



Making Choices: taking risks

A discussion paper

December 2006

Vision and Values

The Commission for Social Care Inspection aims to:

- put the people who use social care first;
- improve services and stamp out bad practice;
- be an expert voice on social care; and
- practise what we preach in our own organisation.

Document purpose	Information for learning and improvement.
Author	Commission for Social Care Inspection (CSCI).
Publication date	December 2006.
Target audience	Directors of adult social services, chief executives and lead councillors of local councils with social care responsibilities in England. Health care professionals, academics and social care stakeholders.
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Online at	www.csci.org.uk/about_csci/publications.aspx
Free copies from	csci@accessplus.co.uk Admail 3804 Newcastle NE99 1DY Order line 0870 240 7535 Fax 01484 770142 Minicom 0845 015 2255
Order code	CCSCI-EXT-107-5000-CWP-122006 CSCI-184

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First published December 2006

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Chief Inspector's introduction

The Commission for Social Care Inspection (CSCI) is committed to putting people who use social care first. We listen to what people say they want from social care and ask them about their experiences. The Commission then assesses how far the services that people receive reflect the qualities that people value. Older people tell us they “want a life” not just services and acknowledge that to achieve that may entail some risks.

Government's public service reform agenda intends that people who need to call upon support from social care, should be able to exercise choice and control to help them live the kind of life they want. Real choice means having real options and support to choose between them. It also means being able to make choices that may not be what everyone would choose and to take reasonable risks to achieve the lifestyle people want.

As the population ages, the expectations of people who are now entering 'old age' will influence the way that social care support is designed, commissioned and provided in an unprecedented way. Most people know what they want from life as they grow older but people have told us that the support and care they get does not always help them get the best out of life. Most people make judgements and take decisions about things that affect them all their adult lives. Yet, from the point at which older people need to call upon assistance from social care to help them with daily activities, concerns begin to surface about risk and risk taking.

This paper highlights some of the risk-related factors that may prevent older people from living life the way they choose, proposes some ways that social care can support people's aspirations and choices and identifies some challenges. A companion paper, located on our website, explores the issues in more detail and includes aspects of practice to illustrate how some of the difficulties can be overcome. Drawing particularly on views and experiences that older people and carers have shared with CSCI, the paper is intended to contribute to Government policy development in creating a national approach to risk in social care and to wider debates around rights, choice and risk. We also hope it will provide a basis for Directors of adult social services to introduce local discussions with people using services, and professionals, about the nature of risk and how it might be managed locally in order to promote people's well-being.

Paul Snell

Chief Inspector

Commission for Social Care Inspection

Summary and key points

This discussion paper draws heavily upon the experiences and views of older people using social care about staying independent and taking risks.

People tell CSCI that risk-taking is part of everyday life but that they want to be able to call upon the right support at the right time to help them deal with risks without losing or reducing their independence. However, rather than supporting them to live the way they want, poor quality services can create risks for older people which they cannot control.

The key challenge for social care is to shift the balance towards supporting individuals who choose to take informed risks in order to improve the quality of their lives. The paper highlights some of the issues and challenges that this will entail in order for older people who call upon support from social care to have the best possible quality of life.

Key points

- Older people tell CSCI that they want to stay independent for as long as possible, with practical and emotional assistance when they need it. They recognise that meeting their choices and aspirations could sometimes entail some degree of risk. Respect for people's rights is enshrined in legislation and government policies to reform public services, including the Department of Health White Paper – *Our Health Our Care Our Say* – support people's wishes to exercise choice and control over their lives. But **older people continue to experience age discrimination from care services and are not always afforded the dignity and respect they have a right to expect.**
- Ageing, by its very definition, is about change. The lives of older people are complex and unpredictable and, by virtue of living longer, they have considerable experience of making judgements about risk. **People using social care need people with the right attitudes and skills to help them prepare for the life changes associated with ageing and to help deal with risk and adapt to it over time – not just to arrange, or even to broker, services.**
- Where they lack capacity, older people need to know that people will act in their best interests to help them secure the best possible quality of life. **Social care can also help older people and carers to have an “anticipatory voice”,** encouraging them to think

through the changes that could occur as they or the people they care for grow older, alongside their aspirations, helping them to assess risks and to make their preferences known. **Frontline staff need to be better trained so that, rather than making decisions for people, they are encouraged and supported to help people make choices that will enhance their quality of life.**

