

Close to home

An inquiry into older
people and human
rights in home care

Acknowledgements

This has been a collaborative inquiry, significantly enhanced by the commitment of an expert advisory group listed below. Their advice and insights have greatly assisted us.

Our advisory group was made up of representatives from:

- Action on Elder Abuse
- Association of Directors of Adult Social Services (ADASS)
- Age UK
- British Institute of Human Rights
- Carers UK
- Counsel and Care
- Care Quality Commission (CQC)
- Department of Health
- English Community Care Association (ECCA)
- Local Government Association
- National Care Forum
- National Pensioners Convention
- Social Care Association
- United Kingdom Home Care Association
- UNISON

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“Where, after all, do universal human rights begin? In small places, close to home... Unless these rights have meaning there, they have little meaning anywhere.”

Excerpt from Eleanor Roosevelt’s “The Great Question” (remarks delivered at the United Nations, New York, March 27, 1958)

Foreword

Barely a week goes by without some news that calls into question how the existing care system can continue to meet the needs of society. As social care reforms gather pace ahead of the government's White Paper expected in spring 2012, this report sets out our specific concerns about human rights in home care for older people and our recommendations.

Our inquiry has uncovered serious, systemic threats to the basic human rights of older people who are getting home care services. Our evidence gives a comprehensive picture of weaknesses in the home care system, their impact on older people and shows how easily breaches of human rights in home care can occur.

Our findings suggest that age discrimination is one of the key factors explaining why older people face risks to their human rights in home care services. We have uncovered worrying examples of where someone's age determines the funding and provision of home care services.

Universal, basic human rights are an essential standard, not an optional extra or burdensome red tape. Our evidence indicates that embedding human rights into the way home care is provided delivers high quality care, without necessarily increasing costs.

This report proposes some steps that would make sure human rights are protected in future – including changes to the law so that, at a minimum, all people getting publicly funded home care are protected by the Human Rights Act. Currently this is not the case.

Local authorities already have responsibilities under the Human Rights Act to protect and promote the human rights of older people needing home care – but often don't understand those responsibilities or how to put them into practice when commissioning services from private or third sector providers.

Most of us will want to carry on living in our own homes in later life, even if we need help to do so. When implemented, the recommendations from this inquiry will provide secure foundations for a home care system that will let us do so safely, with dignity and independence.

Society has to get this right, before it's too late. Tackling this now will make life better for a generation of older people and their families.



A handwritten signature in black ink that reads "Sally Greengross".

**Baroness Sally Greengross OBE
Lead Commissioner for the Equality
and Human Rights Commission's
Home Care inquiry.**

Part 1: About the inquiry

Why this inquiry?

We have conducted this inquiry to find out whether the human rights of older people wanting or receiving care in their own homes in England are fully promoted and protected. There has never been a systematic inquiry into the human rights of older people receiving or requiring home-based care and support. Although far more older people receive home care than either residential or nursing care,¹ the human rights of older people in residential and hospital care have received much more attention.²

The potential risks to human rights when care is provided ‘behind closed doors’, in people’s own homes – a less easily regulated environment – are in many ways greater than in institutional settings. There is also evidence that older people face particular risks to human rights associated with the provision of care and support services, especially at home. For example, there has been evidence of breaches to the prohibition against inhuman or degrading treatment and to the right to respect for private and family life.³

As we explain below, the Human Rights Act 1998 (HRA) provides a legal safety net for many, but – because of the way the HRA has been interpreted by the courts – this protection does not extend to the majority of older people receiving care at home. Over the last 10 to 15 years, there have been significant changes in the provision of home care. This ‘quiet revolution’ has seen a shift from local

authorities delivering care themselves to commissioning (sometimes jointly with health authorities) private and voluntary sector care agencies to deliver home care on their behalf. In 1992, the proportion of publicly funded home care provided by the private and voluntary sectors was only 2 per cent,⁴ but by 2009/10 this had increased to 84 per cent.⁵ Decisions taken by the courts mean that private and voluntary sector organisations are almost certainly not subject to the HRA when performing this role. However, when the HRA came into effect, in 2000, many more older people would have benefited from its protection because at that time 44 per cent of home care was provided directly by local authorities.⁶

The recent changes have also brought a greater use of personal budgets, including direct payments. By 2009/10, 10 per cent of the older people receiving publicly funded social care were arranging their care in this way.⁷ Expenditure on direct payments for older people receiving day and domiciliary care increased from £190 million in 2008/09 to £250 million in 2009/10.⁸ This has contributed to a mismatch between the state’s duty to assess and arrange care – which is covered by the HRA – and the actual provision of home care, the vast majority of which isn’t.

The government’s White Paper on the future of social care is due to be published in spring 2012, and far-reaching changes to the social care system are expected to follow. This inquiry is well placed to

influence these changes. Its findings are providing a strong evidence base to inform the Commission's response to the White Paper. We will capitalise on the opportunities to embed our inquiry findings and recommendations into future policy and legislation.

About the Equality and Human Rights Commission

The Equality and Human Rights Commission is the regulator of equality and human rights. This inquiry builds on our Human Rights Inquiry published in 2008 and dovetails with our forthcoming Human Rights Review to be published in early 2012.

The Commission has a duty under Section 9(1) of the Equality Act 2006 to promote awareness, understanding and protection of human rights, and encourage public authorities to comply with the HRA. We also have a general duty to exercise our functions 'with a view to encouraging and supporting the development of a society in which ... there is respect for the dignity and worth of each individual'.

Under Section 16 of the Equality Act 2006, the Commission may conduct inquiries into issues or sectors where there are concerns relating to human rights and/or equality. Through our inquiry powers, the Commission can require organisations to provide evidence, both in writing and in person. The Commission must publish a report and may make recommendations to organisations or individuals which they need to 'have regard to'.⁹

Terms of reference for the inquiry

The inquiry was launched in November 2010 with the following terms of reference:

To inquire into the extent to which the human rights of older people who require or receive home-based care and support, however funded, are promoted and protected by public authorities, working singly or with others, and the adequacy of the legal and regulatory framework within which they are required and empowered to do so.

While the inquiry is focused specifically on older people – which we have defined as those aged 65 and over – the majority of these home care users would also fall within the legal definition of 'disabled' under the Equality Act 2010.

In particular, the inquiry aimed to identify:

1. The extent to which public authorities are effective in protecting and promoting the human rights of older people, including those paying for their own services, in the initial and ongoing assessment of their needs, commissioning home-based care and support and subsequent contract management.
2. Good practice in the promotion and protection of human rights of older people in home-based care, including by reference to examples of how public authorities have addressed human rights matters in discharging their existing duties to promote race, gender and disability equality or through the development of single equality schemes.

3. Public authorities' understanding of their duties under the Human Rights Act in relation to promoting and protecting the human rights of older people requiring or receiving home-based care and support.
4. The extent to which the legal framework for human rights and community care adequately protects and promotes the human rights of older people requiring or receiving home-based care and support services.
5. The extent to which appropriate information, advice and advocacy is provided to older people directly purchasing home-based care and support in order to protect and promote their human rights.
6. The extent to which inspectorate and regulatory bodies, including professional regulatory bodies, protect and promote the human rights of older people requiring or receiving home-based care and support services, and the extent to which it is appropriate for them to do so.
7. The scope for enhancing the role of inspectorate and regulatory bodies, including professional regulatory bodies, individually and collectively, in promoting and protecting the human rights of older people receiving home-based care and support.
8. The extent to which people, including the families of older people requiring or receiving care and support, based on their experience, have confidence that the system will promote and protect their human rights.

In carrying out this inquiry, we have taken into account the extent to which the diverse experiences and needs of older people related to their disability, age, gender, gender identity, race or ethnicity, religion or belief, and sexual orientation are effectively incorporated.

How we conducted the inquiry

Where our evidence has been drawn from

To gain a rounded picture of how the human rights of older people are promoted and protected, we gathered a broad evidence base from 1,254 individuals and organisations across England. The evidence came from older people, their friends and families, organisations that provide home care and their staff, local authority staff and elected councillors, as well as people from government, the voluntary sector and regulatory bodies.

We used a range of methods to collect the evidence, including:

Written evidence

We sent out a 'call for evidence' aimed at older people, their friends and family, individuals working in this sector and voluntary sector organisations. We received 560 responses – 361 from older people, their friends and family, 148 from individual workers, and 61 from organisations.

Drawing on our interim findings, we also sent 12 targeted requests for evidence to government departments, regulators and national organisations with expertise in the area.

Focus groups

Thirteen focus groups, attended by 178 people of different age groups, aimed to ensure that our evidence base represented the views and experiences of a wide variety of groups, including different ethnic and faith groups and older lesbian, gay, bisexual and transgender people.

Interviews

We conducted 150 in-depth interviews with local authority staff and councillors, organisations providing home care, home care workers and voluntary sector organisations from across England. Verbatim transcripts of these interviews were analysed using qualitative analysis software.

Interviews with older people

Independent Social Research was commissioned to conduct 40 face-to-face interviews with older people using home care services in four different areas of the country.

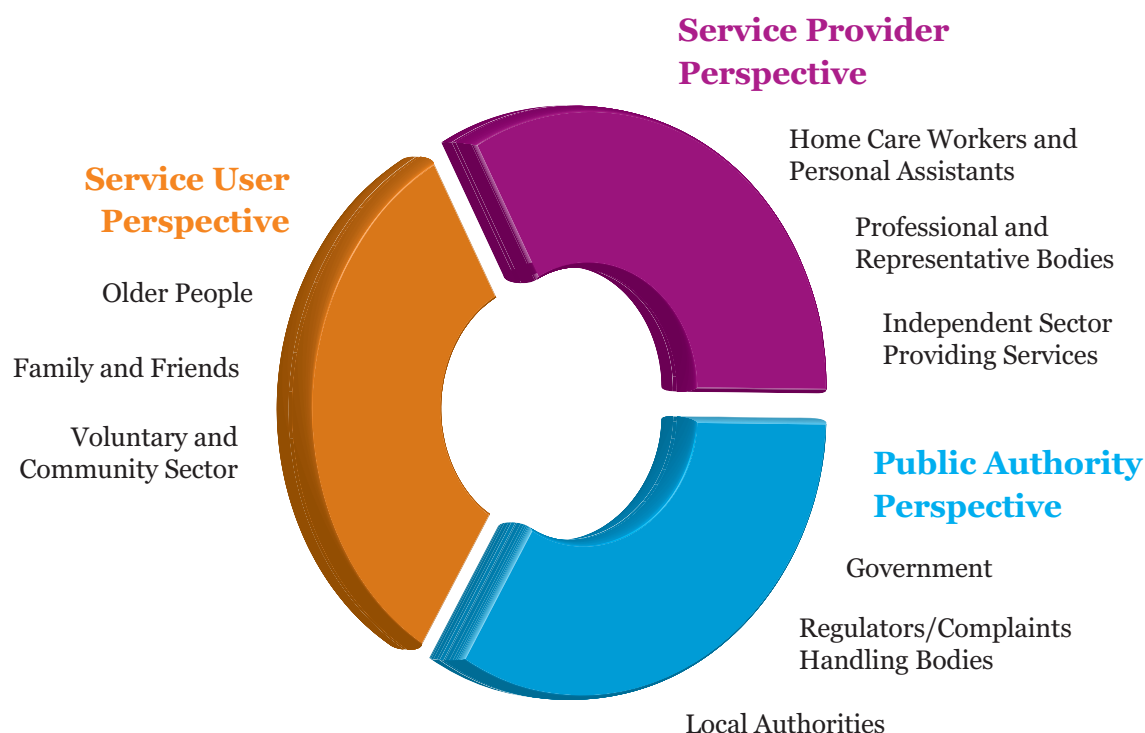
Surveys of local authorities and care provider organisations

IFF Research conducted two surveys on our behalf:

- an online survey of local authorities – we received 83 responses (a response rate of 54 per cent)
- 250 telephone interviews with a range of organisations that provide home care.

Where a person's need for care is primarily due to their health needs, a home care package may be fully funded by the NHS under the 'continuing healthcare' provisions.¹⁰ However home care commissioned or provided by local authorities is much more common for long term care and we therefore chose to focus on home care that was not funded by the NHS.

Evidence Collection



Supplementary reports

Supplementary reports which were obtained or prepared in the process of our evidence collection can be found on the Commission's website. We have drawn on these in writing this report.¹¹

Analysing the evidence: using a human rights framework

We identified a series of areas where an individual's human rights might be at risk in the context of home care services. This was then used as a framework for our evidence.

Our starting point for this inquiry was the rights protected by the European Convention on Human Rights (ECHR) as these are part of our law and can be enforced through the HRA. However, we also took into account certain rights under the UN Convention on the Rights of Persons with Disabilities (CRPD) which are particularly relevant to people using home care services.¹² In addition, we referred to the UN Principles for Older Persons, which were adopted by the UN to help guide national policy programmes for older people.¹³

Drawing from these human rights documents, we adopted a framework for our evidence collection. This framework sets out four broad headings, subdivided into key areas of risk where the provision of home care might compromise an individual's human rights.

Dignity and security

- Physical wellbeing – including freedom from physical abuse or neglect, protection from pharmaceutical/medical abuse and sexual abuse
- Psychological and emotional wellbeing – including freedom from bullying and threats, or disrespectful treatment, and respect for cultural heritage and religion
- Financial security/security of possessions – including protection from financial abuse and, for those without mental capacity, decisions taken in one's best interests

Autonomy and choice

- Self-determination – including the right to live as independently as possible, to make routine decisions and to be consulted about professional decisions
- Support for decision-making about care – including information and advice about options and being given meaningful choices

Privacy

- Respect for privacy – including modesty when dressing/bathing and privacy when one's personal circumstances are discussed by others
- Respect for private correspondence – letters, phone calls, private documents

Social and civic participation

- Maintaining relationships with friends and family
- Participation in community events, groups and associations, religious or non-religious activities

- Civic participation – including the right to vote in elections.

In analysing our evidence, we also took into account the different experiences of particular groups, for example older people from ethnic minority communities and older lesbian, gay and bisexual people.

In Part 3, we look at the experiences of older people using home care services and identify whether breaches of rights protected by the HRA are likely to have taken place. Where appropriate, we considered whether there had been compliance with the CRPD.

The legal and regulatory framework

What are human rights?

Human rights are the fundamental and irreducible rights of every individual, representing moral and ethical principles that are central to a democratic society. They are founded on a framework of fundamental values: dignity, autonomy, equality, fairness and respect.

The United Nations adopted its Universal Declaration of Human Rights in 1948 as a response to the atrocities of the Second World War. This was followed, in 1950, by the European Convention on Human Rights (ECHR), which focuses mainly on civil and political rights. Drafted primarily by British government lawyers, the ECHR was ratified by the UK in 1951. However, before the Human Rights Act (HRA) became law, anyone claiming that their ECHR rights had been breached could not bring a claim in the UK courts. They had to bring a case against the state itself –

that is, against the UK – to the European Court of Human Rights in Strasbourg.

The Human Rights Act 1998

The ECHR was made part of our law by the Human Rights Act 1998 (HRA). The HRA requires public authorities to act compatibly with the ECHR, as far as their statutory powers and duties allow them to do so. As a result of the HRA, an individual who believes their rights have been infringed can bring a case in our own courts against the public authority concerned. However, if their claim fails, the person could bring a human rights claim against the state (the UK) in the European Court of Human Rights. The state is responsible to this court for any breaches of the ECHR caused by a public authority.

The effect of the HRA is that local authorities must take into account ECHR rights in relation to all of their functions. These functions include the provision of public services to individual users – for example, planning, commissioning and monitoring the provision of home care services. This means that local authority social services departments must exercise all their powers and duties in a way that is compatible with ECHR rights.¹⁴

The same principle applies to NHS bodies, which have responsibility for certain types of home care (often provided under partnership arrangements with local authorities). The Care Quality Commission (CQC) is also a public authority under the HRA and so must comply with ECHR rights when carrying out its functions as the regulator of the home care sector.

In addition, private and third sector organisations have to comply with the HRA when they are performing ‘public functions’. However, in 2007 the courts interpreted the expression ‘public functions’ as excluding services provided by private and third sector care homes, even when these were under contract to local authorities.¹⁵ This legal decision leaves little doubt that contracted home care services are also outside the scope of the HRA. The effect of the court judgment has been reversed by legislation¹⁶ – but only for residential care. Most home care services are still not covered by the HRA.

Positive human rights obligations

Public authorities have to do more than just the minimum needed to comply with the ECHR. The European Court of Human Rights has clarified that the state has ‘positive obligations’ actively to promote and protect the rights guaranteed by the Convention. Because of the HRA, these positive obligations must be taken into account by our courts and tribunals and also by other public authorities when they are fulfilling their statutory powers and duties. Positive human rights obligations include duties to:

- prevent breaches of human rights, which may sometimes mean protecting individuals from the actions of others
- take measures to effectively deter conduct that would breach human rights
- respond to human rights breaches, which may include carrying out an effective investigation

- provide information to individuals to explain the risk of their human rights being eroded, where it is clear that this risk exists.

This means that, in some situations, local authorities and other public bodies such as the CQC, might have to take positive steps to protect the human rights of older people receiving home care from private or third sector organisations. For example, if a local authority failed to use its powers to take action in response to a pattern of complaints from older people about abusive or neglectful treatment by a particular home care agency, the authority might be in breach of its positive human rights obligations to protect those whose human rights were at risk. Similarly, if the CQC were to fail to respond effectively to allegations by whistleblowers about a certain home care provider, this could breach its positive obligation to respond to human rights violations.

Local authorities which are not complying with their positive obligations to promote and protect human rights in home care provision (such as by ensuring there is a proper system for reporting and monitoring human rights breaches) may be failing to perform their statutory duties in a way that complies with the HRA. This could expose them to a legal challenge. Likewise, a court could find a local authority was under a positive obligation to ensure that organisations contracted to supply home care services respect the human rights of service users by making this part of the contractual arrangements with the local authority.

The UN Convention on the Rights of Persons with Disabilities

The UK has also ratified a number of other international human rights treaties, many covering economic, social and cultural rights as well as civil and political rights. Some are highly relevant to older people using home care services. Unlike the ECHR, these other treaties have not been made part of our domestic law – but they can have an impact in other ways. They can be a useful tool for interpreting national legislation in the courts and should be used as a set of guiding principles for public policy-making, although their impact has been patchy because they cannot be directly enforced in our courts.

There is no treaty expressly dedicated to protecting older people's human rights, and the UN has paid limited attention to older people when monitoring its other treaties. However, the UN Convention on the Rights of Persons with Disabilities (CRPD) has a clear bearing on the present inquiry, given the age-related increase in the prevalence of disability: nearly half of all disabled people are retired.¹⁷

The CRPD sets out the standards that the UN expects government and public bodies to meet in delivering genuine equality and inclusion for disabled people. It covers civil and political rights similar to those in the ECHR, but also extends to social and economic rights such as an adequate standard of living and social protection – rights that have their origins in the International Covenant on Economic, Social and Cultural Rights. CRPD rights

are acutely relevant for older people using home care services. However, as it is not part of our domestic law, the CRPD cannot be directly enforced in the UK courts.

Regulation of home care services

The Care Quality Commission (CQC) is the regulator for the health and social care sector in England. It monitors the quality of care given by all providers of social care services, including private and voluntary sector organisations. All care providers must be licensed with the CQC and meet their essential standards of quality and safety.

The CQC's essential standards come from 28 regulations and expected outcomes.¹⁸ For each regulation, there is an associated outcome setting out the experiences that service users can expect as a result of the care they receive. The CQC monitors how well providers comply with these standards by checking against the 16 regulations most relevant to the quality and safety of care. For our inquiry, probably the most important essential standard is set out in Outcome 1. This confirms that the CQC expects service users to be involved in decisions about their care and be treated with respect for their privacy, dignity and independence.

The CQC currently takes a risk-based approach to its monitoring, focusing on providers that are identified as being at the greatest risk of non-compliance with the essential standards of quality and safety.



Part 2: About home care

People receiving home care have to trust other people to help them with personal and intimate tasks such as bathing, dressing, meals and getting into bed. When this help is delivered well it is done in a way that respects the older person's privacy, respects their dignity and enables them to decide how things get done – essentially, it follows a human rights approach to service delivery.

Who needs and benefits from home care?

As people get older, they are increasingly likely to need home care. Research suggests that around 20 per cent¹⁹ of older people living at home receive domiciliary services, and in 2009-10, an estimated 453,000 older people received home care through their local authority.²⁰ In fact, 81 per cent of people receiving home care in that year were 65 or over,²¹ and as our population ages, more people will inevitably need home care in the future. People aged 85 and over are the fastest growing group – their numbers have doubled since 1985, and are projected to increase substantially in the next decades.²²

Studies show that older people would prefer to stay at home until it is impossible for them to do so rather than move into residential care²³ and that the benefits of home care are enormous, both to individuals and to the state.²⁴ Home care provision also costs less than a place in residential or nursing care. In 2008-09,

the average weekly cost to local authorities for an older person in residential and nursing care was £497. In contrast, the average weekly cost of home care was £145.²⁵

Who provides home care?

We recognise the vital role that unpaid carers have and the immense value of the work they do in economic terms. However, in this inquiry we focused on care provided by paid workers.

Home care is an important and growing sector of employment. Paid workers include those working for local authorities or private or voluntary organisations, and personal assistants employed directly by older people themselves.

Care workers who deliver support to older people in their own homes can play a pivotal role in promoting and protecting human rights. They may be the only contact with the outside world the person they are visiting has that day (or even that week).

The combination of frequent lone working and high levels of individual responsibility, coupled with the need for highly developed communication and practical skills required by good home care workers are found in few other jobs afforded such low value in our labour market.

What are older people's rights to home care?

The social services department of a local authority has responsibility for assessing a person's need for community care services. Anyone who thinks they may need home care can ask for an assessment, and the local authority must carry one out if the person appears to need the service.²⁶ The government has now introduced a single assessment process for older people, encouraging local social care, health and housing bodies to work together so that personal details do not have to be repeated unnecessarily.

Local authorities may use a telephone service as a first point of contact for community care assessments. As we discuss later, there are sometimes problems with people being turned away at this stage before they are able to talk about their care needs.

Once a full assessment has been carried out, the local authority must decide whether or not to provide – or arrange – care services for the individual concerned.²⁷ If the person has been assessed as having 'eligible needs', a financial assessment will usually follow to decide how much they should contribute towards the cost of the services.

The government has issued guidance to promote fairness and consistency in the assessment process and each authority sets its own eligibility criteria based on this guidance.²⁸

The effect of financial restraints

Over the last five or six years, with increased financial restraints, many local authorities have tightened their eligibility criteria for care, making them very restrictive. Most now only provide publicly funded home care to people with 'critical' or 'substantial' needs. Before 2006, only half the local authorities in England set their eligibility levels at 'critical' or 'substantial', whereas in 2011 4 per cent will only fund care for people with 'critical' needs and a further 78 per cent set eligibility at 'substantial' needs.²⁹ This means that an increasing number of people have to pay for their own home care or manage without support, particularly individuals who are assessed as having 'moderate' or 'low' needs. It also means that whether or not someone is entitled to publicly funded home care can depend on which area they live in.

How is home care paid for?

Most home care is subject to means-testing although sometimes there is no requirement to pay for it; for example, up to six weeks home care can be provided free of charge to avoid unnecessary hospital stays and, occasionally, home care services are funded by the NHS where the person's primary need is for health care.

In summary, an older person's home care might be paid for:

- in full by the local authority (or in some cases by the NHS)
- partly by the local authority and partly by the older person, or

- entirely by the older person (as a ‘self-funder’).

Local authorities play an essential part in protecting the human rights of older people, particularly when commissioning home care from private and voluntary sector organisations. In 2008, an estimated, 4.1 million hours of home care were purchased or provided by local authorities.³⁰ It is estimated that 80 per cent of the home care provided by the independent sector is commissioned by local authorities,³¹ who spent just over £2.1 billion on home care for older people in 2009-10.³²

Many home care providers are highly dependent on local authority contracts. Just over half of independent sector providers do 80 per cent or more of their work for local authorities.³³ There are now almost 6,000 registered home care providers – ranging from large national private and voluntary sector organisations with multiple branches to small providers often operating from a single office.³⁴

The numbers of care providers have been rising in recent years with 68 per cent in the private sector and 19 per cent in the voluntary sector. In a survey in 2009, 74 per cent of those responding were stand alone businesses and 26 per cent were part of a larger business group.³⁵

How are human rights relevant to home care?

Human rights apply to everyone, but they are particularly significant for people who have a greater risk of poor treatment. Our evidence has confirmed

that older people using home care may be at risk of breaches of their human rights, especially when they depend heavily on these services, if they have limited or fluctuating mental capacity, or have little contact with other people, particularly supportive family members.

The right to respect for one’s home is an important part of the European Convention on Human Rights (ECHR). As explained above, the Human Rights Act 1998 (HRA) is the means by which Parliament has brought the ECHR into our own legal system.

Several Articles of the ECHR have key relevance for people receiving home care services:

- Right to life (Article 2)
- Prohibition on inhuman or degrading treatment (Article 3)
- Right to respect for private and family life, home and correspondence (Article 8). As we explain below, this Article also protects the right to respect for one’s dignity and personal autonomy, and the right to respect for social relationships.
- Right to peaceful enjoyment of possessions (Article 1, Protocol 1).

Other Articles which may be relevant to home care are:

- Freedom of thought, conscience and religion (Article 9)
- Freedom from discrimination on any ground in the enjoyment of other ECHR rights (Article 14). This is not a free-standing right; it must be used in conjunction with another right under the ECHR.

Central to the quality of older people's day-to-day experience of home care is the cluster of rights protected by Article 8. Its scope has been clarified by the European Court of Human Rights to include the right to respect for personal dignity,³⁶ one of the most important considerations when receiving home care. Article 8 also recognises the right to respect for personal autonomy, such as being involved in decisions about one's own life, controlling one's own body, and participating in society.³⁷

Certain rights under the ECHR – the right to life and the prohibition against inhuman or degrading treatment – are absolute and cannot be removed or compromised. The rights under many other Articles, including the right to respect for private and family life under Article 8, may be restricted. However restrictions can only be imposed if they can be justified as a lawful and proportionate response to one of the social needs set out in the Article itself. For Article 8, these aims include protecting the country's economic wellbeing, public safety, health or morals, or the rights and freedoms of others.

More information about the Articles of the ECHR, and their relevance to home care services, can be found on our website.

Adopting a human rights approach to home care

Individuals can use the HRA to challenge any ill-treatment that is serious enough to breach the rights guaranteed by the ECHR. However, this legislation was designed to provide a floor, rather than a ceiling, for human rights protection – and to do more than provide legal entitlements that can be enforced in the courts. According to Lord

Irvine, former Lord Chancellor, the HRA was intended to create a 'culture of respect for human rights', so that public services would be 'habitually and automatically responsive to human rights considerations' in all their procedures and practices.³⁸

The Commission's Human Rights Inquiry found that, if a human rights approach is properly understood and applied, it can help to transform the way services are planned and delivered, driving up standards and providing a code of behaviour for organisations. A human rights approach provides an ethical framework for 'person-centred' decision-making by ensuring that rights are only restricted where proportionate and necessary. It can also provide guidance on how to balance competing rights and duties in situations where they conflict.

Similar conclusions were drawn by the Joint Committee on Human Rights (JCHR) in its report on the human rights of older people in healthcare. The inquiry looked at several case studies of NHS trusts that had piloted a human rights approach to commissioning and delivery of services. The JCHR was persuaded that this approach could make a real difference to organisational culture and 'quite evidently' to the quality of service provision for users.³⁹

The Department of Health has adopted a human rights approach to health and social care for older people through its Dignity in Care campaign, which aims to demonstrate how putting human rights at the heart of health and social care services can deliver better outcomes for service users and staff alike. The campaign invites commissioners, providers and service users to become 'dignity champions' for its 10 point 'Dignity

Challenge', setting out clear expectations for older people's services. These expectations include:

- Having zero tolerance of abuse
- Treating each person as an individual
- Supporting independence, choice and control
- Respecting an individual's right to privacy
- Acting to alleviate loneliness and isolation
- Making people feel they can complain without fear of retribution.⁴⁰

By providing an accessible entry point to a human rights approach, the Dignity in Care campaign is a valuable initiative. However, to have a complete picture of human rights, service providers and commissioners also need to understand their duty to comply with enforceable legal obligations under the HRA.

Case study

Care about Rights is a training and awareness programme developed by the Scottish Human Rights Commission, designed to embed a human rights approach into the delivery of care for older people. The programme, targeted at care providers, care workers and older people, aims to demystify human rights so that decision-making and policy-making are better informed and more accountable and older people are empowered to understand and claim their human rights. This approach to training was particularly effective in helping care workers use a human rights approach in balancing risk in decision-making, including resolving conflict between the needs of different service users.⁴¹

A parallel human rights approach to home care in England could bring similar benefits. It could help change the culture of service delivery, support a personalised approach to care and encourage older people to complain without fear of retribution. It could also assist care providers when they are faced with some of the difficult decisions they routinely have to make, such as whether a person's right to autonomy must be overridden in the interests of their welfare. This case scenario, taken from the Care about Rights training programme, illustrates how a human rights approach can help.

Case study

Marian, a housebound woman, became depressed because she had not had a shower for several weeks. The home care provider decided to provide Marian with only strip washes after a care worker pulled a muscle trying to manoeuvre her out of the shower. A human rights approach would emphasise the importance of understanding the fundamental rights at stake – in particular Article 8 (right to respect for private and family life). It would also involve critically reviewing the available courses of actions so as to balance Marian's rights with the interests of the care workers. For example, have alternative options been explored that better meet Marian's needs and interfere less with her rights? Have staff been properly trained in moving and handling? Can more than one worker be allocated, or can a hoist or specially designed wheelchair be used?



Part 3a: The importance and value of home care in the lives of older people

Choosing to live at home

Care in people's own homes allows older people to continue to live as they wish even once they can no longer carry out all their day-to-day tasks without support. As long as older people have the good quality care they need to support them at home, they can keep their independence and control over their lives in familiar surroundings.

“Both my parents have been enabled to stay independent as long as they can due to the adult social care they have been provided with ... [They] are able to enjoy a dignified life, in their communities, at little cost to the state, and remain in control and as independent as they can be.”

Daughter whose parents receive home care, Midlands

Many older people told us that they wanted to remain in their homes as long as they could – but that they could only do this if they received good quality home care.

How satisfied are older people with the care they get?

Around half of the older people, friends and family members who responded to our call for evidence reported that they are satisfied with the service received.

“The Council home care service is ultrareliable, even in bad weather, and they are always cheerful ... I have tremendous respect for the work they do.”

Husband of older woman, North of England

They most often highlighted that they were happy with:

- consistency of staff
- reliability
- staff interacting positively with them or having time to talk to them
- control over tasks to be carried out.

Skill and professionalism in executing duties and tasks

Older people who were satisfied with their home care often praised the skill and professionalism of their care workers. This was very important to older people whose

safety and security could depend on their home care worker, for example if they were being assisted with taking medication or having a bath. A number of people told us about instances where home care workers had gone beyond their expectations to deliver a service that really improved the quality of their life. Sometimes this involved home care workers staying longer than they were paid for in order to make sure support was provided in a sensitive and personalised way.

Small things can make a big difference: home care providers who shared examples of positive feedback they had received from older people highlighted the significant impact on people's quality of life of things that at first sight might not seem so important, such as being able to have a regular shave and keep up the same standards in their appearance as they had before they required support.

We received evidence from many older people who began receiving home care at times of stress and illness in their lives. Some of the experiences they described to us illustrated how the quality of the home care they had received had made a significant difference to their self-confidence and ability to cope at a difficult time in their lives when they had felt extremely vulnerable.

Older people's relationship with home care workers

Care workers can sometimes be the only person older people see from day to day. Bearing in mind the often intimate tasks they carry out, it is important for many older people that they have a good relationship with their care workers.

"We have a good laugh which is what I need, they do the job, but we joke and laugh at the same time. It is important because when you are like us, you don't go out, you don't ... see anybody. They are friends."

Woman, 70, lives with partner, self funded

Many place great value on conversation, being able to have a chat or a laugh together – indeed, for some this is more important than getting all the practical tasks done.

Older people also emphasised the importance of **how** services are provided. The attitude and approach of home care workers while carrying out tasks were of real significance to them.

Older people said they expected and wanted to be treated as individuals by care workers – to:

- be the focus of attention during visits
- have their needs and wishes listened to, understood and attended to
- be spoken to kindly and politely.

Views of home care workers

These views were echoed by the majority of home care staff giving evidence to the inquiry who told us about key elements of their work that they found satisfying, such as:

- helping older people to keep their independence and stay as long as they wanted in their own homes
- talking to older people and getting to know them as individuals
- knowing they had provided high-quality, respectful care
- having the flexibility to offer the support that people wanted
- being able to use their initiative.

Workers described the pride they took in their work and how job satisfaction was greatly increased when they could see the positive impact of their work on the lives of older people and their families.

The following examples show the aspects of their job that care workers found most satisfying:

- “I can contribute to keeping the service user in their own home with their own dignity and independence.”
- “To see people maintaining a life at home, in their own surroundings ... where they feel safe and secure.”
- “When I made a service user a proper English breakfast with all the trimmings and the response made me feel good. Something so easy you take for granted, made their day and mine.”

Home care workers recognised the important role that they played in the lives of many older people they cared for, particularly if they had limited interaction with others.

“We are important to service users as sometimes we are the only people they see regularly.”

Home care worker employed by local authority

The evidence from these care workers suggests that they were instinctively, if not consciously, using human rights principles to inform their work with older people. Giving a high priority to valuing older people as individuals, respecting their dignity and independence and understanding the value of social interaction are all hallmarks of an approach that promotes and protects human rights. It is clear that an important spin-off from using this approach is the increase in job satisfaction that workers described.



Part 3b: Our findings on the protection of human rights in home care

Many older people are highly satisfied with their home care and there is no doubt that good quality home care has a huge positive impact on their lives. However, the problems set out below – whilst not the full picture – do represent a range of older people's experiences and raise issues of real concern.

The evidence gathered from older people and their families, care workers, home care providers and bodies working with older people, and local authorities, shows some good practice, but also some very poor treatment.

We have seen that, because of the HRA, public authorities must fulfil their statutory powers and duties in a way that complies with rights under the ECHR. They may also have to fulfil positive obligations to promote and protect the human rights of people receiving services. The ECHR rights most likely to be relevant to home care include protection from inhuman or degrading treatment and respect for private and family life, including dignity and personal autonomy.

The purpose of this inquiry was not to assess whether human rights had been breached in individual cases, which would depend in every case on the type of treatment, its frequency and severity and the circumstances in which it took place.

Yet it became clear to us that some older people were likely to have been victims of breaches of their rights under the ECHR. In many instances it is impossible to think of any circumstances that would justify the treatment that these older people received.

In the worst cases, we heard of older people not being fed, or being left without access to food and water, or in soiled clothes and sheets. In numerous other instances older people were ignored, strip-washed by care workers who talked over them, confined to their home or bedroom, put to bed in the early afternoon and unable to participate in their community.

Older people's physical and emotional wellbeing

Support with food and drink

Older people, their families and voluntary organisations all brought up concerns about older people getting adequate food and drink.

In some cases they were unhappy with the quality of the food, for instance:

- the care worker was only able or willing to prepare a limited range of food (heating tinned food or microwave meals, sandwiches)

- the food provided was not always suitable (for instance culturally appropriate for Asian or African-Caribbean people)
- concerns with frozen meals replacing hot meal delivery service
- poor nutritional content of meals.

Many further concerns were about older people not being given the support they needed to eat and drink.

In some cases this was due to lack of time. The daughter of an older woman with Huntington's disease described the serious consequences of her mother receiving no help with eating or drinking. This treatment might well amount to inhuman and degrading treatment within Article 3 of the ECHR.

“Carers were supposed to feed and give drinks but simply left them beside a person who was physically unable to feed herself because the carers had to go to their next client. My mother went down to 7 stone. Someone with Huntington's needs an hour per meal to swallow food/drink, and special care when it all falls out of their mouth, and they get very damp and dirty. They also need 4,000 calories per day to maintain body weight due to the chorea movements that constantly burn energy.”

Daughter of older woman, South of England

In other cases, care workers believe they can't help, due to food standards regulations, or possibly health and safety. A number of responses to the call for evidence from older people and their families raised concerns about home care workers saying they could not prepare any food, or in some instances even heat up food in a microwave. One woman described how her elderly mother, who was in the advanced stages of terminal cancer, was forced to heat up her own food. Although the severity of this neglect may fall short of 'inhuman or degrading treatment', it would certainly amount to a breach of this woman's right to respect for private life under Article 8 of the ECHR.

“In one incident an able-bodied, healthy 32-year-old female member of staff stood and watched as a 76-year-old woman with advanced cancer struggled from the lounge to the kitchen to microwave this dish herself, because the worker could not do this 'because of health and safety'; although apparently this did not preclude the worker from dishing up the microwaved meal onto a plate. These 'small' acts of cruelty are being enacted, possibly unthinkingly, every day.

‘It is hard to think of a reason or excuse big enough adequately to cover such a fundamental lack of care from one adult to another at such a basic level as the provision of food.’

Daughter of woman in 70s, self funded

This approach to food safety may, in part, be influenced by a belief that the preparation of food by home care workers is covered by Food Standards Agency regulations which apply strict rules to businesses such as restaurants; or a misinterpretation of health and safety requirements.

The Health and Safety Executive were clear in their evidence to the inquiry that care providers needed to take an approach based on ‘sensible risk management’, focused on how the obvious benefit of the provision of care to older people can be delivered safely.

“HSE expects employers and workers to take a sensible and proportionate approach to assessing any risks ... real risks and not trivial risks ... [they] should focus on how to complete the task safely, rather than providing reasons for leaving it undone.”

Health and Safety Executive

The HSE told us they could see no reason why workers should not heat pre-prepared meals in a microwave.

In some cases, care workers just don’t appear to consider older people’s needs properly. For instance, they would prepare food for people with dementia, but then just leave it for them rather than prompting them appropriately to eat, or would put it in the fridge where the person would not see it and so would forget to eat it.

“I know one lady, she had Alzheimer’s. The carer came in in the morning and dressed her; got everything ready and made a sandwich, ‘You eat that at lunchtime. I’ll put it in the fridge ... because of health and safety,’ and the old lady ... she forgot and by night time ... the sandwich [was still there] ... She hadn’t had anything to eat until her daughter or the carer came in at night. It’s the same with drinks. It’s health and safety kicking in and making it impossible, really.”

Co-ordinator, voluntary sector organisation offering support to older people

Families and voluntary sector organisations supporting older people reported a number of instances where older people had suffered severe weight loss and dehydration because they did not get the support they needed to eat. We were told about the case of one older man with dementia who lost so much weight due to not being supported properly by home care workers to eat that he was admitted to hospital and died three days later. In this case, the individual was probably subjected to inhuman or degrading treatment in violation of Article 3. If his death was as a result of this neglect, there may also have been a breach of Article 2 of the ECHR – the right to life.

Some organisations told us of instances where home care workers placed food in front of older deaf/blind people, but did not let them know it was there, or left it in an inaccessible place – resulting in these people missing meals.

Case study

Sense (voluntary sector organisation working with deaf/blind people)

A Sense worker bumped into a care worker coming out of Sam's house as the Sense worker entered. The care worker was wondering why Sam hadn't eaten his breakfast for the past three days. It transpired that the care worker had left the breakfast out on the kitchen countertop every day, but without letting Sam know that she was there, or that his breakfast was in the kitchen. Neither the care worker nor other care workers doing the later visits had reported that Sam had not eaten his breakfast to the agency.

Concerns about systemic failures to ensure older people have enough to eat and drink in other care settings are well documented. For example the CQC reported in October 2011 that half of the hospitals they inspected are failing to meet the nutritional needs of older people.⁴² Our findings indicate that this is a serious concern in home care too.

Physical abuse

A small number of care providers, local authority staff and individuals mentioned physical abuse of older people receiving home care. Intentional ill-treatment of this nature will almost always be a breach of the victim's right to respect for private life under Article 8 of the ECHR even if it does not reach the threshold for a breach of Article 3.

Physical abuse was most often in the form of rough handling or unnecessary physical force directed against older people. The daughter of one older man receiving home care described how her father had suffered skin injury as a result of rough handling by care workers. Another older woman described being pushed by her care worker, an event which left her shocked and upset.

"Most of the girls [from the agency] were nasty; they were rough. Rather than say 'sit in the chair', they'd push me back into the chair, that sort of thing, and I didn't like that ... It was only on one occasion; I recognised it as a push. She wasn't nice at all ... I couldn't do anything about it. I can't even walk and I think they know this you see; they know you're vulnerable."

Woman, 78, lives alone, with local authority and self-funded care

Neglect of personal care

We heard about a number of instances where the care specified in the older person's care plan was not carried out by the home care workers. As many home care packages do not cover more than the basic tasks necessary for physical wellbeing, any failure to follow the care plan can cause neglect of the older person and is also likely to be in breach of the right to respect for private life under Article 8 of the ECHR. Depending on the severity and frequency of this neglect, it could even reach the threshold for a violation of the prohibition on inhuman or degrading treatment under Article 3 of the ECHR.

“For several weeks Mum was not bathed or had her hair washed.

One time carers decided not to do any of her washing any more, even though [it was included] on [her] care plan, leading to my Mum being left in filthy nightwear and clothes and bedding. They did not inform [the] agency or me as family.”

Daughter of woman in 80s receiving home care, London

Often this seemed to come down to lack of time. It was a very common complaint that staff rushing through tasks could result in some key tasks not being completed or in staff having to do other tasks too hurriedly.

“[Home care workers] often rush and leave early, leaving my Mum in distress, dirty **and without water and food.**”

Daughter of woman in 80s receiving home care, London

“They are supposed to do an hour in the morning and an hour in the evening, but ... she’s gone within 10 to 15 minutes.”

Woman, 85, living alone, local authority funded home care

Some older people told us that the tasks that needed to be done really couldn’t be achieved in the time allocated. For example, one older woman with severe arthritis, which slowed her movements, told us that by the time her home care workers had supported her to wash there was no time left for breakfast, meaning that she was often left with just a cup of tea until lunchtime.

These time shortages experienced by older people often stem from what the local authority has commissioned from a care provider and how the contract is managed, which is detailed in Part 3c below.

Patronising or ignoring the older person

It does not seem a lot to ask for care workers to treat older people as individuals, to listen, and to be kind and polite. However we came across numerous instances where home care provided to older people fell below these expectations.

Older people and their families reported concerns at how some home care workers interacted with them. This included speaking as if to a child or in a condescending or exaggeratedly loud or slow voice, not bothering to check how people wanted to be addressed and adopting an inappropriately informal tone. We were told how patronised people felt by this communication style which appeared to be rooted in ageist attitudes. Older people were clear that they wanted to be communicated with as individuals rather than in a way based on stereotypes around their age.

“Some staff ‘talk down/shout’ at my mother thinking they will ‘get through’ to her by doing so. She is an intelligent woman and isn’t hard of hearing.”

Daughter of older woman, part funded by local authority

We also heard of care workers who were so fixated on completing their tasks in the set time that they seemed to view the person themselves as one of their ‘tasks’

rather than a human being with thoughts and feelings.

Some, when working in pairs, would chat to each other over the head of the older person, ignoring them – sometimes even while they were giving older people intimate personal care. We also heard instances of care workers chatting on their mobile phones while providing care. Although this lack of respect for the dignity of the service user may not be intentional, it still falls short of the standards of care required by Article 8. It also fails to meet Outcome 1, a key component of the CQC's Essential Standards of Quality and Safety.⁴³

“There were two [local authority] care workers there, and they were talking to each other over the client, who was blind, completely ignoring him while they were assisting him. So here is a gentleman who's registered blind, two people are talking to each other while they're doing things to him, as if he's a lump of meat, and they're not even explaining what they're doing.”

Senior manager, voluntary sector organisation

Good practice – the use of ‘life stories’

A number of organisations have adopted a human rights approach to combat this dehumanising attitude towards older people, particularly those with dementia. One approach is through the use of ‘life stories’, where a range of information about an older person's history, key relationships, likes and dislikes is recorded, usually in the form of a

scrapbook. Although this is more commonly used with people who have dementia, it could be relevant to supporting many older people who wish to share this information, especially when they have many different care workers.

We received evidence that this has a positive impact, making sure that services are focused on the person as an individual. When workers have a more rounded picture of the person they are working with, they can begin to take a far more person-centred approach, which can overcome some issues related to the time and task-focused delivery of care. It also supports workers to develop an approach which respects the individuality of each person.

“I think to look at how people were and what people used to do is absolutely vital and (to) try to extend that into everyday life.”

Care provider

We were told about the impact on staff of this approach.

‘People were saying things like, “You know, I understood more about this person... it gave me an opportunity to see them as a person, and that helped me understand their behaviour so we started to change the way that we deliver care.”’

The Department of Health has recently funded a project aimed at supporting and embedding the delivery of Life Story work into work with older people with dementia.

Financial abuse

We were told about a number of instances of financial abuse of older people receiving home care. In their evidence to the inquiry, Action on Elder Abuse shared a number of examples of older people, often with dementia, who had had money systematically stolen from them over a period of time by current and former care workers. Regular theft of this sort by care staff is likely to breach the right to peaceful enjoyment of possessions under Article 1, Protocol 1 of the ECHR, as well as being a breach of the right to respect for private life under Article 8. Of course, it also amounts to criminal activity.

We were also told repeatedly about the important role that well trained care workers play in protecting older people in vulnerable situations from financial exploitation. This was illustrated by one older person we interviewed, who explained that when his current care worker was appointed she noticed that he was underweight and there was very little food in the flat. This was due to the actions of two supposed ‘friends’ who had been taking the older man’s pension and all his savings over time, under the guise of helping him with banking and shopping. The care worker supported by her agency brought in the police, with the older man’s agreement, and his situation has now improved greatly as a result.

Lack of autonomy and choice

Older people expressed a widespread desire to be treated as a person rather than as ‘a task to be undertaken’. People need to feel in control of their lives, particularly if they are frail and feel vulnerable. Yet we were inundated with

examples of control being removed from older people in numerous avoidable ways.

Respect for personal autonomy is one of the rights protected by Article 8 of the ECHR. Autonomy is also a central principle of the Convention on the Rights of Persons with Disabilities. In the delivery of home care, the lack of control and choice many older people have over the timing of their home care visits can undermine their personal autonomy and this treatment could, in some circumstances, be a violation of Article 8.

The time of day when home carers were scheduled to visit and whether they arrived on time are of great importance to older people. It affects what else they can do during the day and issues such as timing of taking medication.

Many older people told us they had little or no control over what time the home care visits took place. We heard of many instances where older people were forced to stay in bed for long periods of time, sometimes in soiled incontinence pads. In one instance an older woman was put to bed at 5pm and not helped to get up until 10am – a period of 17 hours. This is likely to amount to an unjustifiable breach of the right to respect for autonomy under Article 8, as well as a breach of the right to respect for dignity.

“Going to bed too early causes many problems – spending long nights lying sleepless, missing evening entertainment and time with spouses and family, not to mention the humiliation of being treated like a child.

The earliest we were told of someone being put to bed was 2.45 pm.

“The carers ... get Mum ready for bed at 4.30pm. Mum would prefer this later but the only slot given was after 9.30pm and this was too late for her, and they sometimes did not come. So I agreed to 4.30pm. This does not always work; last week one carer arrived at 2.45pm to get her ready for bed. Apart from loss of dignity, she needs her stockings on longer.”

Daughter of woman in her 90s, North of England, part-funded local authority care

Inflexibility

A number of older people raised the issue of inflexible services where workers adopted a rigid approach, delivering the tasks they had listed to the letter, without taking account of older people's fluctuating conditions, changing circumstances or individual wishes. This inflexibility can be driven by the time and task approach to commissioning which some local authorities adopt, as detailed in Part 3C below. Although the failure to take into account individual wishes might not qualify as a breach of the service user's rights under Article 8, it would fall short of standards required by Article 19 of the CRPD, which expects the state to ensure that disabled people have the same right to choice and control as non-disabled people.

In some instances this mechanical adherence to a set list of tasks flew in the face of common sense. In one example a care worker refused to help an older woman off the toilet or seek assistance when she was stuck. Instead of helping her, the care worker performed the allocated tasks and left the older woman

on the toilet with her lunch waiting for her downstairs until she managed to get unstuck. This lack of respect for the older woman's dignity could amount to a breach of Article 8 of the ECHR – the right to respect for private life.

“I had a lady who was on the toilet when the carer came, she shouted, ‘I'm stuck, I need some help.’ The carer shouted up, ‘Can't do that, but I've made you a booty and I'm going now.’ ‘But I'm stuck on the toilet,’ and she said, ‘I've made you a booty.’”

Local authority officer, North of England

In other cases an inflexible approach prevented the care workers from meeting the express wishes of older people. For example, one older woman wanted help with meal preparation and assistance to get out into her garden whilst maintaining control over her intimate personal care.

“[The team of care workers] made clear they expected to wash and dress my mum, despite her wishes to do this herself. They appeared ill equipped to think of the other aspects of living in a house that use someone's energy with which they could help and, in so doing, leave the person with sufficient energy to be able to continue to wash and dress herself.”

Daughter of recently deceased older woman, South of England

A few older people had decided to fund their own care rather than seek publicly funded care, precisely so that they could decide how their care worker's time was

used. In some cases it was due to a wish to be looked after by someone they knew, or a belief that they could obtain a better quality of care than that provided by the local authority. They were happy with these private arrangements, even though there seldom appeared to be much of a safety net if their care worker was to fall sick or leave their job suddenly.

Lack of respect for privacy

Some older people told us about what appeared to be a complete disregard for their privacy when home care workers were supporting them to undress, bathe and dress. Where individuals experience such insensitive treatment on a regular basis, this may well fall short of the standard of personal care required by Article 8, which includes the right to respect for personal privacy and dignity. If the instances are isolated ones, the CRPD could be relevant: the state is expected to ensure that every disabled person has the same right as anyone else to respect for their physical and mental integrity (Article 17).

As mentioned earlier, this lack of respect for privacy seems to stem from workers or their managers not thinking about the older person as an individual who needs to be accorded dignity and respect for their personal privacy.

“There is a constant parade of new staff passing through the house, to be ‘trained’. [My] personal dignity is not respected.

‘Trainees’ turn up unannounced and the agency fails to contact us beforehand to ask permission.

I have MS and am very severely disabled, and feel my dignity when being showered and dressed is not being respected when I have several trainees observing quite an intimate routine.”

Man, aged over 65, East of England, self-funded care

One interviewee described how her husband looked like a ‘scared rabbit’ lying naked on his bed while being strip-washed by home care workers. She felt that no attention was paid to his dignity but that with only a little effort on the workers’ part, for example covering him with a towel, the process could become far more bearable for him.

The high staff turnover rate of care workers also impacts on older people. They described the emotional impact of having intimate personal care tasks performed by a large number of different people, and the frustration of having to repeatedly disclose personal information every time a new care worker came to the house. One older woman recorded having 32 different home care workers over a two week period, which could quite possibly amount to an unjustifiable breach of her right to respect for private life under Article 8.

One older man who was unable to get up without support described his terror as he lay in bed and, after hearing a key in the lock, saw a stranger standing in his room. It turned out that the person was a new care worker, replaced without notice from the agency. At the very least, this would appear to be a failure to comply with Article 19 CRPD, which gives disabled people the same right to choice and control as non-disabled people.

As in other aspects of care, a common theme was the impact on people's dignity when staff have to rush tasks that intrude on personal privacy:

- Older people told us they felt demeaned and stripped of their dignity when staff perform intimate care tasks in a distracted and rushed way, without having time to talk to them about how they would like care tasks to be carried out.
- The impact of staff rushing could be greater on older people with dementia, who might need longer than others to recognise workers and recall why they were there. One interviewee described the extremely distressing impact of staff rushing into the home of an older person with dementia and quickly removing their clothes for a strip-wash – before the older person had fully realised who the care worker was and the purpose of their visit.
- Older people told us that care workers not having time to talk to them while carrying out care tasks not only added to their sense of isolation, but made them feel like objects having things done to them rather than individuals receiving a service. Some were made to feel as if they were a burden or an impediment in the way of a busy worker.

These three issues illustrate how time pressures on care workers undermine the prospect of older people's privacy and dignity being respected. This evidence suggests that it may be difficult for providers to adopt a human rights-based approach to home care unless the problem of time constraints can be addressed.

Lack of personal security

Concerns were raised about the risk to personal security of constant changes of home care workers, especially when older people were not informed of changes. The impact was even more significant for particular groups of older people, for example older people with visual impairments and people with dementia.

“It is frightening to open your door to someone you don't know and whom you can't see. Couldn't someone phone me to say there's going to be a different person today?”

Older person with visual impairment – from Joseph Rowntree Foundation written response to call for evidence

“If you've got a client who has dementia ... they need regular bodies. Somebody different coming every day, perhaps two and three times a day, is a real problem for them because they then get to the stage where they'll just let anybody in.”

Co-ordinator, small voluntary sector organisation, North of England

Insufficient attention to diverse needs

Interviewees from voluntary sector organisations offering support to older people emphasised that older people are not a homogeneous group with similar needs. However they felt that they were treated as such by some local authorities and care providers.

“I spend a lot of my time now trying to explain to the council for example that older people are not a homogenous group, and I think that’s how they’re seeing them, they’re just old. Actually they are gay, they are black, they are disabled, they have mental health problems.”

Director, voluntary sector organisation, South of England

The experiences of different groups of older people attending our focus groups demonstrate that a one-size fits all approach towards the provision of home care can impede respect for diversity and create anxiety for some service users.

Sexual orientation and transgender

Participants at lesbian, gay and bisexual and transgender focus groups expressed real fears about their future as they had very little confidence that home care workers would be trained and supported to provide a sensitive service, free from prejudice. Organisations supporting lesbian, gay and bisexual older people told us about people they had had contact with feeling the need to remove all signs of their sexual orientation from their houses, such as pictures of their partner, in order to avoid negative reactions.

“Older Lesbian, Gay, Bisexual and Trans people quite often, we have found, face harassment or misunderstanding ... or ignorance of their needs in services so they often have to go back into the closet for fear of the reaction that they might get from care providers.”

Voluntary sector organisation in focus group

The main fears expressed were:

- the impact of constant changes in home care workers, as they would need to ‘come out’ as each new worker started
- negative reactions from staff involved in assessment and delivery of home care.

These fears were sometimes realised. One older transgender woman described being stared at like a ‘freak’ by her home care workers and sometimes sitting crying after they had left. An older gay man with dementia decided to stop receiving services because of the homophobic reaction of care staff. This had led to him having to move into residential care earlier than necessary as his elderly partner had struggled to cope alone with caring responsibilities. Examples such as this raise potential concerns under Article 8, the right to respect for private and family life. It also raises issues under Article 14 (which guarantees the enjoyment of ECHR rights without discrimination of any kind) in conjunction with Article 8.

Older lesbians, gay and bisexual people told us that they would like to see assurances in literature produced by care providers that their specific needs wouldn’t be ignored and prejudice from staff would not be tolerated. They emphasised how reassuring they would find steps of this kind. However, some care providers we interviewed perceived sexual orientation as a ‘personal issue’ that had no bearing on the delivery of home care and was best not raised. Others did flag it up as an area where action was needed due to ‘ignorance and lack of competence in the workforce’.

Cultural heritage and religious beliefs

The state has a positive obligation to ensure the peaceful enjoyment of the right to respect for religion and belief under Article 9 of the ECHR. We were told of some encouraging examples of care providers taking into account religious and cultural needs; for example, care workers supporting Jehovah's Witnesses who do not take certain medication or, for Muslim clients, showing respect for the Qur'an.

On the whole, however, it was suggested that not enough consideration is given to these issues. More training to raise awareness was seen as fundamental by local authorities, providers and voluntary organisations.

“People have told us from all sorts of backgrounds ... that to them (ignoring their cultural and religious beliefs), that's almost like a form of abuse because it's so important to them, that they feel like they're not being respected ... It's something that's not being adhered to in the way that they want, and then that takes away from their choice and autonomy. It's distressing for people.”

Director, national brokerage organisation

Care packages do not generally cover giving support to attend church/temple etc – this only happens if it is being paid for or provided by a voluntary group or the older person's family. In the interviews with older people, some mentioned the important role religious activities played in social interaction and support. For one older man church members were

instrumental in getting him into sheltered housing and access to home care. In another case, church members provide the older person with a lot of social support.

The provision of culturally appropriate food and not just 'standard' frozen meals is very important to some older people: for instance, a number of voluntary organisations highlighted that many older Muslims they worked with don't trust that food provided is Halal.

Disabled older people

Evidence submitted to the inquiry from organisations working with older disabled people and from older people themselves highlighted the fact that for many older people, particularly those over 85, sensory impairment is the norm, with only a minority of older people not experiencing some degree of hearing or sight loss. Over seven out of ten people over the age of 70 have some form of hearing loss and one in five people aged 75 and over are living with sight loss.⁴⁴

We were told by organisations supporting older people that it was quite common for older people's impairments not to be taken into account in home care. Questions were also raised about skills of home care workers in relation to issues such as communicating effectively with older people with sensory impairments. Some interviewees believed that younger disabled adults would be less likely to experience these difficulties to the same degree. These reports suggest concerns about compliance with Article 14, which guarantees the enjoyment of ECHR rights without discrimination of any kind, taken in conjunction with Article 8.

Social and civic participation

The proportion of the population living alone increases with age, and many older people we interviewed spend much of their time at home on their own. In the UK in 2010, around 25 per cent of those aged 65 to 74, and 45 per cent of those aged 75 and over, lived alone.⁴⁵

Our interviews with older people revealed a pervasive sense of isolation and loneliness for virtually all; this was especially bad for those who lived alone. Many older people who responded to the call for evidence also told us they did not get regular opportunities to leave their homes and our evidence suggested there were relatively few packages of home care that included support for activities outside the house. Article 8 of the ECHR includes the right to create and maintain social relationships with other people. In some limited circumstances, this could mean that local authorities have a positive obligation to remedy extreme isolation experienced by individuals who depend on care services to maintain relationships with others by getting out of their homes. We received evidence that packages of home care for younger disabled adults and for children commonly include support for social activities. Once again, this raises concerns about compliance with Article 14, which guarantees freedom from discrimination in the enjoyment of ECHR rights, taken in conjunction with Article 8 (the right to respect for private and family life).

“I’m stuck here all day long, and I look at the sun and I think, I wish I could get out there ... if you’re stuck between four walls of a day, every day, that is like living in a box being squeezed in.”

Woman, 78, lives alone, local authority funded

“I am on oxygen 24 hours and I walk with a stick, and I would love to go out shopping or even just driving around and someone to talk to.”

Woman, aged over 65, living alone, South of England, local authority funded home care

Almost all older people we interviewed felt cut off from everyday life and deprived of human company, referring to ‘gaol fever’ and inescapable boredom. The minute passage of time in a day became a major focus, with one older woman sleeping as much as possible to pass the empty expanses of time.

We heard of some older people trapped in their homes, sometimes due to the lack of simple physical adaptations, or often due to lack of transport and support to get out. One older man said he was still waiting, three months after contacting a social worker, for the front and back doors of his house to be adapted so that he could leave his home in his wheelchair. He hadn’t gone outside on his own since he had acquired his wheelchair six months previously, following an amputation. This severe restriction on the man’s contact with the outside world is likely to be in breach his right to respect for private life under Article 8.

Some organisations also highlighted that older people with sensory impairments (for example, older people with hearing impairments, older deaf/blind people) suffered even greater risk of isolation. Another group also repeatedly highlighted as being at increased risk of isolation were older people living in rural areas, where there are fewer community facilities and access to public transport is limited.

As we have observed, care plans for older people rarely make provision for social participation. However, there are a large number of voluntary sector organisations, including local Age UK organisations, the Alzheimer's Society and other community groups, that provide a range of services – including befriending schemes and neighbourhood warden services – designed to address older people's social isolation. In some areas local befriending services have been commissioned by local authorities.

In interviews, concern was expressed that financial constraints were having an adverse effect on such services. In some cases, befriending activities had ceased altogether. In other areas, face to face visits had been replaced by telephone based services which were perceived as an inadequate alternative because they would be difficult to access for many older people with sensory impairments and lacked the direct personal contact valued by older people.

The impact of isolation

Interviewees from organisations working with older people thought that older people's experience of isolation had an impact on other areas of their life, including their mental and physical health and confidence.

“Social isolation of older people ... does have a big impact on their emotional wellbeing. And also it seems to impact ... on their memory ... when they don't see anybody and they lose certain skills.”

Manager, voluntary sector organisation, North of England

A number of submissions from organisations stressed the importance of recognising and addressing issues of isolation, and 'reframing' home care for older people to include elements that would considerably increase older people's quality of life such as support to develop and maintain relationships and participate as a member of the community.

Maintaining family relationships

Respect for the right to family life is expressly protected by Article 8 of the ECHR. A number of older people and their family members told us about the disruptive impact that poorly delivered home care had on their family life. Relationships, routines and normal family life were disrupted by artificially early bedtimes, late or early arrival of care workers and the stress of care and support delivered without dignity or respect.

One woman reported that she wanted to die due to her lack of control after an injury to her spouse, who was her main carer, led to her needing home care. This lack of control included being told by an assessor that her husband's bed should be moved out of their shared bedroom to make it more convenient for staff to provide care, an incident that would be inconceivable if a human rights approach had been embedded into the assessment process.

“I said, ‘No way, that’s my husband’s bed’. But she just said ‘that’s got to come out’.”

Woman, 76, lives with partner, direct payments from Independent Living Fund

The experience of home care workers

We received evidence from home care workers who worked for local authorities and in the private and voluntary sectors. The vast majority of workers highlighted aspects of their jobs which they were dissatisfied with, and identified elements which stopped them working in the way that they would like. These issues reflected the areas that older people themselves raised with us.

One of the most frequent issues raised by workers, particularly from the voluntary and private sectors, was not having enough time to deliver care to a standard that they wanted. One in four workers who responded to the call for evidence mentioned this as one of the least satisfying elements of their job.

“The least satisfying is not having enough time, you try not to hurry them [older people] (or to let them know you haven’t enough time) but you are aware that your next client is watching the clock and waiting for you to arrive.”

Home care worker – voluntary sector provider, South West

They also mentioned the stress involved in travelling between service users, sometimes considerable distances, under time pressure and their frustration at not being able to take a ‘common sense’ approach and use their initiative in their work.

The impact on older people

It is hard to overstate the negative impact of the failure to apply human rights principles to the day-to-day care of older people. We saw many tears and came across frustration, expressions of a desire to die, and feelings of being stripped of self-worth and dignity – much of which was due to avoidable factors. Many affronts to dignity stem from easily rectifiable issues, such as not covering somebody with a towel while washing them. If this treatment is persistent, it can make life a misery.

Many of the instances cited would not necessarily make the news but their accumulated impact on older people can be profoundly depressing and stressful.

“It wasn’t just one thing, they’ve mounted up...”

Man 69, living alone, local authority funded home care

“It was terribly stressful. I’d never had anything like that before. It was this intrusion into my home, I felt worse than a baby ... a package that was just left there. They would come in and do this and that, and go again, and then come back. I just wanted to curl up and die. I was diminished. I wasn’t me any more ... A pudding, not quite a human being. My life was ... taken over.”

Woman, 76, lives with partner, direct payments from Independent Living Fund



Part 3c: How well do local authorities promote and protect older people's human rights?

Local authorities have positive obligations to carry out their functions in a way that promotes and protects the rights in the ECHR. This applies to every aspect of their day-to-day work. However, our findings reveal that local authorities may not have a comprehensive grasp of their human rights obligations as they relate to home care and as a result may incorporate human rights into their commissioning in a superficial way.

There are major opportunities for local authorities to promote and protect older people's human rights in:

- the way they commission home care
- the way they procure and monitor home care contracts.

They also have a role, more directly with older people, in:

- assessing older people's needs
- reviewing older people's ongoing needs and the care they are receiving
- providing information to people in need of home care (this is covered in Part 3d).

One local authority has taken steps to embed a human rights based approach in all these areas, using the Department of Health's 'Dignity in Care' model we describe in Part 2.

Halton Borough Council employs a Dignity in Care Co-ordinator, whose role is to integrate a 'whole system' human rights based approach across all health and social care services including home care. All partner organisations and care providers work to embed dignity via a Dignity Champions' Network, having signed up to Halton's Dignity Charter and appointed Dignity Champions. Providers report back regularly on the practical steps they are taking to promote the human rights of people using their services.

A senior local authority manager highlighted the benefit of having a dedicated co-ordinator:

'It (dignity) becomes the norm really for [us] ... It becomes the norm to recognise that within contracts and ... in the provision of services as well.'

Commissioning home care

Local authorities have the power to provide home care themselves, instead of procuring services from external providers. However, 84 per cent of publicly funded home care is now provided by private and voluntary organisations commissioned by local authorities.⁴⁶

Commissioning can play a vital role in protecting and promoting human rights.

“Because of the nature of home care provision, regulation and inspection – while crucial – may not be as effective at monitoring compliance in home care services as it can be for care homes. Therefore commissioning must play the central role in ensuring home care services meet needs and promote and protect human rights.”

Alzheimer’s Society

Our evidence has highlighted that, while there is evidence of poor commissioning practice, there are also plenty of pointers to how commissioning home care can support and improve providers’ performance in protecting and promoting human rights and increase the quality of care.

Local authorities can influence the protection of human rights in care services:

- in their strategic planning
- when specifying the services that must be provided

- in the way they procure and manage the contracts with care provider organisations.

Most local authorities who responded to our national survey reported that they take account of human rights in both their commissioning plans and procurement processes. However, it was apparent from our interviews and detailed analysis of commissioning and procurement documentation that local authorities have a patchy understanding of human rights and their own obligations in protecting and promoting these rights for older people.

We see this as a missed opportunity. At a strategic level, commissioners are in a position to identify the needs of the local population and plan how these should be met, in a way that complies with their equality and human rights obligations. We would like to see this happening in a more systematic way so that local authorities are doing as much as possible to prevent the human rights of older people receiving or requiring home care from being put at risk.

Including human rights in contracts and service specifications

Commissioning bodies have considerable scope to influence the way care services are organised and delivered – they can specify particular practice and outcomes aimed at protecting and promoting human rights.

We found that, in practice, human rights are often only superficially addressed in commissioning documents:

- They usually just list the Human Rights Act or related legislation in the standard terms – often in legal appendices, without any substantive requirements

setting out how providers should be addressing human rights.

- They tend to refer to principles of dignity, respect and independence without mentioning human rights or linking them to their duties under the HRA. We have termed this a ‘human rights lite’ approach – one that adopts aspects of human rights language without fully understanding the underlying legislation or taking on board its obligations. As the Equality and Human Rights Commission’s Human Rights Inquiry found, ‘the propensity of public authorities to use these general terms, without linking them to their legal underpinning in the Human Rights Act ... dilute[s] the potential impact of the Human Rights Act, and make[s] the obligations on public authorities appear optional and aspirational’.⁴⁷
- Some service specifications include a requirement for the provider to ‘act as though they were carrying out a public function’ and/or ‘as though they were a public body under the HRA’. This is a welcome approach, and could allow the local authority to sue the provider for any breach of human rights obligations. However, these clauses alone would not provide any right of redress for service users against care providers who breach their human rights. For this to be possible, there would need to be an express contract term giving the service user ‘third party’ rights to sue the care provider for any human rights breach.⁴⁸
- Even where human rights are referred to in contracts, this is often not consistently translated into practice, or meaningfully incorporated into service delivery and contract monitoring.

Significant limitations and problems follow from this, as one local authority acknowledged:

“On a formal contracting basis most documents will refer to the human rights of people receiving services. However, simply including such statements within the contract is not the same as promoting people’s rights. What is more crucial is that specifications outlining the service make a reality of the issues of human rights, and monitoring tools such as quality assurance frameworks are designed to look at how services are provided, but even more crucially to ensure that providers are aware of how their services will be monitored and the areas that commissioners feel are crucial.

The other issue with inclusion in contracts is that the documents will not necessarily prioritise areas that providers are expected to comply with. Therefore issues such as human rights will sit along[side] more mundane areas such as payment terms and conditions and will not always be viewed with importance.”

Local authority response to survey

Other matters of concern in commissioning documents included:

- Lack of consistency on equality obligations – while nearly all the service specifications referred to race, gender or disability equality, there were fewer references to other protected characteristics⁴⁹ such as age, religion and belief, or transgender.
- Commissioning too often ignores or gives very low priority to issues such as the role of social care in tackling social

isolation and promoting autonomy – all of which have a bearing on mitigating risks to older people's human rights. We were repeatedly told by interviewees from local authorities and voluntary sector organisations that this is less likely to be the case with home care for children and younger adults.

There were a few examples of local authorities actively seeking to combat isolation for older people – for example, when commissioning domiciliary care one local authority particularly emphasises to prospective providers the importance of, and need to deliver on, social interaction and community participation. This includes an expectation that providers will link older people into local community groups and activities and employ community development workers.

Procurement and contract monitoring

Throughout the procurement and contract management processes, local authorities can actively manage and monitor how well the home care they have commissioned is protecting human rights in practice, and take action if any risks to human rights become apparent. This is an important element of their positive obligations to promote and protect human rights. As was the case with commissioning, we found that opportunities to protect human rights were being missed in the ways local authorities procure and monitor home care contracts.

Procurement

We recognise the pressure on local authorities to reduce costs in the current financial climate. However, the key issue is to get the balance right between cost and quality to make sure the human rights of older people are not compromised.

We identified several trends in procurement that are of particular concern to commissioners and providers as well as organisations representing the interests of older people.

The bias towards cost criteria in awarding contracts

According to the United Kingdom Homecare Association (UKHCA), local authority tender procedures for home care services used to operate a widespread convention under which providers' bids were assessed on the basis of 70-80 per cent of total marks for quality/compliance issues and 20-30 per cent for price. However we came across examples of local authorities basing their procurement decisions on 70 per cent of total marks for cost and 30 per cent for quality, with one as low as 80 per cent cost and 20 per cent quality. The UKHCA's recent experience is also that, in some local authorities, the marking schedule has been reversed to give price considerably more weight.

Conversely some local authority officers were clear that their authority's focus was consistently on quality.

“As a council, quality is a big thing, and that goes all the way to the top. I know other local authorities ... budgets seems to define what they want. That’s not what commissioning social care’s about. It’s very different to buying paper and pens. Very, very different ... We focus more on quality assurance ... I wouldn’t go to the shop and buy a cheap loaf of bread that’s gonna go out of date the next day, ‘cause it’s rubbish. It’s rubbish quality and I wouldn’t expect the same for the people of [this area]. So why do they [other local authorities] buy something that’s not fit for purpose? I don’t get that.”

Local authority commissioning manager

Commissioning home care at very low hourly rates

In our survey of local authorities, 33 per cent had negotiated contracts on lower payment terms in the previous 12 months and a further 19 per cent expected to do so in the following 12 months.

A number of home care providers told us they would not be able to provide services to an acceptable or safe standard at the low rates paid by some local authorities.

Only around a third of home care providers who took part in our survey thought that the rates currently paid by local authorities support them to promote and protect the human rights of older people.

“We’ve heard about £8 or £9 per hour contracts being let and I just wonder what quality you can get for that? ... We would certainly not consider going to £8.50 ... But I would just like to understand how you could actually deliver a quality home care service on £8.50 ... I don’t know. Possibly local authorities who have taken that bold move would refer to the national providers, that’s how you get your cheaper price. We couldn’t deliver a quality assured service in [our area] for £8.50 ... without major risks.”

Local authority commissioning manager

One private sector agency described being contacted by a local authority who discussed a contract with an hourly rate of between £9.00 and £9.50 with a care provider. The provider told the local authority they could not deliver home care for this price.

“We just are not prepared to reduce what we feel are our essential quality standards to be cheaper.”

Manager, small voluntary sector care provider, North of England

Local authority officers gave examples of home care providers who had accepted contracts at such a low rate that they were subsequently unable to deliver the contract – in some cases where firms had gone bankrupt. In these instances the local authorities had to invest time and effort finding replacement care for people at short notice.

However the price of services is not the only indicator of human rights compliance:

“It is recognised that the current financial climate presents real challenges to local authorities in commissioning services but it is noteworthy that the standards of care are not always linked to the price of services. There are many providers of good quality care which promote the human rights of older people whose costs are lower than average.”

The Association of Directors of Adult Social Services

The practice of using reverse e-auctions

Reverse e-auctions are where providers place online bids for contracts in real time, competing to offer the lowest price that meets all of the service specifications. Proponents claim that this is a dynamic, competitive process that helps to achieve rapid price cuts, not normally possible using more conventional bidding processes. However several interviewees highlighted concerns that the process promotes a focus on reducing costs at the expense of quality.

“There is absolutely no way we would enter into an e-procurement auction and see the prices hammered down in relation to home care. It’s too risky. That would undermine our whole approach. So no, we didn’t do that.”

Local authority commissioning manager

The need for supportive leadership

Commissioning officers in some local authorities whose leadership, both senior management and elected members, maintained a consistent focus on quality told us that they were able to make commissioning decisions without the pressure to contract with very low-cost providers, which they felt would damage the quality of their services.

Clear and explicit leadership was a notable common feature in all of the good practice local authorities, starting with councillors and running through senior management. The interviewees in these authorities were clear that the messages about the central importance of quality and dignity which guided their decision-making came from the top.

Elected members in some local authorities saw the potential to, and expressed enthusiasm for, integrating a human rights approach into their scrutiny function.

However only around a quarter of local authorities train all elected members with lead responsibility for social care about their important role in protecting and promoting human rights.

A partnership approach to commissioning care services

The local authorities with clear leadership around quality also adopted a partnership approach to working with independent sector care providers in their local area. Local authority officers described the steps they had taken to engage positively and build a shared understanding of the importance of a human rights based approach and

how this could be incorporated by providers into service delivery.

This meant that when commissioning managers set strict targets on quality issues which affect older people's human rights, such as late care visits and turnover of care workers, the providers were clear about why this was done, and did not see the targets as punitive or irrational.

“We've done groundwork with providers and we've got a positive relationship ... We've built an understanding of what dignity means ... why it's important that somebody receives the call [care visit] within the time frame. Why it's important that we have a limited number of carers. So it's about that work rather than the providers feeling its penalties.”

Local authority manager

A number of the local authorities also offered free or subsidised training to providers to support this work. Some smaller providers see this as important, as they do not have the same in-house training support as larger providers, and quality training can be expensive.

Consulting providers

These local authorities also asked home care providers for feedback and invited them to suggest innovations. Providers appreciated being consulted and having their responses listened to. They felt that this approach helped to promote high quality services by drawing on their knowledge built up through experience of the practicalities of delivering home care on a day to day basis and frequent direct contact with older people.

Home care providers contrasted this practice with the top-down, 'command and control' approach adopted by other local authorities, where changes were imposed on providers without consultation.

“We have steering groups at [local authority] where they ask for our feedback ... which I think is good ... Rather than just saying, 'There you go, go and do that', they ask us first, 'Do you think this will work? What are the best ways to do it?'”

Small private sector provider, North of England

The role of the Association of Directors of Adult Social Services

The Association of Directors of Adult Social Services (ADASS) has a significant role in promoting human rights standards through commissioning. It represents Directors of Adult Social Services in local authorities in England with statutory responsibilities for the commissioning and provision of social care.

As individual members, ADASS members have statutory responsibilities to promote social inclusion and wellbeing, to lead on adult safeguarding, and have leadership responsibilities in local authorities to promote good standards in home care.

The effects on the service for older people

Particular concerns were raised about cost reductions leading to shorter time slots for care visits, and the impact this can have on the human rights of older people.

Local authority interviewees also raised concerns about the risks to the quality and safety of care and warned about the dangers of cutting costs too far, or too quickly, without fully assessing the risks involved.

“If the price of your service is so low then you will have to start to strip out the time that people spend with individuals, or the time that the organisation spends in developing the staff. That’s a major risk.”

Local authority commissioning manager

Organisations giving evidence to the inquiry considered that squeezing hourly rates or placing too much emphasis on cost rather than quality increased the risks of:

- rushed visits
- in extreme cases, ‘call cramming’ where providers over-book home care visits on a care worker’s rota making it impossible for them to spend the allotted time on each visit
- not paying workers for travel time
- reduced pay and conditions for care workers leading to increased staff turnover
- greater difficulty recruiting good quality care workers in some areas
- reduced scope for training, especially for smaller providers
- less supervision of care staff or opportunities for group meetings.

Given the findings of our inquiry that the risks listed above are all factors impacting on the protection of human rights, we consider that human rights are more likely

to be protected if commissioning is based on the costs of care with sufficient resources for support, training and travel time.

The effects on the care market

Until recently there was polarisation within the care sector between those providers who largely provided local authority commissioned home care and those who focussed on privately funded care. More recently the evidence indicates that smaller home care providers are being consolidated into larger ones at a steady rate. Medium to larger scale home care providers have been more successful than smaller providers in gaining local authority contracts, while some smaller providers have chosen to transfer their business from local authorities to private care.⁵⁰

It was widely recognised in written evidence that local authorities, as the largest local purchasers of home care, were in a powerful position, particularly in economically deprived areas, where private purchase of home care is limited. We were told that care markets had been adversely affected where local authorities had appointed a few large providers at very low rates. This led to smaller providers, perceived to be of high quality, disappearing from the local area. Doubts were raised about the long term sustainability of this approach.

“I think where some local authorities are now, around the pressure financially to drive down the cost ... The risk is a collapse of the market ... You go for that lower price, the market collapses but in collapsing you place people at risk.”

Local authority commissioning officer

A number of interviewees from local authorities viewed it as important to maintain a balance within the local care market by type and size of providers, given the distinctive strengths of different sized organisations.

“The approach we looked to develop was very much about the local market. If you were to look at our profile of providers, we have local private businesses that are small and have been established for a long time, that have a local identity. We have voluntary and community sector organisations. So there’s a real sense of a mix and that mixed approach is something that we’ve consciously developed.”

Local authority commissioning manager

“It balances it quite well really, because when the smaller ones [providers] can’t pick up packages, the larger one is able to do that.”

Local authority contracts manager

One local authority described steps it had taken to support the development of local services that were culturally sensitive to the needs of older people from ethnic minority groups, which they had identified as a gap in the local care market. The uptake of direct payments from ethnic minority communities has increased as a result.

An issue that was repeatedly raised in interviews with local authority staff was the importance of having commissioning and procurement led by officers who have a detailed knowledge of home care and the local care market. Interviewees believed that a nuanced understanding of the short

and longer term impacts of commissioning and procurement decisions both on older people and the local care market was fundamental to commissioning services that were both high quality and sustainable.

Contract monitoring

Again, we found a range of practice – from process-based (checking outputs and processes) to a more proactive, person-centred approach.

Interviewees from local authorities and voluntary sector organisations seeking to adopt good practice felt that including human rights principles and quality of outcomes in contract monitoring and management (rather than just checking outputs and processes) was the way to make sure providers prioritised and delivered on these areas.

Good practice that we were told about included:

- Quality monitoring using face-to-face interviews with service users, commissioned from a local voluntary sector organisation that specialises in working with older people – this uncovered issues that would not have been raised in paper-based questionnaires.
- Training older people from the local community as ‘citizen assessors’ to talk to older people receiving home care in their own homes about their experiences, as a key source of intelligence to inform their work.
- A proactive, hands-on approach to contract monitoring that places older people’s views and experiences at the heart of assessing quality of care:

“I don’t want the officers spending time sitting there reading policies and procedures, I want them to get out, observe what’s really happening in the services ... we’ve made what we call the values, the things that matter to people, first in the [monitoring] document, because that’s what we think is actually more important.”

Local authority commissioning manager

The key value of a person-centred approach to contract monitoring is that it is much more likely to help protect older people’s human rights than a more process-based approach. It also means that any problems that may place human rights at risk are likely to be picked up early. The prioritisation of obtaining the direct experiences of older people is also relevant for the formal regulation of home care by the CQC (see Part 4).

Assessing and reviewing older people’s needs

As well as commissioning local authorities also have a statutory role to assess **individuals** and review their home care needs. Our inquiry considered whether human rights were protected and promoted within these processes.

‘Screening out’ people from services?

Local authorities have a legal duty to carry out an assessment for anyone who appears to need community care services. The first point of contact to begin the process of arranging home care may be a local authority telephone contact line.

Concerns were raised that this can mean people in real need being turned away, with the result that they only receive support when their needs reach a crisis point. Telephone contact lines also create barriers for older people with cognitive or hearing impairments and, for this reason, local authorities could be failing in their legal duty to make reasonable adjustments if this is the only route to getting home care.⁵¹

A few interviewees from voluntary sector organisations highlighted what they saw as a failure by the local authority to carry out full assessments. It was alleged that some local authorities were using their telephone contact lines as a form of screening. The director of a voluntary sector organisation that supports older people described how older people would typically call the local authority saying they ‘needed a bit of help around the house’. However, instead of exploring the older person’s needs in more depth, the staff on the telephone lines would take the request at face value and simply pass on details of a local voluntary organisation that could provide light gardening and housework. The interviewee saw this as a way for a local authority, struggling with tight resources, to avoid their statutory obligations and reduce demand for home care services.

Age UK expressed concerns that where local authorities have central telephone access points for all their services, this presents a significant obstacle to some older people getting a full assessment. Telephone screening interviews are more likely to overlook pertinent points about the difficulties the older person is experiencing, so they are not given a

formal assessment. Given the reported tendency of older people to understate their needs and be reticent about disclosing the need for personal care or difficulty coping over the phone to a stranger, the level of support at home they actually need could go unrecognised.

Apart from undermining the promotion and protection of people's human rights, screening practices of this sort could amount to an unlawful refusal by the local authority to carry out its statutory duty to assess a person's needs. The *Penfold* case established that there is a low threshold for local authorities to undertake assessments; for example, they should provide them for a person needing services that the authority does not currently provide, or where the person would have to meet the full costs of the care they need.⁵²

How assessments are carried out

In some assessments, staff had taken their time and shown skill and sensitivity in finding out about the older people's needs and preferences.

However a few older people were unhappy with their assessments. One woman witnessed a heated discussion between her daughter and the assessor, which she had found humiliating, about whether overnight care could be provided to help her to the toilet. The assessor said that incontinence pads were the only viable option, although she was not incontinent.

“[Daughter] That’s when I terminated the interview and walked out ... I wanted to hit her ... no, I wasn’t happy with that comment. You’re taking away their dignity.”

Woman, 75, living alone, local authority funded home care

Concerns were raised by both local authority officers and voluntary sector organisations supporting older people about the practice of conducting full assessments and reviews by telephone. Should an assessment by telephone fail to elicit all the relevant information, a local authority would be in danger of failing to identify or meet the needs of the service user – leading to potential human rights risks. Social workers experienced in conducting assessments told us that there were many important non-verbal pieces of information – such as the state of clothing, or being underweight – that could be picked up from a face-to-face visit, which could indicate how well an individual might be coping and what support they might need. They also stated that, in their experience, older people tended to understate the extent of their needs and were often reluctant to admit that they might need support, so this sensitive information needed to be teased out in a setting which allowed them to communicate openly.

Other interviewees mentioned the introduction of computer-based self-assessment systems which are commonly used for personalised support, including direct payments. These were viewed by some interviewees as inaccessible to many older people and, as with telephone interviews, would not pick up when older people understated their needs.

A small number of interviewees raised the question as to whether these methods were being used as a way of rationing scarce resources through under-assessing needs.

Carers' assessments

Carers also have a statutory right to have their needs assessed,⁵³ and local authorities have a duty to explain this. However, we were told about a number of situations where carers' assessments had not taken place. In one example, we heard about an older woman caring for her husband, who had dementia and Parkinson's disease, who was driven to a point where she threatened suicide due to feeling overwhelmed with caring responsibilities and sleep deprivation. It then transpired that she had not received a carer's assessment or any support. It is likely that the local authority's neglect of the carer's needs would amount to a breach of the right to respect for private life under Article 8 of the ECHR, as well as being a breach of their statutory duty to conduct the assessment.

Reviews

Again, we heard of mixed practice with regard to reviews of service users' needs.

Local authorities have a general duty to conduct reviews, which is backed by government guidance. However, in some areas we were told about long delays. One local authority manager highlighted the impact this had on service users.

"When people ... get a review and suddenly are told, if you like, that their services have changed or they will change because they're not eligible any more or, 'Sorry

we hadn't reviewed you for three years but actually now we looked at you again and you're not eligible.' It's incredibly bad practice really. I'm sure it happens everywhere."

Local authority manager

In other places it was claimed that reviews were currently taking place more frequently than before, with the perception that the primary purpose was to look for opportunities to cut individuals' care packages. One local authority contracts manager told us that they were currently urgently reviewing all service users who had two workers at a time to support them, with a view to reducing the number of these 'double up' calls.

Our conclusions

Our findings indicate that – for a variety of reasons – commissioning bodies are not making the most effective use of the scope that they have for protecting and promoting human rights. As a result, there are concerns that they are not fully meeting their own obligations as public authorities under the HRA. This seems to stem primarily from a lack of awareness about the full extent of their HRA duties, including complying with positive obligations to promote and protect human rights.

We found that practice on commissioning varied a great deal. Some local authorities adopted a quality-driven approach, incorporating human rights principles at all stages of the commissioning process, while others appeared to focus on price above all other considerations – an approach which is likely to reduce the quality of services. However, very few are

consistently adopting commissioning principles that are firmly underpinned by an understanding of human rights.

A small number of local authorities have attempted to incorporate human rights into their practices in a meaningful way throughout their commissioning, procurement and contract management – human rights was sometimes one of the specific factors considered when assessing providers' performance.

Halton Borough Council uses the 'Dignity Challenge' approach pioneered by the Department of Health, which we described earlier.

“In our commissioning and contracting, we include the 10-point Dignity Challenge in our service specifications for block contracts, within principles and standards, and within the outcomes required for spot contracts. Dignity and human rights are underlying themes – ‘golden threads’ in our Quality Assurance Framework [QAF]. This means that providers will be assessed according to the degree to which they meet these standards, being mainstreamed into the QAF rather than as a tick list. In the procurement of services prospective providers have to evidence how they meet these underlying themes prior to the award of a contract and this becomes part of the contract monitoring process. We also publicise the annual Dignity Day to providers to highlight its importance and to give providers the opportunity to showcase good practice.”

Halton Borough Council written evidence

Some local authorities have adopted the Dignity Challenge as a framework for commissioning older people's services – with a clear understanding that this approach is underpinned by legal obligations under the HRA. This is a welcome development, one which we hope other local authorities will follow.



Part 3d: Choice and control over care

As for anyone else, it is important for older people to stay in control of their lives and what happens to them, and to be able to have a say in the care they receive. As mentioned earlier, the right to respect for private and family life under Article 8 of the ECHR includes the right to respect for personal autonomy. This is also a central principle of the UN Convention on the Rights of Persons with Disabilities (CRPD). Local authorities can help to fulfil these human rights requirements by offering older people a personalised approach to home care, giving them as much choice and control as possible over the nature and timing of services. Providing personalised services is a central element of a human rights approach to home care.

From our interviews with older people, it was clear that few of them – apart from some who had made private care arrangements – had taken much active part in arranging their care. For most of those we spoke to, their care was arranged with the help of their local authority. The majority of these felt they had had little say, and some were surprised to hear they were entitled to any choice.

Even though many local authorities specify that service users should have choice and control over their care, most older people said they had little or no choice over the tasks that were carried out or the timing of care visits. Many felt that home care was something that was being

‘done to them’, rather than a service that they could engage with and arrange to suit their lives and needs.

Older people’s understanding of their entitlements

We found that most of the older people using home care had little or no understanding of how the home care process works or what they were entitled to, what they had a right to expect, or the different options for managing their care.

Some found the system too complex and difficult to understand. We heard about one older person who would have become homeless had it not been for his family intervening.

“The biggest problem with home care is the complexity of the different services.

My father-in-law was suffering as he did not understand the system; he was given conflicting advice about carers, and he was left to cope with being made homeless.

My husband got involved, insisted on talking to managers, got advice from the CAB, discovered who was responsible and what he was entitled to, and suddenly the local authority could not do enough for my father-in-law.”

Daughter-in-law of an older man receiving home care

Even family members supporting older people to get home care found the systems too bureaucratic.

Information and advice

Much of the evidence from voluntary sector organisations flagged up the lack of understandable information for older people on either home care or their human rights. Even when the information is available, it is often not easy to find, or easy to access. For instance, it is often online, although nearly 6 million people aged 65 and over have never used the internet: 42 per cent of those aged 65-74 and 76 per cent of people aged 75 and over.⁵⁴ We were also told of information that is inconsistent, out of date or incorrect.

For people funding their own care, good information on how to obtain home care and how to protect their human rights is even more vital. Apart from a right to an assessment of needs, the only thing self-funders are entitled to from their local authority is this information. In practice they may get no more than a list of contact details for local care providers without any indication of the quality of the providers or their areas of specialism.

Older people's involvement in assessing their needs

A human rights approach to assessment would respect older people's autonomy by genuinely involving them in defining their own home care needs. Most older people we interviewed had had one or more formal assessments, but they generally had no detailed recollection or understanding of the process. Many older people found that although home care workers and payment arrangements were put in place, they had no clear sense of having had any input into – let alone control of – the process.

Anyone can ask for an assessment of their care needs, for example if they are finding it increasingly difficult to manage their basic day-to-day needs. However, there was little evidence that older people we interviewed were aware of their right to an assessment or had asked for one.

Many were first assessed for home care at a time of crisis – usually encouraged by family, or health or social care professionals. This may partly explain why older people often didn't seem to feel involved with the arrangements for their care, or feel that that they had control over them.

Choosing a provider

Many older people we spoke to were unsure how their provider had been chosen, or assumed there was no choice. In some cases, individuals who had expressed a preference felt that they were not listened to.

“[The agency] was provided by social services. I did not have a choice of provider, and though when I last came out of hospital I did request that the provider who I had had three months prior continue to be used, this did not happen and I had new care staff ... I felt no one paid any attention to my request. It is doubtful it was even considered.”

Woman, over 75, local authority funded, South of England

Some older people had had their provider changed against their preference, causing upset and disruption. For example, one older man had recently been told by the local authority that his care provider had been replaced. Although he was much less happy with the services of the new agency, he felt he had little choice but to accept it, even though he was paying towards the cost of care from his own funds.

There was some good practice. In a few of the interviews it emerged that the local authority had replaced an agency because the interviewee was unhappy with the service they were getting. However, there was little evidence that the older people concerned had been consulted or involved in the change process. They simply accepted the next agency chosen by the local authority.

Some older people and their families, particularly those paying for their own care, told us about feeling overwhelmed when faced – often at a difficult time – with choosing a home care provider. In some cases they were only given a long list of care providers, and had no other source of information. In written evidence, some explained the difficulty of differentiating between organisations without any indication of quality. A provider complying with CQC standards demonstrates that they meet the minimum standards rather than indicating levels of quality.

The CQC used to award ‘star ratings’ as a guide to the quality of each provider, but it no longer follows this system. Some older people told us that they had found this very helpful in selecting care providers. According to ADASS, the star system also provided information that enabled local authorities to require improvements from care providers.

Offering greater choice and control through personalisation

If properly implemented, personalisation has the potential to enhance older people’s choice and control over their care, and so promote their human rights – in particular their right to respect for personal autonomy.⁵⁵

In the past, a service-led approach to social care has meant that individuals have been expected to fit in with the services provided. As the Social Care Institute for Excellence has highlighted, personalisation challenges those commissioning and delivering care to take a radically different approach.

Personalisation means thinking about care and support services in an entirely different way. This means starting with the person as an individual with strengths, preferences and aspirations, and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives.⁵⁶

Personalised care is typically delivered through personal budgets, which should allow people to control the funding available for their care and make choices about the support and services that they need. People can choose how they receive their personal budget. The most common ways to receive a personal budget are as a direct (cash) payment where an individual takes on management and budgetary responsibilities or as an account managed by the local authority ('managed account' or 'virtual budget') but where the money is spent as you choose. People can also benefit from personal budgets through third party trusts or other third party services. Local authorities usually decide how much money to put in a personal budget by using a formula called a Resource Allocation System (RAS) which allocates points according to how care needs assessments questions have been answered.

The benefits of personal budgets and direct payments are widely recognised in terms of the opportunity to obtain an individually tailored blend of services which can give greater freedom of choice and autonomy. However, it is also accepted that the benefits may be greater for some people and for some sectors of the population than for others.⁵⁷

Older people's experiences of personal budgets

Consistent with the national picture, only a handful of older people and their families who provided evidence to the inquiry reported receiving personal budgets. Most were positive about their experience, and preferred the increase in choice and control. They usually contrasted their current satisfactory situation to previous arrangements where poor quality and, in some cases, unsafe care was provided.

"When I was using [the] agency I did not have my decisions taken into consideration for the most part. I was expected to conform to behaviour they found acceptable."

Now on an individual budget I make all the decisions. I am 100 per cent happy with my support workers."

Woman aged over 65, North of England, local authority funded care

"The care agency chosen [by social services] did not provide an adequate service. They failed on many occasions to give the correct medication, which severely affected my father's health."

We transferred to self-directed support and now employ personal staff. My father now gets an excellent service which supports the care that we can give as a family. They are a lifeline."

Daughter of man aged over 75, part-funded local authority care, North West

Factors preventing older people taking up direct payments

The Commission has found that some older people do not wish to use personal budgets and indeed, the take-up is lower for older people than for most other groups.⁵⁸

A number of older people told us that they were not prepared to change to a personal budget by way of direct payments, even some who were unhappy with the care they were receiving. They voiced practical concerns about being responsible for a direct payment, concerns that were supported by many providers, local authorities and voluntary sector organisations:

- concerns about responsibilities
- lack of support to manage responsibilities
- lack of information to make an informed choice
- increased risk of abuse or breaches of human rights.

Concerns about the responsibilities

Some older people and their families, who did not currently receive direct payments, were nervous that they might be required to do so. Their concerns included:

- the burden of managing employment responsibilities
- feeling unable to cope with the demands of organising their own care.

The concerns of older people and their families were echoed by a range of organisations and individuals who

submitted evidence. Many interviewees from local authorities and voluntary sector organisations doubted whether older people were fully aware of the range of responsibilities that came with being a micro-employer. This would include organising back-up for annual leave, sickness or maternity cover. Others pointed out how difficult some older people were likely to find raising complaints or areas of dissatisfaction with an individual who was not providing a satisfactory service, given the significant difficulties that older people experience in raising concerns with organisations providing care.

“The idea that you might just employ an individual yourself ... can work very well for some people, but can also not be what people are looking for, partly because they don’t want the risks and the legal responsibilities of that but also because not everybody wants an employer/employee relationship with the person that supports them.”

Director, national voluntary sector organisation

Local authority interviewees, in particular, stressed the important role that supportive family members play in helping their older relatives manage the bureaucracy of employing a personal assistant.

The difficulties for some of taking on managing their own care were spelled out by one older person responding to the call for evidence.

“Please realise that personalisation will not help me at ALL as I am completely unable to make phone calls and look up companies who provide care to organise it myself, and certainly could not conceive of trying to employ anyone myself, and anyway they would need sick cover etc. How would I organise that?”

I just wish that social services had enough funding to provide agencies with enough money to employ the right number of staff at a good wage to do the job properly.”

Older woman, 75, local authority funded care

Although this person uses the umbrella term ‘personalisation’ it is likely she is referring to direct payments given her fears about being able to use the phone and organise care at short notice.

Lack of support to manage responsibilities

If they receive direct payments, people have to comply with certain accounting arrangements and paperwork requirements, which some older people (particularly those with limited capacity) cannot manage without support such as a brokerage or advocacy scheme. A number of older people preferred to be on a managed account, where the local authority manages their personal budget, because they felt unable to keep all the necessary records.

Interviewees from voluntary sector organisations pointed out that, as in most areas the eligibility threshold for receiving direct payments is to have critical or substantial care needs, these older people would be very likely to need targeted

support to manage their budgets effectively – particularly as many came into the home care system at a time of crisis.

Some submissions from organisations outlined examples of effective support and advocacy by organisations with an in-depth understanding of the issues affecting older people. For example, a local Age UK organisation described their ‘support broker’ scheme for self-funders.

“The support brokers visit people and discuss what they want and help develop a personal support plan, then assist with putting the arrangements in place as instructed by the client. Each support broker works in a limited geographical area and so becomes very familiar with what is available in their local patch. Schemes like this support people to have an informed choice of what services they receive and control over the care that they receive. They get as much support as they need until they have the confidence to take on the management of their care themselves. They also have a known point of contact should they need more help in the future.

Age Concern Wigan Borough support people in receipt of direct payments and offer help in recruitment and employment of staff. The fact that this scheme is independent from the local authority and is run by a well respected local organisation gives people confidence that they will get the help and support they need when taking on the complex responsibility of managing their own care.”

Age UK, North West region

Although a brokerage service is an option which some older people said was attractive to them, concerns were also raised about

the cost of this being taken out of the money allocated for care, reducing the amount of care they would be able to afford.

Some voluntary sector organisations supporting older people highlighted the need for ongoing support with managing direct payments, rather than just at the initial set-up phase.

“They [local authority] might set everything up for them and say, ‘Look it’s a really simple system. We’ve got this, it’s great.’ And then they go away and leave them to get on with it. But you’re dealing with elderly carers that are stressed; that are in a new situation where they’re having to do all this paperwork. A crisis happens, and they get stressed ... and the paperwork gets backed up, the care doesn’t get paid for. It’s not straightforward at all.”

Support worker, voluntary sector organisation supporting people with dementia

Voluntary sector organisations also raised concerns that some of the available support has a ‘one size fits all’ approach. They felt that some organisations providing this support and advocacy did not have enough knowledge of specific issues affecting older people to offer appropriate support – for instance, understanding how ageist assumptions can limit people’s choices. We came across one organisation commissioned to provide brokerage whose support appeared to be influenced by stereotypical assumptions about older people preferring to ‘stay at home and put their feet up’ rather than be involved in their community. This is of concern, given our findings on the extent and impact of isolation for older people.

Our findings highlight that older people will only be in a position to benefit fully from options available through personal budgets where effective and ongoing support is available through such means as advocacy and brokerage services – a point which echoes the Department of Health’s statement quoted below, and earlier studies.⁵⁹ It appears that in some areas this is available but in others it is limited, non-existent or only available for a fee.

Lack of information to make an informed choice

In their evidence to the inquiry, the Department of Health acknowledged the importance of appropriate information and support as crucial to implementing personal budgets successfully.

“We know that people will need support if they wish to take on this greater responsibility. People will have differing levels of capacity and understanding and public authorities will have to ensure that they provide the information and support that people want and need in order to fulfil their legal duties under human rights legislation.”

Department of Health response to call for evidence

The evidence to the inquiry indicates that that support and information is not fully available yet.

A wide range of interviewees from providers, local authorities and voluntary sector organisations flagged up a concern that there appeared to have been a rush to put older people onto personal budgets –

either by way of direct payments or managed accounts – without always making sure they had the information and support they needed.

More generally, in the interviews and focus groups that we conducted with older people it was notable how little they were aware of the personalisation agenda. Questions on the topic often drew a blank.

Lower safeguards against abuse and other human rights breaches

As we explained in Part 1, local authorities' positive human rights obligations may sometimes include a duty to protect individuals from the actions of others. If there is clearly a risk of human rights being breached, local authorities may have an obligation to provide information explaining this risk to individuals who are under threat. There may also be a duty to monitor situations where breaches of human rights are likely. Thus, in certain limited circumstances, local authorities could be arguably under a positive obligation to protect the human rights of people who receive direct payments – for example, by giving them information so they know the steps they can take to safeguard their fundamental rights.

We took evidence from a small number of older people who had appointed their own care workers (often a family member) using a direct payment. They did not tell us they felt more vulnerable to abuse of trust or other problems.

However, a wide range of individuals and organisations, including care providers and local authorities, voiced concerns that the personal assistants taken on by older

people are not covered by the regulation that applies to care workers.

“The drive towards personalisation, whilst welcome because of greater choice and control of solutions tailored to the needs of individuals, also means there is a need to balance risk, choice and safeguarding people from abuse, harm and neglect. This includes consideration of people’s human rights.”

Local authority survey respondent

Many contrasted the steps that local authorities take to guard against abuse with the lack of any similar safeguards for personal assistants. Some were also concerned that it would be easy for people looking to abuse or exploit older people to spot adverts by older people wanting a personal assistant. One older man expressed his frustration about not having control over how his care worker spent her time, but said he would not transfer to a direct payment because he would feel too vulnerable to being ‘ripped off’.

Like home care workers, personal assistants are not required to have any qualification but unlike home care staff, personal assistants lack the benefit of support and supervision from an agency. Although there are some safeguards available to older people directly engaging personal assistants – such as police checks or references – we were told that few older people actually carry out such checks. This was partly because they feel it would appear mistrustful, or sometimes because they did not know how to go about doing this. However we are aware that local authorities can take various steps to mitigate risks in employing personal

assistants; for example, by commissioning payroll services for recipients of direct payments, funding independent advocacy services and developing registers of personal assistants or supporting local organisations to do so.

Local authority targets for personalisation

The Department of Health set a target for local authorities to have 30 per cent of all eligible service users and carers on personal budgets by April 2011.⁶⁰ Some interviewees felt this was leading local authorities to move people onto personal budgets in a way that does not give them the benefits of greater control and choice.

In a small number of local authority areas it was alleged that older people were ‘pressurised’ into accepting personal budgets, without being presented with a balanced picture of all of the alternatives available to them.

In some areas, it was also claimed that older people had been moved to personal budgets managed by the local authority without gaining any choice and control over their care provision. The local authority continued to commission the same care provider to carry out the same tasks as before at the same times. Some saw this as contradicting the spirit of personalisation, aimed more at fulfilling the local authorities’ targets than putting older people at the heart of the services.

“We received a phone call from a Council Care Manager who said, ‘By the way, as of last Monday this service user is on a direct payment.’ All that’s happened here is that

the Council has just moved the money from the Council to the individual but is still in control. They’re still doing the commissioning. They’re still telling us what will happen. The actual reality of what support that person is getting has not changed one jot. And I would wager that the service user has absolutely no understanding of the change.”

Manager, large private sector provider

The European Court of Human Rights has made it clear that protection of human rights must be ‘practical and effective’, rather than ‘theoretical and illusory’.⁶¹ The approach to personalisation adopted in the example above suggests that this local authority may be falling short of its HRA obligations to respect older people’s autonomy, protected by Article 8.

Concerns about the level of direct payments

We were also told that the level of direct payments from local authorities often does not allow for the creative, flexible packages of care that people had been led to expect from this system of funding. Our evidence suggests that these packages, clearly of huge value to service users, are more readily available for younger disabled adults. Interviewees, mainly from voluntary sector organisations, stated that the funding for older people only covered essential basic physical care such as support to get up or eat.

For example, the daughter of one older man wanted to spend some of the direct payment on support with assisting her father to get out and walk his dog so he

could keep his pet. This was not only very important to him emotionally, as company in his home and in terms of exercise, but also a key way for him to get out and socialise in his local community, and would therefore make a fundamental difference to his quality of life. However the personal budget was only enough to cover his essential physical care needs, such as washing and dressing.

Providers also told us that in their experience the amounts allocated to older people in direct payments gave them little flexibility, even to buy enough care to cover their essential needs, and forced them to buy the cheapest possible care.

In some cases we were informed that local authorities may deduct up to 10 per cent when a service user transfers from managed care to direct payments, reducing even further the amount that older people have to spend on care.

Personalised service does not have to mean a personal budget

When we asked older people what would improve their current home care service, most of those who volunteered an opinion indicated that they would like it to be more responsive to their needs and wishes:

- covering a range of different tasks
- flexibility to respond to changing situations rather than a rigid list of tasks to be carried out at specific times, regardless of anything else going on in their life, and
- care workers who listened to them.

These issues indicate a strong desire for the theory of personalisation to be translated into reality in their care – to have a flexible, responsive service, shaped around them as an individual rather than controlled by organisational convenience. Essentially, this means an approach to personalisation which genuinely supports their individual rights to respect for personal autonomy and dignity.

Some interviewees felt that older people were being offered a false dichotomy: either have services commissioned by the local authority, or if the person wants a flexible and creative service shaped around their own needs have a direct payment. These interviewees felt that older people should be offered a truly personalised service no matter how the funding was arranged.

One local authority talked to around 2,000 older people in their area, face-to-face, to find out what they wanted from home care. This in-depth listening exercise showed that older people wanted flexibility and quality in their services. As a result, the local authority is reshaping their commissioned home care services, aiming to make truly personalised flexible services available to all older people receiving home care in their area, regardless of how these services are paid for.

In our view, the drive towards personalisation in social care should be implemented with greater consideration of the potential for genuinely promoting older people's human rights. Support should be given to older people to make

an informed choice about the type of funding most suitable for them. Irrespective of funding arrangements, models of personalised home care that adopt a comprehensive human rights approach should be extended so that older people's needs and choices are truly at the centre of the services they receive.



Part 4: Key challenges to the human rights of older people

The inquiry evidence and other studies point to several interlinked factors which undermine the human rights of older people who get or need home care. These are:

- the impact of age discrimination
- a lack of informed choice about home care
- a lack of investment in care workers
- output-driven commissioning, and
- the climate of financial constraints.

The lack of an adequate legal and regulatory framework is another factor which puts at risk the human rights of older people who need or receive home care. This issue is examined in Part 5.

The impact of age discrimination

We know from our Triennial Review that discrimination against individuals with particular characteristics can lead to treatment that falls short of human rights standards – such as inadequate dignity and respect in health and social care services.⁶² Our inquiry evidence illustrates this by revealing threats to the basic human rights of older people using home care services which in some respects link to discriminatory practice and negative, ageist attitudes.

Different treatment for different age groups

Figures indicate that less money is spent on care packages for individuals over 65 compared with other age groups. Even after taking into account a wide range of needs, outcomes and other factors, the unit cost of the support received by older people is significantly lower than that received by younger people. On average, it is estimated that older people would need a 25 per cent increase in support for these age differences to be removed.⁶³ Older people also have, on average, around a 10 per cent lower chance of receiving support from a social worker than younger people with the same needs.⁶⁴ An evaluation report on the Individual Budget pilots noted discrepancies between the resources allocated to adults of working age and the lower level allocated to older people.⁶⁵ Studies have also shown that direct payments are less likely to be offered or considered when older people's needs are assessed by social workers.⁶⁶

Some of the organisations giving evidence to the inquiry believed that poor commissioning practice in home care was as much about underlying age discrimination as lack of understanding of human rights.

“I just think as a society ... it doesn't matter about older people. They're not individuals, they haven't still got lives to lead ... If you said that some authority was doing reverse auctions for ... adults with a mental health problem, there'd be an absolute outcry. People with a learning disability ... there'd be an outcry. But it's okay to treat older people [like that] ... to reduce older people to units of time ... I don't want that for me or anybody. I suppose it's just really basic stuff isn't it? Why does anybody think that's all right?”

Local authority care manager

Other local authority interviewees pointed out that care packages for older people were less likely to include support to allow them to take part in their local community than those for most younger adults. This was ascribed to ageism.

“We are still ageist across the statutory agencies, there's no two ways about it ... you wouldn't think twice about younger people getting a lot of support around social interaction, about social networking ... you wouldn't think twice about funding that. There's no way on this earth a) we could afford to, or b) we'd really have the inclination to do that [for older people].”

Local authority senior manager

Age discrimination in social care directly affects older people's human rights. We heard from some care provider agencies that the resources allocated through local authority commissioning were often not enough to deliver the amount and quality of home care required in their contracts. As a result, older people had 15-minute visits, from care workers who were rushed

and unable to finish the tasks that were allocated for each visit.

“A provider outside London described the care specified by a council for a 15 minute visit: ‘Prepare food as per service user's request; prepare jug of drink; prompt him to drink, eat and take medication; ensure house clean, if necessary.’ The provider also noted the need to complete the care record within that time.”

United Kingdom Homecare Association

Older people gave numerous examples of human rights being at risk or actually breached, such as when they hadn't had a hair wash for weeks or were left without a meal because of the lack of time. As illustrated by the quote above, our evidence also shows that support for social interaction and going out was not included in care packages which tended to be limited to support for basic physical needs.

The amount of money allocated to individuals in their personal budgets is calculated using a formula known as a Resource Allocation System (RAS). Concerns about how these tools were designed, their lack of transparency and the impact on older people were raised by a number of voluntary sector organisations.

Through their work in this area, Age UK have identified three ways in which local authorities could potentially discriminate against older people in allocating resources;

- By using different Resource Allocation Systems for older people and younger adults. The Resource Allocation System recommended by ‘In Control’, for example, uses different resource tools

for younger adults and for older people. The two tools cover broadly similar areas but with different weightings; the one for younger adults places more emphasis on social involvement whereas the one for older people places more emphasis on health conditions.

- Where a 'points based' system was used to allocate resources, older people might receive fewer points for the same level of need.
- Points based systems entailed allocating a sum of money per point; in some cases older people would receive lower amounts per point.

Ban on age discrimination

We have seen that Article 14 of the ECHR gives protection against discrimination in the enjoyment of other ECHR rights. Our findings included evidence that, in contrast to younger disabled adults, older people's care packages rarely include support for activities outside the home – a discrepancy which raises concerns about compliance with Article 14 taken in conjunction Article 8 – the right to respect for private life.

However, the HRA does not provide a self-standing prohibition on discrimination. Anti-discrimination rights are now consolidated into the Equality Act 2010. Although the Equality Act contains provisions banning age discrimination in services and public functions, these are yet to come into force, possibly in April 2012.⁶⁷ At that point, age-related discrepancies in financial support for home care will become unlawful under the Equality Act – unless they can be 'objectively justified'. We welcome the fact that the Department of Health has expressed support for these provisions being brought into force, and is committed

to ending age discrimination in health and social care. With this goal in mind, the Department of Health has already commissioned a good practice guide on social care from the Social Care Institute of Excellence (SCIE),⁶⁸ which emphasises the importance of making sure resources are allocated fairly regardless of age. One London borough has chosen to adopt the same application of the Fair Access to Care criteria and the same Resource Allocation System for adults of all ages. We hope more will follow.

Lack of informed choice on care

Positive obligations linked to choice on care

As explained in Part 1, because of the HRA public authorities must comply with the rights guaranteed by the ECHR. So, in carrying out their powers and duties, local authorities must respect older people's personal autonomy, protected by Article 8 of the ECHR. As far as possible, they should be given the opportunity to make decisions for themselves about the home care options that are available.

In carrying out their functions, local authorities also have positive obligations to promote and protect human rights. This means that in some circumstances they may have to provide older people needing home care with information about their human rights if it is clear that their rights are at risk.

Lack of understanding

Our evidence showed that many local authorities had a patchy understanding about the practical implications of these human rights obligations, but also that

older people and their families have little or no information about what their rights are, let alone what to do if they are at risk.

Our face-to-face interviews with older people revealed that most had little understanding of the quality of service they should expect. The information that was available was often inaccessible (some being entirely web-based and out of reach to households without internet access) and made no mention of their rights, let alone their human rights. It was sometimes inconsistent, incorrect or out of date.

Self-funders were highlighted as receiving limited information from local authorities to allow them to choose services with the quality and security they needed – sometimes receiving just a list of local independent care providers.

Since information is the only type of support that most self-funders are entitled to receive from local authorities, it is worrying to hear of instances where it has been inadequate. Arguably, local authorities have a positive obligation to provide self-funders with information about risks to their human rights, particularly when someone is forced to fund their own care because they just fall short of a ‘substantial’ or ‘critical’ threshold for eligibility.

For older people and their families – including self-funders and people receiving direct payments – to exercise real choice and autonomy they need comprehensive information about local care providers and the services they offer. Older people who sent written evidence explained how difficult it is to differentiate between organisations without any indication of quality. The current system of reporting whether or not a provider complies with CQC standards only informs

the public that a provider complies with minimum standards. We were told that what people need is information about providers’ performance on particular aspects of service that an older person might be interested in – for example, respect for cultural needs or supporting people with dementia – so that people can choose a provider that suits them. In view of that, it is all the more important that as much information as possible, including detailed inspection reports, should be made available to the public.

Interviews and written evidence also stressed the need for adequate support and information to be given to older people about personalised care, so that they could make an informed choice between managed accounts and direct payments if they wished to pursue this option. Many of the people who submitted evidence on this issue thought that the information provided in many authorities was inadequate.

Brokerage services, where an organisation other than the local authority takes on the responsibility for managing the personal budget, is an option which some older people found attractive. However, the availability of age-tailored support and brokerage is thin on the ground. It is being provided by voluntary sector organisations representing older people (such as local Age UK organisations) in some places. In other places the local authority might help older people to set up direct payments, but then they are often left to their own devices.

Lack of investment in home care workers

Care workers are uniquely placed to see when the human rights of the older people

they support may be under threat. They may be the only person to visit the older person in their home on any given day, or even week. Unfortunately, our inquiry findings show that many care workers have little time to do their work properly, let alone sit down and chat to someone to find out if there are causes for concern. Given that many older people themselves are reluctant to complain, this may mean that risks to human rights may go unnoticed. The situation is even more acute for people with dementia or those without supportive family and friends.

This state of affairs must be addressed before the human rights of older people receiving home care are properly protected.

Care workers are low paid, and may get little training and inadequate supervision and support. The workforce is predominantly female and part time⁶⁹ and there are no qualification requirements.

“The workforce ... currently accounts for 80 per cent of the total expenditure in social care, but inevitably affects 100 per cent of how individuals experience the service.”

National Pensioners’ Convention response to call for evidence

Pay and working conditions

Social care staff make up around 1 in 10 minimum wage workers, and home care staff are recognised by the Low Pay Commission as working in a sector with a high proportion of minimum wage workers. In 2009 care workers’ hourly pay rates in the private sector were around 50p less than those of retail sector

workers.⁷⁰ For that year, the average minimum pay rate for home care workers employed by independent sector agencies was £6.40 an hour.⁷¹ We were told that, in practice, this figure can be lower when care workers are paid according to the time allocated for each visit, and not paid for their travelling time.

Although the National Minimum Wage (NMW) Regulations do not require workers to be paid for travelling time, their pay when averaged over all qualifying working hours must be at least the NMW level. Qualifying working hours for these purposes includes time spent travelling between visits. It is estimated that travelling time between visits adds approximately 20 per cent to a care worker’s paid time,⁷² which would imply a minimum hourly pay rate from 1 October 2011 of £7.29⁷³ to meet NMW levels.

Only a very small number of the local authority service specifications we analysed included any reference to the terms and conditions of home care workers, and only one mentioned that pay rates should be above the NMW to take travelling time into account.

“My mother was ... entirely dependent on visiting carers for all her needs. Ladies came on buses to provide the 30 minutes four times a day. Sometimes the journey could take them nearly 2 hours with a final half mile uphill to walk from the bus stop. They were exhausted and not paid for travel time. If they were unable to get to a shift it often went without cover.”

Daughter of older woman previously receiving home care currently in residential care, South of England

A number of local authorities responding to our survey identified the poor pay and conditions of home care workers as a key barrier to promoting human rights. The effect on staff retention, training levels and the quality of staff attracted to the industry all have a knock-on effect on older people.

“The workforce is low paid. Human rights are best promoted through providers being able to offer a competitive wage that would attract better quality staff who understand human rights issues and live the values.”

Local authority responding to survey

This was also raised by Unison who submitted evidence of a continued downward pressure on pay and increasing numbers of workers receiving payment below the National Minimum Wage. They attribute this partly to the emerging employment practices of ‘stretching unpaid hours.’⁷⁴

“Low pay and stretched unpaid hours correlate directly to the high rate of turnover in the workforce. The lower the pay, the higher the churn and turnover rate in the workforce. This benefits no one, making well-trained, person centred care extremely difficult to deliver.”

Unison’s response to the call for evidence

Workers’ pay makes up a significant proportion of home care providers’ overall costs. Home care providers indicated that when rates are cut by commissioning bodies, the pay and conditions of workers are likely to be affected.

“The Care Agency which has won the social services contract for my area has obviously pared its bid down to the bone to win the

contract and the regular supply of work that this brings.

They have insufficient staff to fulfil all their obligations, particularly at weekends, and as their pay rate is low they have a huge staff turnover, meaning that staff are often inadequately trained. This has an obvious impact on their clients who are often left for long periods of time between visits.”

Private sector provider, South of England

One local authority identified improving care workers’ employment conditions as being of central importance in helping them deliver a high quality home care service to the older people in their area. This was reflected in their approach to procurement of home care providers.

“We wanted to improve the care workforce ... We wanted to see staff on salaries, no zero hour contracts, proper career structures ... staff who are skilled up and trained to provide a variety of needs ... So we have asked providers to clearly tell us in their bids, how are they going to do something to improve the workforce and staff. ... I just think there isn’t any job that is more significant or important in people’s lives than ... the dom[iciliary] care worker. And yet ... dom care workers, they get minimum wage, they get rubbish hours, they don’t get holidays.”

Local authority commissioning manager

Interviewees from local authorities and independent sector home care providers raised concerns about the impact of commissioning at very low rates on

workers' pay and conditions. Given the very low rates in some local authority contracts, some could not see how these would cover the essential costs of service delivery. Although providers are free to take contracts and incur a cost, this may not be a sustainable approach to commissioning home care.

These concerns have been echoed by the Low Pay Commission, which has repeatedly recommended that the commissioning policies of local authorities should reflect the actual costs of care, including the National Minimum Wage.

“We were concerned by evidence indicating that the level of fees paid by public sector bodies when purchasing care services from the independent social care sector did not reflect minimum wage costs.”⁷⁵

Low Pay Commission Report 2011

Core skills including literacy and English, induction and training

The inquiry evidence indicates potential risks to human rights when care workers lack core skills to do the job, including literacy and English. A number of older people felt the verbal and written English language skills of some care workers – often, though not always, from migrant communities – meant they couldn't do some aspects of their job as well. They couldn't fully understand conversations with older people, keep accurate written records or pick up on areas of concern, and there was the possibility of serious misunderstandings.

“Miscommunications are often very risky if you have recorded, or you think you have, that you've given some medication. Informal carer arrives and doesn't realise, then you've got a double medication potentially. We have seen that.”

Director, voluntary sector care provider, South of England

Conversely an interviewee working with people with dementia had experience of migrant care workers paying greater attention than others to communicating with older people because English was not their first language.

We heard of good practice to improve the skills of care workers. Some providers take steps to arrange NVQ training for care workers who need to improve their literacy and numeracy, which was seen as very beneficial.

Others stressed the need for a robust induction that 'exceeds mandatory standards' and covers all aspects necessary to deliver high quality care – including human rights considerations such as dignity, respect and autonomy. