/OPM (2009 – forthcoming) Disabled People's experiences of targeted violence, harassment and abuse.

bridging social capital required to sustain informal support. The VCS can also play a role in creating economies of scale within care and support, for example through pooling individual budgets by becoming co-operative or mutual societies. Central and local government will need to find new and innovative ways to stimulate and harness the civil economy to meet the needs which the scarce resources of public services alone cannot, such as through setting up ‘time banks’.

2.6 Funding that balances affordability and sustainability with fairness

Proposal 2.6.1

The Commission proposes additional incentives to promote the pooling of budgets by statutory agencies to achieve ‘invest to save’ outcomes including between health and social care, and others including the Department of Work and Pensions. This must be shaped by robust cost-benefit analysis. Integration of personal budgets in health with individual budgets in social care and employment support under an overall ‘right to control’ provides one such incentive.

Actions by the Commission

The Commission will initiate cost benefit analysis during 2009-10 concerning both macro and micro cost benefits of reform. Details are provided in the next chapter.

The Commission expects and will monitor closely to ensure that any proposed approaches to funding are subject to rigorous impact assessment both in relation to equalities – including socio-economic factors – and relations between groups, including intergenerational relations.

Rationale

Arriving at a new settlement for the funding of care and support is challenging governments in developed countries around the world as their population’s age and demand rises. Governments need to balance meeting demand for formal care and support in an ageing society with affordability for families, political support, fiscal rules and, critically, fairness. As the Commission shows in this report, the Government must consider the wider cost-benefits and opportunity costs²⁸ of any approach under consideration, viewing publicly funded care and support as a social and economic investment, if it is to arrive at a funding settlement which is not based on a false economy.

An ‘invest to save’ approach may require the Government to introduce stronger incentives – including potentially ring-fencing money – for statutory agencies to pool budgets both to ensure such money is not swallowed up by crisis intervention and to ensure that its effectiveness can be measured and the

benefits distributed in ways which stimulate further investment. Whilst ‘pooled budgets’ between health authorities and local government have been feasible since 1999, they have not realised their true potential. Strengthening them might involve, for example, using a percentage of NHS expenditure for investment in services and resources known to improve health, such as home adaptations to reduce accidents or supporting people to engage in social activities to improve mental health. Personal budgets in healthcare, aligned with individual budgets in social care and other areas such as employment as part of a broad ‘right to control’ provide a further opportunity to re-direct money towards improving outcomes which bring long-term savings.

Examples of such cost benefits are provided in the next chapter.

The Commission believes any funding settlement for care and support should be based on the principle of ‘progressive universalism’,²⁹ with everyone receiving something but with those with the fewest resources gaining the greatest help. Furthermore the Commission believes equality impact assessments, properly integrated into the policy development framework, will help the Government identify and navigate as best it can the key equity questions relating to different potential options. We discuss this in more detail in the final section of this report.

The funding settlement for care and support will have a major bearing on future relations between young and old and this should be a central consideration. An equitable spreading of financial risk is likely to be required to avoid an unsustainable level of subsidy between the generations.

It is not the Commission’s role to formally assess whether the overall funding that is devoted to social care is adequate to address future needs. That is a matter for central and local government. It is the Commission’s role, however, to identify where the consequences of decisions about funding will have an impact on the delivery of key equality and human rights outcomes. This leads us to make the following observations:

First, no system in the developed world has succeeded in making adequate provision through a system led by private payments, even though private spending has an important role to play. Money will have to be found via the public purse to pay for increased demand and general taxation will have to underpin the state’s obligation to provide adequate care and support for those unable to pay the full costs themselves.

Second, research by the Resolution Foundation finds that ‘around 70 per cent of low earners are likely to be ineligible for any state funding for care and support, yet their low incomes (only just above those qualifying for free or subsidised care) mean privately purchased care can be unaffordable’.

29 ‘Progressive universalism’ means services from which everyone benefits and to which everyone contributes, but which target their greatest resources at the most disadvantaged or those with the greatest needs.

Third, low earners are also more likely to be informal carers of older relatives. As eligibility for state services tightens, and these groups are unable to afford private care, the pressure to provide informal care increases. This will cause more low earners to reduce working hours or leave work altogether, reducing their incomes further.

A number of organisations, including the Institute for Public Policy Research and the Resolution Foundation have employed a phrase first coined by the Commission to describe this emerging situation as ‘the care crunch’.³⁰

However, there is no one model currently under discussion which does not have attached to it risks concerning equity and fairness, and there is a need to strike a balance: there is no pain-free option.

There have been indications in recent months that Government ministers may favour a model of ‘co-payment’ as the way to answer the question of how to fund care and support for future generations. This would involve a degree of universally guaranteed provision by the state, with the balance of costs being met from individual finances, by means of savings, equity release or some form of insurance.

There are concerns that a ‘co-payment’ model³¹ may risk generating or entrenching inequalities, especially amongst those on lower and middle incomes, and would need to account for the reduced or non-existent earnings potential of those who are disabled during their working lives, or who have left work or reduced working hours to care for others. This has particular implications for women.

An equity release³² model may have benefits in accounting for differentials in asset wealth and could provide a much needed injection of that accrued wealth into the system at a time when public spending is tight. In doing so it may help care and support get through the recession whilst avoiding damaging intergenerational relations. However, it may also be problematic for two reasons. Firstly, given not everyone will require care and support (or as much care and support) it risks skewing asset inequality (and inheritance inequality) along a new fault-line which is likely to grow as our society ages. Secondly, it is

30 See Baroness Campbell’s response to the Government’s consultation on the future of social care, 12 May 2008, available at www.equalityhumanrights.com/en/newsandcomment/speeches.

31 Co-payment’ would involve everybody paying the same proportion of their care and support costs, with the remainder being paid by the state.

32 Equity Release is a means of using the value of your home to receive either a lump sum of cash or regular monthly instalments. In all instances, age is the primary factor in determining the percentage of the value of your home that can be released. A person of an older age can release a higher percentage of the value of their home, than a person of a younger age, as they are not expected to live as long.

unlikely to provide a long-term solution as such assets are not finite and, because they would otherwise be passed from one generation to the next, such a system may provide only a once in a generation fix.

While the Commission has not carried out any detailed technical analysis of different funding models, some of the social insurance proposals that have been suggested by, for example, the International Longevity Centre (ILC) and the Joseph Rowntree Foundation (JRF) do seem to offer a possible way forward. The common positive features in such proposals are that they:

- a) Are based on a known rate of co-payment (which provides transparency and predictability);
- b) Would offer a flexible range of payment options (thus enabling people to tailor their own financial planning to suit individual circumstances); and
- c) Uphold the principle of fairness through collectively insuring against predicted risks (which is a founding principle of the welfare state that still has widespread political and public support).

The Commission agrees with the ILC that the presumption should be that everyone would pay into any insurance scheme automatically unless they opt out (and that this should only be after they are given appropriate warnings about the risks of so doing). Given what is known about people's propensity to save however, we also believe that consideration should be given to going even further by making at least a minimum contribution mandatory.

On the crucial question of whether contributions to any social insurance scheme should be restricted to older people (as suggested by the ILC) or spread over the longer term throughout adult life, the Commission tends to favour the latter. First, spreading co-payment contributions over the course of people's adult life would, in our view, be more consistent with the principle of sharing risk and – provided that contributions are equally distributed across all age groups – would avoid the very real dangers of creating intergenerational inequality and conflict. At a practical level, this would also enable people to spread the payments over a much longer period of time unlike the ILC proposals which would top-load payments in older age with the result that many people (particularly those on modest incomes) may find it harder to make sufficient provision.

One model that would be worthy of further examination for example might be a hybrid version of the model used by the Joseph Rowntree Housing Trust (JRHT) where resident fees are charged on a sliding scale according to age. This suggests that the same principle could be applied to a more general actuarial based care and support insurance scheme (with payments starting at age 21 and continuing to retirement age). This would enable starting contributions to be set at a low level when people are younger but rise proportionately if people choose to start contributing later in life. Annual increases would be pegged at the rate of inflation (or just above, as suggested by JRF) with the result that, by the time they reach retirement age, everyone would have contributed an equal amount into the insurance pool. So, for example, to produce a contribution of £15,000 (which was the sum that ILC suggested people might pay as a lump

sum into a national care fund) would require starting contributions at age 21 of less than £5 per week, rising to around £7 a week if contributions were delayed to age 30 or around £11 if delayed to age 40.

In conclusion, it is clear that a one size fits all solution is unlikely to be found and that a range of options will need to be made available to suit the differing circumstances of younger and older people, those who have and have not been economically active, and so on – with the guiding principles at all times being to ensure that equality of access to support is maintained and that risks are spread fairly. Given that there are some groups who are unlikely to be able to make a full co-payment, whatever model is applied, it is difficult to envisage any future solution that does not include some form of differential subsidy to take account of levels of disposable income. This should not be seen in negative terms however as it is entirely consistent with the principle of progressive universalism.

2.7 Equality and human rights law and practice re-calibrated to respond to our ageing society

Proposal 2.7.1

The Commission seeks a reformed framework of equality law which will:

- Incorporate or be accompanied by a clear timetable for the implementation of protection from discrimination on grounds of age in relation to goods, facilities and services.
- Include provisions for challenging ‘associative discrimination’ in all areas of equal treatment, including employment, education and goods, facilities and services in order to implement and build on the Coleman Judgement.
- Place an explicit duty on inspectorates, including the CQC, to promote and measure implementation of the single equality duty by public authorities and their agents.
- Clarify the responsibilities of public authorities to promote equality through procurement and commissioning.

Actions by the Commission

The Commission will assist local authorities and their agents to meet their equality and human rights obligations by:

- Making recommendations in the Commission’s forthcoming Human Rights Inquiry report to be published in spring 2009.
- Assisting public authorities to develop mechanisms to integrate positive obligations under the Human Rights Act with their work on public sector duties.
- Identifying and promulgating good practice on the promotion of equality and human rights through care and support.

- Producing and disseminating new practical guidance on good practice on involvement, equality impact assessments and promoting equality through procurement.

The Commission will conduct a review into the extent of compliance across local authorities with the public sector equality duties and will consider using its legal powers to enforce compliance amongst failing authorities.

The Commission will share expertise on equality and human rights with community care legal professionals and advice agencies and work with them to identify and intervene in care and support cases where equality and human rights law might be invoked.

The Commission will conduct research to identify the existence and extent of ageist policy and practice in the care and support system and make recommendations for reform.

The Commission will contribute to the review by the Law Commission of Community Care legislation to ensure its consistency with equality and human rights law and principles.

The Commission will report on Britain's performance in relation to care and support as part of the Commission's monitoring of Britain's international treaty obligations, including the Convention on the Rights of Persons with Disabilities, the Convention on the Elimination of all forms of Discrimination against Women and the Convention in the Rights of the Child.

The Commission will work with employers to develop the concept of 'agile working' and to explore how modern, flexible workplaces can better reflect the changing demography and life-demands of the working population, developing and disseminating best practice through the Commission's 'Working Better' initiative. The Commission believes the right to request flexible working should be open to everyone.

Rationale

The Commission's Human Rights Inquiry is investigating how the Human Rights Act makes a positive difference to people's lives, and to the effective delivery of public services which focus on individual needs. Human rights can help to restore the power balance between the state and individuals, and service providers and service users.

Early in 2008, an amendment to the Health and Social Care Bill clarified the human rights of all publicly funded residents of all third and private sector run care homes. Yet disabled and older people increasingly draw from a mixed economy of public, private and voluntary services providers – transactions which exist beyond the reach of the Human Rights Act. Public sector reform is seeing a blurring of the divisions between public, private and voluntary sectors in the provision of public services. Private and third sector providers constitute up to 96 per cent of provision of

social care, and the percentage of gross expenditure on care services purchased by councils from private and voluntary sector providers grew from 59 per cent to 70 per cent between 2001-02 and 2006-07 amounting to £10.9 billion. The nature of social care and support (private, intimate, often to people with difficulties expressing consent or exercising control and by people on low pay and flexible terms) raises particular and additional human rights and equalities issues. This makes a strong case for beginning to seek clarification on the rights and duties of providers, managers, care workers and users alike, and to start to build a shared human rights culture across public services – regardless of the sector of the provider. Equality and human rights law and inspection and regulatory regimes must keep pace with these changes if important developments such as the public sector duties are to have real impact.

The Equality Bill, to be published shortly, presents a significant opportunity to modernise Britain’s framework of equality law to ensure it reflects the changing make-up of British society. Our ageing society as well as wider demographic change including increasing ethnic and cultural diversity will not only change who we are, but also our experience of discrimination and disadvantage.

This includes the growing numbers who, without change in public attitudes, public policy and the behaviour of our institutions will encounter ageism. Such ageism appears particularly prevalent in our existing system of social care. For example, the Commission for Social Care Inspection (CSCI) operates two standards for registering social care facilities (one for under 65 years and one for over 65 years). The registration requirements of the former include standards regarding supporting service users to engage in an active social/community/work life. These standards do not appear in the registration requirements for services that support those who are over 65 years.

Further, the independent living fund is not available for those who are over 65. Earned income is excluded from calculations regarding charging for services, but pensions are included. Quality of life factors which are used in assessments for state-funded support for adults of working age, and issues relating to recovery for people with mental health problems, do not appear to be generally implemented for older adults. A number of respondents to the Commission’s consultation felt that assessments for older people focus on a narrow eligibility for services at the lowest cost. The following example from a voluntary sector agency in response to our consultation illustrates the impact of such practices:

When he turned 65, the local authority reduced his individual budget, stating that the approved hourly rate for over 65s was lower. What was he supposed to do? Sack his Personal Assistants and recruit cheaper PAs to do exactly the same work?

Growing numbers are also likely to experience ‘discrimination by association’ with a disabled or older person, including those providing informal care and support or those who will need stronger rights to flexible working in order to balance caring for a relative with paid employment.

Recent research by CSCI on the experiences of lesbian, gay, and bisexual people and those of transgender status within care and support services found that 45 per cent of those using such services said that they had faced discrimination. Yet only 9 per cent of service providers in the research sample said that they had carried out any specific work to promote equality for these groups and only 2 per cent had done so for transgender people.³³ As one respondent to our consultation said:

*LGBT people delay seeking care... and are alienated when they get there...
Their social care needs are not much explored.*

An analysis of 2007 self-assessment data supplied to CSCI by social care services showed only 33 per cent reported they had taken any specific action on disability equality. Given the clients of social care are almost wholly disabled people and care and support will for many of those people be central to providing equality of opportunity, this presents an extremely disappointing picture which the Commission plans to investigate and take appropriate action to address.

33 CSCI (2008) Putting People First: Equality and Diversity Matters – providing appropriate services for lesbian, gay and bisexual and transgender people.

3. Capabilities, co-production and cost-benefits: our vision in detail

The last chapter set out the Commission’s proposals and actions concerning the reform of care and support. These are designed collectively to achieve our vision of an approach to care and support which acts as a springboard by promoting capabilities, is co-produced through partnerships and where the benefits are clearly understood to accrue to society as a whole. In this chapter we explain our vision in more detail and how it can be achieved by building on the positive results of existing reforms.

Promoting ‘capabilities’

The Commission proposes that a reformed system of care and support is based upon capability theory, originally conceived by the economist Amartya Sen, and recommended by the Equalities Review.³⁴

A capabilities approach is an approach to human rights and equality which focuses not simply on people’s *freedom from harm*, undue interference or discrimination, but on what is required to accord them the *freedom to flourish* as human beings, ensuring they have genuine autonomy to shape a life worth living. For example, a person with a learning disability can reduce the probability of being harassed or attacked by never leaving their home at night – in this sense they may be free from that particular harm. But being safe is not a freedom in its own right – it is what allows us to get on with the rest of our lives, like going out for the evening and enjoying ourselves. A capabilities approach would cite safety as a freedom which enables us to be and do other things, not an end in itself. This approach was captured by the then Minister for Health, Rosie Winterton, in the Foreword to the Department of Health publication *Human Rights in Healthcare – A Framework for Local Action*:

*Quite simply we cannot hope to improve people’s health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an opportunity to make real improvements to people’s lives.*³⁵

The capabilities approach maintains commitment to the universality and indivisibility of human rights, but it expressly recognises that people are not equally placed to realise them in practice and therefore require different resources and interventions to do so.

Sen calls inequalities in the achievement of such freedoms ‘capability deprivation’. For example, people face different barriers and require different resources in their freedom to take part in productive and valued activities such as caring for children, employment or voluntary work. Using the capabilities approach, care and support is part of the means to the end of people overcoming the capability deprivations facing them and achieving these freedoms. It is not an end in itself.

34 Fairness and Freedom – the final report of the Equalities Review (2007).

35 Department of Health (2007) ‘Human Rights in Healthcare – A Framework for Local Action’.

The promotion of individual autonomy is at the heart of the capabilities approach, both as a desired outcome and also in relation to the role of individuals in choosing which capabilities are of greatest importance to them and also how they might best be overcome. For example, a young disabled person may see getting a job as their most important objective, and might use an individual budget, drawing on both local authority and Jobcentre Plus funding to put together a package of support to help them achieve this goal, whereas an older person might prioritise help with basic tasks like shopping and cleaning to help them stay living in their own home.

The Commission believes this approach lends itself well to establishing a care and support system which:

- is based on promoting universal human rights-focused outcomes;
- assesses needs fairly according to the extent of ‘capability deprivation’ faced by individuals in achieving these outcomes;
- fully engages the person or people requiring support in personalising, co-producing and having the opportunity to control care and support to satisfy their own choices and aspirations; and
- can be characterised as having broad social and economic value.

The philosopher Martha Nussbaum has identified core things people need to be able to function and flourish as human beings. These are very close to the 10 freedoms identified by the Equalities Review in 2007:

Longevity, including avoiding premature mortality.

Physical security, including freedom from violence and physical and sexual abuse.

Health, including both well-being and access to high quality healthcare.

Education, including the ability to be creative, acquire skills and qualifications and access training and life-long learning.

Standard of living, including being able to live with independence and security; and covering nutrition, clothing, housing, warmth, utilities, social services and transport.

Productive and valued activities, such as access to employment, a positive experience in the workplace, work/life balance, and being able to care for others.

Individual, family and social life, including self-development, having independence and equality in relationships and marriage.

Participation, influence and voice, including participation in decision-making and democratic life.

Identity, expression and self-respect, including freedom of belief and religion and the ability to express one’s sexuality.

Legal security, including equality and non-discrimination before the law and equal treatment within the criminal justice system.

For significant numbers of individuals and families now and in the future, care and support will be instrumental in determining whether or not they realise these freedoms.

The Commission has been working closely with the Government Equality Office and the Centre for Analysis of Social Exclusion to develop an ‘Equality Measurement Framework’, based on the capabilities approach which could inform the development of a national framework of outcomes for care and support proposed in this report.

Encouraging co-production and partnership

To achieve these freedoms for all, the Commission believes that we need to re-articulate care and support not simply as a narrowly defined set of services or transactions for a minority but as an issue relevant to the way we will all lead our lives in the 21st century. The Commission believes that equality and human rights outcomes can best be secured where there is the effective development of an infrastructure of care and support. This needs to encompass both reform of specific public services and action to create the social and economic conditions which will enable care and support to be ‘co-produced’ by a range of partners. This includes those individuals requiring care and support and their families, local government, the NHS, voluntary and community organisations, local communities, business and employers and those who plan and design our built environment, housing and infrastructure. New structures and systems for local planning, governance and performance measurement including Local Strategic Plans, Local Area Agreements and Comprehensive Area Assessments need to be fully harnessed to create such an infrastructure.

Whilst this report focuses primarily on public service reform, it is also important that the debate on care and support comes to consider and address the following challenges:

- Transforming attitudes to older and disabled people – in particular the widely held view that all such individuals are vulnerable or unable to contribute to society, rather than in vulnerable situations and without the support to participate in society – and the value we attach to their participation and well-being.
- Striking an appropriate balance between valuing and recognising unpaid care-giving and avoiding assumptions concerning the availability and willingness of people, especially women, to provide it.
- Ensuring we can balance our working lives with our wider lives including the care and support we provide and the extent of flexibility which can be offered by modern employers.
- Exploring the relationship we wish to have with public services and our own role in achieving positive outcomes, for example through involvement in the design, delivery and evaluation of services.
- Determining the role of national and local government in shaping and sustaining the nature of our relationships with our immediate families, relatives, friends and neighbours in order to create circles of informal support.

- Developing the role of the third sector including user-led organisations and co-operative societies in delivering, securing and sustaining care and support.
- Identifying and responding to our respective abilities to successfully navigate markets to satisfy our needs and aspirations and the support we need to do so.
- Clarifying and shaping our attitudes to public services generally, including our willingness to pay for public services using different models of taxation and co-payment.
- Striking the right balance between nationally set outcomes and entitlements and locally determined priorities and solutions striking the right balance between promoting good health and treating ill-health.
- Ensuring the challenge of delivering care and support is at the heart of thinking around ‘place-shaping’ including in relation to our built environment and infrastructure such as housing, transport, public services, shops and amenities.
- Harnessing the potential of information and communications technologies.

The Commission will continue to develop its own thinking on these questions in partnership with its stakeholders.

Measuring and communicating the costs and benefits of reform to society as a whole

The third element of our vision concerns the need to measure and communicate the benefits of reform such that they are increasingly understood to accrue to society as a whole. Rather than viewing care and support as a ‘drain’ on society, which families, communities, employers and other stakeholders reluctantly support in as minimal a way as possible, the Commission believes it should instead be viewed as a pivotal part of our national infrastructure, like transport and energy.

The Government has itself identified ‘a failure to see expenditure on independent living as a form of social and economic investment’³⁶ while care and support is also seen simply in cost terms – a passive service for dependents.³⁷ Unpaid care is valued and promoted almost solely in terms of the direct savings to the economy of not having to pay for replacement public services. Little attention has been given to the social and economic costs and sustainability of unpaid care – with particular implications for gender equality given it is overwhelmingly working age women who provide it.

Consequently, care and support services regularly fail ‘invest to save’ tests for expenditure increases set by the Treasury and have seen relative under-investment over the last decade in contrast with other public services. For example, whereas

36 Prime Minister’s Strategy Unit (2005) ‘The Life Chances of Disabled People’.

37 OECD 2005 & Zarb, G. (1999) ‘What Price Independence?’, in Turner, M. (ed) *Facing Our Futures*. London: NCIL.

care and support services will receive a 2.7 per cent increase year-on-year in real terms up to 2010-11, increases to the NHS budget are projected to be 7.2 per cent year-on-year.

The challenge of long-term investment in social care will be considerable in the present fiscal environment. The Wanless Report³⁸ showed that projections for social care mean that population changes and the ageing of the population are a much greater cost pressure for social care than for health care. The report projected core resource requirements in social care for the next 20 years, and suggested that based on 2002-03 prices, core spending on adults in England will rise from £6.3 billion to £11 billion by 2022-23. This represents an average real terms increase of 2.3-2.8 per cent over that period. However the Institute of Fiscal Studies (IFS) predicts that departmental spending will increase by only 1.7 per cent per annum from 2011-12. This does not include any resources for delivering higher quality, for example stabilising the care home market, addressing quality gaps in existing services, the impact of changing technologies, and the need for services targeted at children and families.

The IFS also has estimated that public spending will need to be reduced by up to £37 billion in 2013-14 if present economic trends continue, and there are a number of competing priorities for the present Government including long-term investment in health, education and infrastructure.³⁹ Given the current challenges on public spending posed by the global economic downturn, any argument for further investment in social care will need to be rigorously attuned to cost-benefit principles, in particular that a well funded social care system may reduce the long-term burden on the NHS and ancillary social services as well as helping to migrate disabled people of working age and/or their families from benefits and into paid employment.

Care and support has a key role to play in ensuring that society has:

- a diverse and effective workforce;
- a healthier and less dependent population;
- a lower benefits bill; and
- decreased demand on the national health services.

Viewed in this context, care and support would be ascribed a greater level of public and political salience.

Below we outline other potential cost-benefits at different levels.

38 Kings Fund (2006) 'Securing Good Care for Older People – Taking a long-term view'.

39 See <http://www.ifs.org.uk/publications/4417>.

Cost-benefits to the individual and family

At the individual and family level it is important to recognise that the inefficiency inherent in existing publicly funded systems and in informal care and support mean that a different, targeted and often relatively small increase in ‘formal’ care and support to individuals and families could help people in many ways. These include the flexibility and support to access employment and income, improve family relationships, help people to maintain good physical and mental health, reduce reliance on welfare benefits and contribute to productivity and growth, in addition to creating new employment opportunities in the economy.

It is also important to consider any gap between the interests of individuals requiring care and support and family members or others, such as neighbours, tasked with providing it. For example, savings gained by an individual being cared for by a relative may see increased costs for a family member who has to give up work or reduce their earnings as a result. This will have an impact on both their and their children’s well-being and ability to save for their own care and support in later life, as well as putting pressure on family relationships.

Looking at care and support at this level helps us to consider care and support costs from the perspective of the impact on family finances and well-being, taking account of the pressures of a number of costs associated with support and care needs faced by family members.

The most compelling contemporary evidence concerning the benefits of the broad approach proposed by the Commission was collected by the Department of Health concerning the outcomes of the ‘In Control’ pilots. In Control is a social enterprise which has been piloting the use of self-directed (sometimes call person-centred) support and individual budgets. It found the approach to be broadly cost-effective in meeting the Department of Health’s existing outcomes for social care and suggested a system far more adept at promoting human rights and equality. For example, since starting on individual budgets, with associated support, in the In Control pilots:

- nearly half of people (47 per cent) surveyed reported improvements in their general health and well-being (only 5 per cent saying their health had got worse);
- over three-quarters (77 per cent) said their quality of life improved (1 per cent reporting it worsening);
- nearly two-thirds (63 per cent) said they took part in and contributed to their communities more (2 per cent saying they took part less);
- 72 per cent said they had more choice and control over their lives; and
- 36 per cent thought their economic well-being had improved (only 5 per cent felt it had got worse).⁴⁰

It should be noted, however, that in the initial evaluation, older people did not display the same levels of satisfaction as other groups. The Commission is pleased to note that the Department of Health has endeavoured to identify why this was and to look at improving access to self-directed support for this group.

The Commission is concerned about the impact of an over-reliance on families providing informal care and support on human rights and equality. A survey by the Princess Royal Trust for Carers in 2006 found 71 per cent of carers said they were stressed; 83 per cent of carers were frustrated by their caring role; more than half felt overwhelmed, angry, depressed and taken for granted; four in 10 carers felt they had not had a choice in deciding to care; and about a third felt sad about the loss of the previous relationship they had with the person they now cared for.

A family survey by Mencap, found that 8 out of 10 carers had reached breaking point. Over half had never had a Carers Assessment. Eight out of 10 had never been offered a choice of service and 6 out of 10 families on a waiting list for a short break had been waiting for at least six months.

This evidence suggests existing policy on informal care is failing to promote rights to family life and could over time begin to damage intergenerational relations.

In contrast, a relatively small increase in investment to provide targeted interventions could help overcome many of these risks and the costs they create for society as a whole.

According to the 2001 Census, over 225,000 people providing 50 or more hours of unpaid care per week state they are in 'not good health' themselves. More than half of the people providing this much care are over the age of 55, and it is at these ages that the 'not good health' rate is highest.

Cost-benefits to service providers

At the service level it is important to consider both the costs to the specific service (local authority care and support) and the impact of the performance of one service upon the costs and challenges faced by others. As the Wanless Report underlined, health and social care are inextricably intertwined. For example, increases in the number of older people being admitted to hospital in an emergency partly reflect reductions in the availability of appropriate social care.

A failure to institute an efficient system of home adaptations for older people can result in a higher incidence of home accidents, with costs of treatment borne by the NHS, and the resulting far higher costs of increased dependency passed back to care and support services in the long-term.

Research commissioned by the Office for Disability Issues on the cost-benefits of home adaptations found that:

- Falls leading to hip fracture cost the UK £726 million in 2000. Housing adaptations, including better lighting, reduce the number of falls.
- Housing adaptations can also reduce depression, which in turn may both reduce the number of falls and improve mental health.

- Providing adaptations and equipment can speed hospital discharge or prevent hospital admission by preventing accident and illness. Estimated savings from the Welsh Care and Repair Agencies' Rapid Response programme are between £4 million and £40 million.
- Adaptations support carers, preventing back injuries and reducing both carers' stress and health service costs. Supporting carers may enable an individual to remain at home rather than being admitted to more costly residential care.
- Good housing adaptations can enable seriously disabled people to move out of residential care, with estimated potential savings of £10 million a year on residential care costs in England.
- Home modifications can prevent or delay residential care for disabled older people. One year's delay will save £26,000 per person, less the cost of the adaptation (average £6,000).
- The right adaptations can reduce high levels of home care. An hour's home care per day costs £5,000 a year – the potential savings per year would be millions of pounds.⁴¹

This question focuses attention onto the mechanisms which allow services, local and national, and with other different structures, to share both costs and savings of any changes to the system of care and support. For example, in future, NHS and social care budgets should be pooled via the integration of individual and personal budgets allied to a right to control.

Macro cost-benefits

At the macro-level, including public spending, productivity, taxation, economic growth and overall social cohesion and well-being, it is important to identify both the impact of private and public spending on care and support and the implications of the way care and support is organised for society and the economy as a whole. For example, over-reliance on informal care could contribute to skills shortages as millions more leave the labour market and drive up social security costs, weaken family relationships and damage intergenerational relations.

Conversely, the requirements of an ageing society for personal social services can be viewed as an opportunity for public investment to create new jobs and promote economic growth. Investing in the participation and well-being of those requiring care and support could enable people to extend their working lives or contribute in other ways, such as providing childcare for grandchildren.

Re-fashioned care and support services that promote human rights, equality and good relations will result in an increased likelihood that people will engage with

41 Heywood, F. and Turner, L. (2007) 'Better outcomes, lower costs: Implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence', ODI/University of Bristol.

supporting their own families and will work, reducing reliance on benefits and increasing income to the Treasury.⁴²

There is high potential for savings at a macro-level to the Treasury from a combination of increased tax revenue from increased involvement of disabled people and unpaid carers in the labour market and the accompanying reduction in benefits payments paid out. It is estimated that the Government loses £9 billion in lost revenue due to disabled people being 30 per cent less likely to be in work (compared to those with the same qualifications and demographic profile). Whilst many of the people providing care do paid work as well, family and caring responsibilities account for 26 per cent of economic inactivity in the UK working age population compared with 19 per cent in Germany and 18 per cent in the Netherlands (TUC 2004). A third of carers have never been in paid employment and 20 per cent have declined work opportunities because they are responsible for providing care and support.⁴³ Of the groups who suffer the greatest penalty in the labour market – disabled people, people aged over 50, lone parents, Pakistani and Bangladeshi women – alongside low skills, care is the common denominator. All these groups are strongly linked to child poverty. Welfare payments to carers alone amount to £1 billion per annum. The Institute for Public Policy Research⁴⁴ has estimated that in 2001, all those of working age who were economically inactive and tied into unpaid care for over 20 hours a week lost a potential £5.47 billion in income.

By 2041 it is thought that nearly 90 per cent of all those providing intense unpaid care, for 20 or more hours a week, will be under the age of 65 and therefore of ‘working age’.⁴⁵

42 HM Government 2007, 2008a; Moullin 2008; Hurstfield et al 2007; Heywood & Turner 2007.

43 Darton, D. and Hurrell, K. (2004) ‘People working part-time below their potential’, BMRB for the Equal Opportunities Commission.

44 Moullin (2007) Care in a New Welfare State: Unpaid care, Employment and Welfare.

45 Pickard (2008b).

The need for further research

The cost benefits of personalised and preventive care and support is an under-researched area, placing care and support in an extremely vulnerable position given projected spending cuts and tightening fiscal rules.

Actions by the Commission

The Commission will work with partners to begin researching the macro and micro social and economic costs and benefits of different options for reform and investment in care and support, from a human rights and equality perspective.

Conclusion

The Commission welcomes this critically important debate. We hope this report and the actions we plan to carry out make a valuable contribution to creating an infrastructure of care and support which genuinely acts as a springboard, not simply a safety net. Whilst we have made a number of proposals in this report, we believe the following are the most critical:

- Action to instil an equality and human rights culture across care and support, including a national rights-focused framework of outcomes laid down in statute and actioned by the Commission in partnership with the Care Quality Commission to ensure compliance with the law.
- Identifying and rooting out ageist policy and practice.
- Ensuring everyone requiring care and support is empowered by information, advice and for those who require it, independent advocacy.
- Building a detailed and robust evidence base concerning the cost-benefits of reform and targeted investment.

Appendix 1 – Summary of proposals and actions

2.1 Care and support based on clear outcomes and founded on human rights and equality

Proposal 2.1.1

A national framework of guaranteed outcomes, based upon human rights principles, should be developed for care and support.

Actions for the Commission

The Commission will contribute towards the development of a national framework of human rights focused care and support outcomes that should be developed and agreed across government, the statutory and third sectors.

The Equality and Human Rights Commission will negotiate a memorandum of understanding enabling it to work alongside the new regulator for health and social care, the Care Quality Commission (CQC) to develop a robust human rights approach, promoting and measuring achievement of the agreed outcomes across the range of public and private provision. This should include CQC working with the Commission, other inspectorates and regulatory bodies on ‘themed inspections’, for example in relation to personal safety or health and well-being.

2.2 Access to publicly funded care and support based on clear, fair and consistent criteria

Proposal 2.2.1

The Commission proposes that everyone should be entitled to a self-directed assessment of their needs, irrespective of their income or of the funding available to local authorities to provide support, based on a clear framework of universal outcomes consistently applied across local authorities and other public authorities as appropriate.

Proposal 2.2.2

The Commission believes that equality and human rights outcomes are most likely to be achieved where people receiving care and support are able to move from one local authority area to another in the confidence that they will continue to receive an equivalent level and quality of support in their new place of residence, at least for an agreed transitional period. A ‘portability’ duty might be placed on local authorities to co-operate with one another to ensure effective transition, so enabling people requiring care and support and their families to enjoy equal freedom of movement.

Actions for the Commission

The Commission will consult on its proposal for a ‘portability’ duty to explore the implications of this approach with partners in local government.

2.3 Individuals and families in control of their care and support

Proposal 2.3.1

Everyone seeking care and support should be given access to accurate, accessible and tailored information and advice, and where appropriate, brokerage and advocacy, including in relation to human rights and non discrimination and equality.

Proposal 2.3.2

Primary legislation should introduce a right to control via individual budgets for all adults assessed as requiring care or support, including carers. The legislation should specify the circumstances in which the right might be challenged. Such legislation should include regulation-making powers, allowing Government to include, replace or withdraw funding streams and services from the legal provision as necessary over time.

Proposal 2.3.3

Local authorities should make provision, including working in partnership with other agencies or via a budget-holding lead professional to ensure that independent advocacy is made available to those who require it, in particular people with learning disabilities, mental health conditions, dementia or who are on the autistic spectrum.

Proposal 2.3.5

The National Skills Academy for Social Care should build on the commitment of Skills for Care, the General Social Care Council and the Social Care Institute for Excellence and play a central role in the transformation of care and support from a service-led to user-led culture.

Actions for the Commission

The Commission has a role to play both in providing high quality advice and guidance through our own helpline service, as well as contributing towards capacity building at the local level through our grants programme⁴⁶ for local organisations including user-led organisations which have an important role to play in delivering credible advice, information and guidance.

The Commission will produce and disseminate good practice guidance for local organisations and individuals concerning ways they can use equality and human rights legislation to influence policy and practice.

The Commission will conduct research concerning the availability and quality of independent advocacy across England, including making available grant funding for the piloting and evaluation of a series of independent advocacy

46 See www.equalityhumanrights.com/en/aboutus/grants.

projects targeting individuals, families and communities who may otherwise not experience the full benefits of personalisation.

The Equality and Human Rights Commission will work through others in helping to tackle low pay which has a disproportionate impact on women and BME workers, many who work part-time, and in order to raise productivity and efficiency through improved training and development as well as developing the supply of skilled and motivated social care workers for the future.

2.4 The right balance between safety and risk to promote choice and independence

Proposal 2.4.1

Local adult safeguarding boards should be placed on a statutory footing and the police and local partners should be placed under a statutory duty to participate and contribute, including in the sharing of information.

Proposal 2.4.2

Local authorities should routinely offer to facilitate and pay for Protection of Vulnerable Adults and Criminal Records Bureau checks, and through their information, advice and guidance function make clear the risks to individuals of not doing so. The Commission does not believe such checks should be made compulsory in legislation.

Actions for the Commission

The Commission has commissioned research into disabled people's experiences of targeted violence, harassment and abuse and will publish its proposals and actions to improve disabled people's safety and security in late spring 2009.

2.5 Local strategic partnerships that play a central role in developing and maintaining local care and support

Proposal 2.5.1

Local Strategic Partnerships and their constituent members should uniformly assume an explicit role to help shape, manage and sustain the local care and support infrastructure with success measured through Comprehensive Area Assessment.

Proposal 2.5.2

The Voluntary and Community Sector (VCS) requires sustained support from central and local government to promote and facilitate the voluntary giving of care and support. The Commission would welcome a new performance indicator for the Local Area Agreements and Comprehensive Area Assessment concerning performance on encouraging volunteering.

Proposal 2.5.3

More local authorities should facilitate the development of care and support ‘time banks’⁴⁷ to encourage the voluntary giving of low-level support such as cleaning, shopping, gardening and basic home repairs and maintenance.

Actions for the Commission

As part of the Commission’s good relations remit, we will work with local partners on approaches to improving networks of informal support, including via the Commission’s grants programme.

The Commission strongly supports the development of the ‘Lifetime Neighbourhoods’ agenda by the Department for Communities and Local Government and will work with the department and partners to develop a forward-looking agenda which ensures policy and practice on housing, planning, transport, the built environment and social cohesion are based upon a proper understanding of the implications of an ageing population.

2.6 Funding that balances affordability and sustainability with fairness**Proposal 2.6.1**

The Commission proposes the creation of a ‘prevention and promotion fund’ – ring-fenced match funding for support to achieve specific ‘invest to save’ objectives including in relation to health and employment. The Commission believes there is a serious case for examining whether funding for such an initiative could be channelled through the NHS, the Department for Work and Pensions and the Department for Communities and Local Government within the framework of cross-departmental PSAs, in order to incentivise further investment.

Actions for the Commission

The Commission expects and will monitor closely to ensure that any proposed approaches to funding are subject to rigorous impact assessment both in relation to equalities – including socio-economic factors – and relations between groups, including intergenerational relations.

47 See footnote 25.

2.7 Equality and human rights law and practice re-calibrated to respond to our ageing society

Proposal 2.7.1

The Equality and Human Rights Commission seeks a reformed framework of Equality Law which will:

- Incorporate or be accompanied by a clear timetable for the implementation of protection from discrimination on grounds of age in relation to goods, facilities and services.
- Include provisions for challenging ‘associative discrimination’ in all areas of equal treatment, including employment, education and goods, facilities and services in order to implement and build on the Coleman Judgement.
- Place an explicit duty on inspectorates, including the CQC, to promote and measure implementation of the single equality duty by public authorities and their agents.
- Clarify the responsibilities of public authorities to promote equality through procurement and commissioning.

Actions for the Commission

The Commission will assist local authorities and their agents to meet their equality and human rights obligations by:

- Making recommendations in the Commission’s forthcoming Human Rights Inquiry report to be published in spring 2009.
- Assisting public authorities to develop mechanisms to integrate positive obligations under the Human Rights Act with their work on public sector duties.
- Identifying and promulgating good practice on the promotion of equality and human rights through care and support.
- Producing and disseminating new practical guidance on good practice on involvement, equality impact assessment and promoting equality through procurement.

The Commission will conduct a review into the extent of compliance across local authorities with the public sector equality duties and will consider using its legal powers to enforce compliance amongst failing authorities.

The Commission will share expertise on equality and human rights with community care legal professionals and advice agencies and work with them to identify and intervene in care and support cases where equality and human rights law might be invoked.

The Commission will conduct research to identify the existence and extent of ageist policy and practice in the care and support system and make recommendations for reform.

The Commission will contribute to the review by the Law Commission of Community Care legislation to ensure its consistency with equality and human rights law and principles.

The Commission will report on Britain's performance in relation to care and support as part of the Commission's monitoring of Britain's international treaty obligations, including the Convention on the Rights of Persons with Disabilities, the Convention on the Elimination of all forms of Discrimination against Women and the Convention in the Rights of the Child.

The Commission will work with employers to develop the concept of 'agile working' and to explore how the modern workplace can better reflect the changing demography and life-demands of the working population, developing and disseminating best practice through its 'Working Better' initiative. The Commission believes the right to request flexible working should be open to everyone.

Appendix 2 – List of those consulted

The following people were consulted in the development of this report either through a one-to-one interview, participation in roundtable seminars or reviewing drafts of the final report:

- Gary Fitzgerald, CEO: Action on Elder Abuse
- Neil Hunt, CEO : Alzheimer’s Society
- Ian Johnston, CEO: British Association of Social Workers
- Katie Ghose, Director: British Institute of Human Rights
- Caroline Waters, Director People and Networks: BT
- Imelda Redmond, CEO: Carers UK
- Martin Routledge, Putting People First Lead: Care Services Improvement Partnership
- Steve Strong, Personalisation Team; Care Services Improvement Partnership
- Ian Winter, Social Care Lead/Regional Change Agent: Care Services Improvement Partnership
- Thomas Morn, Principal Policy Adviser: CBI
- Dame Denise Platt, Chair: Commission for Social Care Inspection
- David Walden, Director of Strategy: Commission for Social Care Inspection
- Mark Ivory, Editor in Chief: Community Care Magazine
- Sarah Spencer, Chair: Equality and Diversity Forum
- Stephen Burke, CEO: Counsel and Care
- Ann Begg MP, Chair: Cross Party Equality Committee
- John Bolton, Director of Strategic Finance: Department of Health
- David Behan, Director General of Social Care: Department of Health
- Jenny Morris, Independent Consultant: Department of Works and Pension
- Tim Bishop, Director of Partnership: East London NHS Foundation Trust
- Ramesh Verma, CEO: EKTA
- Catherine Gringer, Head of Communications: Employers Forum on Disability
- Ann Mackay, Director of Policy: English Community Care Association
- Martin Green, CEO: English Community Care Association
- Saghir Alam, Member of the 2025 Equality Advisory Group
- Anna Boaden, Mencap
- Caroline Tomlinson, In Control
- Ceri Goddard, British Institute of Human Rights
- Geoff Firmster, RNIB
- George Mills, EHRC
- Kate Groucutt, Carers UK
- Mark Brooks, Values into Action
- Melanie Danan, Interlink Foundation
- Sacha Rose, RAISE
- Seema Shah, Kingston BME Carers
- Stephen Lowe, Age Concern England
- Katharina Von-Schnurbein, Spokesperson for Employment, Social Affairs and Equal Opportunities: European Union
- Mike Wardle, Deputy CEO and Director of Strategy: General Social Care Council
- Mick Lowe, Director of Strategy: General Social Care Council
- Kate Jopling, Head of Public Affairs: Help The Aged
- Baroness Howarth of Breckland, Crossbench Peer: House of Lords
- Andrew Cozens, Strategic Adviser for Children, Adults and Health Services: IDeA

- Simon Duffy, Chief Executive: In Control
- Sophie Moullin, Research Fellow Social Policy: Institute of Public Policy Research (now at Prime Minister Strategy Unit, Cabinet Office)
- Lisa Harker, Director: Institute of Public Policy Research
- Baroness Greengross: Chief Executive: International Longevity Centre
- Alex O’Neil, Principal Research Manager: Joseph Rowntree Foundation
- Jane Standing, Chief Executive Officer: Kairos in Soho
- Colin Young, Director of Services: Leonard Cheshire Disability
- Paul Burstow MP, Lead Liberal Democrat, House of Commons: Liberal Democratic Party
- Jago Russell, Policy Officer: Liberty
- Dr Jose-Luiz Fernandez, Deputy Director: London School of Economics
- Julian Le Grand, Professor of Social Policy: London School of Economics
- Trish O’Flynn, Senior Policy Consultant: Local Government Association
- David Congdon: Director of Policy MENCAP
- Jo Williams, (ex) CEO: MENCAP
- Anna Bird, Policy Officer: MIND
- David Larpent, Chair: National Care Forum
- Neil Coyle, Senior Policy Manager: National Centre for Independent Living
- Gillian Dalley, CEO: Relatives and Residents Association
- Paul Jenkins, CEO: Rethink
- Andy Rickell, (ex) Disability Commissioner: Scope
- Julie Jones, CEO: Social Care Institute of Excellence
- Don Brand, Senior Policy Adviser: Social Care Institute of Excellence
- Professor Gillian Parker, Director: Social Policy Research Unit (SPRU) University of York
- Caroline Glendinning, Professor of Social Policy, Chair Social Policy Association: SPRU University of York
- Phillippa Russell, Chair: Standing Commission on Carer

Contact us

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