- Worries about risk – by other people, organisations, wider public perceptions and the media – can affect the personal choices that individuals calling upon support from social care are able to make and the amount of control they have over their everyday lives. Rather than encouraging independence this can make older people more dependent; it can prevent them from achieving the outcomes they want. **Organisations and individuals with an interest in promoting the well-being of older people need to consider whether they have got the right balance between enabling the personal choices of individuals versus the perceived risk to organisations if things go wrong.**
- The outcomes-based approach to regulation and performance assessment being developed by CSCI places issues of risk firmly in the context of people being independent, having choices and exercising control. Of course robust safeguards need to be in place to ensure people are protected from mistreatment. But there is also a **need for robust, yet sensitive, approaches to dealing with risk in social care that take account of the need to maintain independence and well-being alongside health and safety considerations.**
- Commissioners, providers and regulators in social care need to play their part in promoting this cultural shift; but the challenge extends to policy makers and those responsible for delivering better public services across central and local government – and to **local communities that are well-placed to promote the rights and choices of all older citizens.**

We hope that this discussion paper will contribute to the development of a national approach to risk in social care and to wider debates about risk. Most importantly, we want to ensure that older people have a strong voice and are placed firmly in the driving seat when it comes to decisions about how they live their lives.

Background

Why older people?

“Let’s be more robust in confronting the reality of our longer lives. We are making choices for ourselves.”¹

“Age, in itself, is not a disability but it brings disabilities and we have to adjust... We still want to be masters of our own destiny.”²

“The people in the home said ‘we can’t let you go out as we can’t take the risk that you might get run over’ ”³

1.1 The debate about balancing rights and risks to support people in achieving the right outcomes for them is of fundamental importance to **all** adults using social care, including carers. This paper focuses on older people because:

- **Demographic challenges** – There is a higher proportion of older people in the population than ever before.⁴ By 2007 the number of Britons aged over 65 will exceed the number of those aged under 16 for the first time.⁵ By 2031 the number is projected to exceed it by almost 4 million.⁶
- **Financial implications** – Earlier this year, the review of social care funding led by Sir Derek Wanless concluded that, at the current rate, spending on personal care for older people in England would have to treble by 2026 to meet the needs and expectations of the ageing ‘baby boomer’ generation⁷
- **It’s personal!** Changing expectations and forces of demography mean that this is an agenda that connects with most people, either because they are thinking
 - ‘What do we want from life as we grow older and how will we get the right support when we need it; or
 - ‘How do we help our elderly relative or friend to get the support they need or – increasingly – that we need ourselves as their carer’.

- **The current state of social care** – As eligibility criteria tighten, evidence is emerging that older people are experiencing increasing difficulties in obtaining services.⁸ Ageist assumptions that older people do not want to take on the responsibilities associated with direct payments⁹ mean that they may fail to access the same benefits as younger adults. There is evidence, too, of age discrimination and ageist attitudes when care services fail to treat people with dignity and respect.^{10 11} The same study highlighted shortfalls in meeting the needs of people from black and minority ethnic communities and support for mental health and well-being.¹²
- **Legislative changes** – From 2007, the Mental Capacity Act 2005 – which assumes that a person has capacity unless proven otherwise – will require all decisions to be made in the ‘best interests’ of people that lack capacity. People with capacity must be allowed to take unwise decisions.¹³ This Act, together with other legislation designed to promote Equalities and to safeguard Human Rights¹⁴ have the potential to create the right conditions to empower older people to exercise more control.
- **Getting older implies change** – at the personal level, for organisations adapting to an ageing population and in terms of the impact of ageing on society. Older people, those working with them and those planning for all our futures need to take time to anticipate choices, think through the risks associated with change and prepare for them.

1.2 In fact, Government’s agenda to reform public services challenges everyone to think differently about ageing and to behave differently towards older people. Some key questions that emerge from CSCI’s discussions with older people are:

- *Why do older people who need to call upon social care for assistance get **treated as if they’ve “just arrived from another planet as a problem older person”**¹⁵ and can take no responsibility for what happens to them?*
- *How can we shift the prevailing paternalistic culture in social care to encourage people to think how they can **enable older people to do things** rather than worry about all the reasons why they can’t?*
- *What needs to change to ensure that social care for older people is about having relationships based on mutual respect – that can **deliver the outcomes people want in order to lead fulfilling lives?***

What do people say they want?

“We want to remain in control over our own life and money... even in a residential home.”

“It’s not possible for life to go on without taking reasonable risk. But there are grey areas that people should get support on how to balance the risks without sacrificing independence.”¹⁶

- 1.3** People tell CSCI they want independence and choice – choice to decide where, how and with whom they live their lives. They want services to be flexible enough to fit around them as individuals that are consistent, reliable and safe. They want support from competent people who they can trust, that afford them respect and dignity as people as well as meeting their physical needs. Importantly, they want to determine how services are delivered.
- 1.4** Older people using social care told the Commission that, like other people, if they are to “have a life”, they expect to take some risks. They said that risks are different for each person and can change from day to day and throughout life so risks need to be shared and to be managed with them. Good person-centred assessment should respect people’s rights and wishes and translate into flexible, responsive support that puts people firmly in the driving seat. They said that sometimes there can be conflicts about risk taking between individuals and their carers or relatives – particularly where there are questions about a person’s mental capacity. In addition, risk-averse public attitudes and media opinion can inhibit people from exercising choice.
- 1.5** Older people at a CSCI seminar agreed that growing older should not, in itself, be a reason for losing independence or control over their lives. Each older person needs help to find the right solutions for **them** but some described problems with getting the help they need. People talked about the barriers to accessing information that they saw as key to helping them make choices and adapt their behaviour to deal with risk. People who do not speak English as a first language said translated information was no substitute for talking to real people who could listen and respond to their individual needs. Lack of support to plan for the future particularly worried people who were not eligible for public funds. Carers spoke about difficulties in getting the right support, in the right way, at the right time. People concluded that risk-taking is part of everyday life but that they want to be able to call upon the right support and information when they need it to help them make informed choices and to deal with risks without losing or reducing their independence.



The policy context

1.6 Government public service reform policy signals a different sort of relationship between the state and the individual. In social care, it heralds a significant shift in power from organisations to individuals. It means putting individual citizens in control and enabling them to exercise greater choice about the way that support and care is provided to help them live their lives. Some people have told CSCI that they have opted to use direct payments precisely because they take control and make choices that might not otherwise have been open to them.¹⁷ Bringing together a number of policy drivers and funding streams, individual budget

pilots¹⁸ will test out whether people can experience these benefits whether or not they choose to have cash payments and employ staff.

- 1.7** The debate about rights, risk and choice is central to taking forward this public service reform agenda to put people using social care in control. But the debate will be limited if it only focuses on people's physical or mental capacity as there are many other factors that can inhibit people from living life the way they choose. For instance, patterns of commissioning that result in inconsistent and unreliable service delivery or poor care practices can also create risks that take control away from people.
- 1.8** Debates and development of policy around risk and choice for older people should centre around what outcomes people want and how social care can support this. The seven outcomes for adult care services outlined in the White Paper, *Our Health Our Care Our Say* (below) provide a framework for assessing where people's overall well-being can be at risk and for managing those risks. These outcomes have a rights base too. For example, for people to be afforded dignity in care, it is important to focus on their fundamental human rights and freedoms – including the right to exercise choices about things that affect them. Such choices – even informed ones – may entail risks.

Outcomes for adult social care¹⁹

- Improved health and emotional well-being
- Improved quality of life
- Making a positive contribution
- Choice and control
- Freedom from discrimination
- Economic well-being
- Personal dignity

1.9 Respect for people's rights is intrinsic to social care values and should be central to public service ethos in the UK. The Human Rights Act 1998 (HRA) is of fundamental importance to promoting and protecting the rights and freedoms of older people and carers. However findings from a joint review of progress in implementing the National Service Framework for Older People²⁰ showed that older people continue to experience discrimination in the delivery of social care and health services. The debate about rights, choice and risk in social care needs to start from the point of asking how people want to live their lives and to tackle the barriers that prevent them from doing so.

How does “risk” inhibit older people from living the way they want?

*In law, every adult has the right to make their own decisions and is assumed to have capacity to do so unless it is proved they do not.*²¹

“It’s like, if you make a choice not to take risks that’s fine, but if someone else stops you, it’s not.”

*“You should be able to make your own decisions, depending on what level you feel safe at. You spend your whole life making decisions about things – your work, your relationships, your children. You don’t want to suddenly give up that responsibility because you’re older.”*²²

- 2.1** A Government report in 2002 said that there are nearly as many different definitions of risk as there are types of risk.²³ Two years later, a challenging paper suggested that more and more events are described in terms of risk in an effort to deal with uncertainty and yet the concept remains elusive.²⁴ A report from HM Treasury the same year defines risk as “*uncertainty of outcome, whether positive opportunity or negative threat, of actions and events.*” It says that identification and assessment of risk should consider the likelihood of something happening and the impact if it actually does happen. It emphasises that risk is unavoidable but describes the amount of risk that is seen to be tolerable as the “*risk appetite*”.²⁵
- 2.2** Principles and concepts from **organisational risk** management – such as within the Treasury model – can inform understanding of dealing with risk in social care up to a point. However, there are some weaknesses in organisational models of risk management when applied to social care. People’s lives are unpredictable and complex and may become increasingly so as they grow older. People may need access to help from practitioners with sensitive problem solving skills that can help them identify and assess risks, to take action to mitigate them but also to deal with them as they emerge and adapt over time. This model assumes that the benefits of certain outcomes

have already been identified. This may be the case for organisations but judgements about **personal risk** should always ensure that the benefits to that individual are considered alongside any negative consequences that might occur.

- 2.3** Life is uncertain for everyone but people decide what outcomes they want and, having assessed the likelihood and impact of risks and weighed up the benefits, they adapt to the risks that go with the actions they decide to take. Some people, including those who are disabled, physically frail or have more limited mental capacity, need to call upon support from social care to achieve the best outcomes for them and to live safely. Government has assured their right to expect certain standards of care by establishing National Minimum Standards for regulated services. It has specified that safeguards should be in place should their fundamental rights and freedoms be infringed. It has also established provisions in the Mental Capacity Act 2005 to ensure that everyone acts in the 'best interests' of those that may lack capacity.



"If people are in desperate need but social services can't come it's risky. People need to push but we don't have the confidence."

"If you start to think that everyone you come into contact with needs a police check you'll never get a life."

"I receive a cleaning service but it creates risk I think. You never know who they are going to send. You might let someone in who's not from the service. You don't know who to trust."²⁶

2.4 Rather than being supported to deal with personal risk in order to achieve what they want from life, older people using social care may experience:

- poor quality support which creates risks for them over which they have no control; in the context of
- a prevailing risk averse culture where risk is regarded as threatening and to be avoided wherever possible.



2.5 The companion paper to this document explores this in more detail. The issues emerging from discussion with older people and carers include:

- **Capacity and choice** – The need to start with the assumption of capacity and act in people's 'best interests'. Helping people to have an 'anticipatory voice' by planning ahead and making their preference known.
- **The nature and culture of risk in social care** – How can we shift

the balance of power from organisational to personal risk assessment? How an outcomes-based approach to dealing with risk can help promote positive risk-taking.

- **How poor quality services create risks for people** – with examples from people using services and evidence from inspection about how poor information, assessment, care planning and provision can result in unsatisfactory outcomes.
- **Being safe can also mean taking risks** – In the pursuit of safety from harm, practitioners may over-protect people and inhibit their rights and choices.
- **Risk and responsibility** – posing questions about acceptable levels of risk and 'whose risk is it anyway', and highlighting the need for good information, infrastructure and support to put people in control.
- **Managing conflicting rights and choices** – especially if there are different views, between older people and their carers or relatives, about acceptable risks.
- **Public expectations and the role of the media** – acknowledging that there may be different perspectives on who is to blame when things appear to go wrong.

- **What is a safe environment?** – Do regulations help keep people safe but get in the way of enabling them to achieve their aspirations? Or are providers giving undue weight to minimising organisational risk rather at the cost of well-being of individuals?
- **Risk of physical harm versus risk to independence and choice** – highlighting that, without effective risk management in partnership with them and the right support, people can lose control and become increasingly dependent.

Risk to independence – A case example

Mrs Daniels is an 82-year-old widow who has lived alone since her husband died ten years ago, choosing to remain in the home she had lived for nearly 40 years. Her only close family members live some 50 miles away and visit infrequently but her informal network has always been supportive. She has chronic arthritis and osteoporosis and is becoming increasingly physically frail but her mental capacity is sound.

A fall resulted in complications that left Mrs. Daniels housebound and virtually immobile. Recovering from the shock of the fall, Mrs. Daniels resolutely refused acute care but appealed for help at home. Social services were unable to respond immediately but her daughter arranged some private domiciliary care and her GP referred her to the intermediate care team. In the first two weeks after her fall, Mrs. Daniels was visited or contacted by about 25 different people and told her story many times over. Nurses, GP, community care officers, care staff and an occupational therapist told her not to attempt to walk alone in case she fell again. There was no clear plan and, while she struggled to retain her dignity, independence and some control over her life, no one had enough time to stay and support her to walk. Five weeks on, the adult care team had visited once but Mrs. Daniels had not received a copy of the assessment or care plan. Each day that passed, she ceased to believe that she would ever walk again.

Caregivers honoured Mrs. Daniels' wishes to remain at home after a fall, preventing possible admission to hospital or a care home. However, lack of co-ordination and person-centred planning, including assessing and making judgements about risk in partnership with her, meant that individuals judged what they believed to be in the best interests of Mrs. Daniels. Consistent advice **not** to attempt to walk alone in the interest of keeping her physically safe could have undermined the potential for Mrs. Daniels to resume activities of daily living, resulting in her increasing dependence upon others for her care. The control she is able to exercise could diminish along with her independence.

How can social care support older people's aspirations and choices?

"I recall my mother saying, when she first faced a raft of assessments, that the professionals (unintentionally) treated her as if she had just arrived on the planet as a problem older person, rather than as a woman who had already managed some 86 years without the involvement of services."²⁷

"You need to help people to manage risk in a way that's acceptable to them."

"Every risk needs to be managed on an individual basis – you can't write it all down in detail because you don't know what his choices are going to be for that day."²⁸

3.1 Some key messages about what could make a difference for older people with 'hints and tips' from people using services include:

- **Deliver person-centred support for choice** – The White Paper ²⁹ vision about putting people in control can only be achieved if practitioners think creatively and services focus on people as individuals with aspirations and fears – rather than just on their problems or conditions.
- **Put services around people not people into services** – Good social care assessments build up a picture of someone's whole life and recognise that older people want opportunities to try new things; they also acknowledge that older people are skilled at managing risk.
- **Rethink the social work contribution** – Combining traditional skills, learning lessons from other areas and drawing from organisational risk management models, social work with older people and carers needs to be re-defined. The future role might include helping people to prepare for the life changes associated with ageing ³⁰, drawing upon their experiences, exploring their aspirations and supporting them through conflicting relationships. It might

also be about working with people to identify, assess and mitigate risk as well to deal with risk as it arises and adapt to it over time – thus, enabling people to achieve their desired outcomes. The future role could be about more than arranging – or even brokering - services.

- **Manage risk with people not for them** – working in partnership to support them in diverse and changing circumstances and making life-changing decisions, such as on discharge from hospital.
- **Learn from the experience of younger adults** – for example, key initiatives to promote self-directed care such as “In Control”.³¹
- **Learn lessons from other sources – carers, and new initiatives** – evidence about what works is emerging from a range of sources; sometimes it is just the simple things that help people to adapt their behaviour to live an ordinary life.
- **Help people to design and create solutions that are right for them** – they often generate ideas for themselves that can work for others.
- **Harness social capital and community support** – engaging local people – the voluntary and community sector, councillors, neighbours and friends – to help voice their aspirations, deal with social and individual risks and stay independent.

Older people designing the right solutions for them – Maggie Kuhn and Homeshare³²

Maggie Kuhn – founder of the *Gray Panthers*, an older people’s rights group in the United States – was a tireless campaigner on human rights, age discrimination, pension rights and nursing home reform until she died at the age of 89. She is quoted as having said “*The worst indignity is to be given a bedpan by a stranger who calls you by your first name*”. She criticised housing schemes for older people on the grounds that, while they may help people keep safe, they segregated older people from the mainstream. She opted to share her home with younger adults who received low rent in exchange for help with chores and companionship.

Maggie Kuhn founded the “Shared Housing Resource Centre” which continues to develop and promote a network of homesharing across the United States and other parts of the world. A relatively small, but growing, Homeshare network exists in the UK and Adult Placement Schemes are exploring the potential further with support from the Department of Health. It won’t suit everyone – some older people may be concerned about the risks. But there will be others who embrace the concept and find that it provides mutual inter-generational support that can help deliver the best outcomes for them.

Challenges

“You need to break down the institutional mindset. Whatever has been good for my husband has been good for me.”

“Person-centredness is not a plan – it’s about how people behave.”

“We should be there speaking up, otherwise people make decisions which are not ours and we lose control.”³³



Delivering the public service reform agenda to put older people in control presents a number of challenges. These include:

- **Policy challenges** – To be truly citizen-centred, policy development and implementation across government needs to start with people, how they want to live their lives and what they can contribute. Development of a national approach to risk in social care needs to connect with other key initiatives across government. Different approaches, or lack of coordination and coherence could create risks for people. Issues of choice and risk for older people need to be central to debates about transformational government³⁴, value for money and social care funding.
- **Councils** – Local councils play a key leadership role in promoting rights and well-being for all citizens. Alongside their

safeguarding role and that of securing sufficient good quality care services for all citizens that need them, councils need to promote the general well-being of older people; for example, better housing and transport for older people can minimise risk and social isolation by enabling people to participate in community life. The Director of adult social services has a pivotal role across the council and with partners but also in listening to people and promoting development of innovative and flexible support options.



Councillors, as local community leaders and members of Overview and Scrutiny Committees, are well-placed to promote wider public awareness of people's rights as well as to challenge wherever older people are not afforded the dignity and respect they have a right to expect.

- **Providers** – need to be encouraged to embrace the new agenda, develop their vision for developing person-centred services that support choice and build partnerships and alliances to facilitate change. They need to consider whether efforts to minimise organisational risk are appropriately weighted against the potentially adverse risks to the overall well-being of people using their services. Though well placed to develop new models of care, there are particular challenges for providers who are competing in a market where there is a shortage of people with the right skills and a need for better information about what works.
- **Citizens and communities** – Dealing with risk is not just something for professionals or organisations in social care. But, in developing and improving practice, it is important to ask people using services what they think about applying organisational models of risk management to help them deal with personal risk. With the right support, people using services can be empowered to have a stronger local voice alongside other active citizens, professionals, families, volunteers and others that contribute to their local communities. The voluntary and community sector have an important, but not exclusive, contribution to make in ensuring the right infrastructure is in place to facilitate this.

- **Better regulation** – As performance assessment and regulatory activities become more outcome focused, achieving the right balance between promoting independence and choice and ensuring people are protected from harm will be a challenge for all regulators working in situations where people’s circumstances may make them vulnerable. A recent paper from the Better Regulation Commission³⁵ has called for a new public debate about the management of risk and asks us to think differently about the interaction of risk and regulation. It is important to ensure that the values underpinning independent living and good social work practice contribute to that debate as well as to improvement in the quality of care and management of risk. It is also vital to ensure that the experience and best interests of people using services remain at the heart of any changes in the regulatory framework.

Acknowledgements

We would like to thank the people using social care, carers, interpreters and advocates whose contribution to CSCI seminars in Manchester and Leicester helped us to understand more about the relationship between choice and risk. We are also grateful to the people of West Sussex who recently shared with us their early experiences of being part of an individual budget pilot.

We'd especially like to thank members of the CSCI Older People's Services Improvement Board – an advisory body established by CSCI to influence the way it works - and others who helped us explore issues about choice and risk further, who helped to plan the Leicester event, who chaired and led discussions and who have been part of an editorial reference group for this discussion paper. Particular thanks are due to Mary Parkinson, Enid Irving, Mary Grant and Stan Davison.

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 - 29 Department of Health (2006) *Our Health, Our Care, Our Say*. London: Department of Health.
 - 30 See, for example, the report from the Social Exclusion Unit which describes the

changes that people in the later stages of the life cycle need to adapt to as they grow older. Office of the Deputy Prime Minister (2006) *A Sure Start to Later Life: Ending Inequalities for Older People*. West Yorkshire: ODPM Publications.

- 31 For further information see www.in-control.org.uk
- 32 See Kuhn M., Long C., Quinn L. (1991) *No Stone Unturned: The Life and Times of Maggie Kuhn*. New York: Ballantine Books.
- 33 CSCI seminar participants.
- 34 Cabinet Office (2005) *Transformational Government. Enabled by Technology*. London: Cabinet Office – sets out Government plans to make services more accessible and convenient by moving to a culture of shared services, supported by technology and designed around the citizen.
- 35 Better Regulation Commission (2006) *Risk, Responsibility and Regulation – whose risk is it anyway?* London: Better Regulation Commission.



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CCSCI-EXT-107-5000-CWP-122006

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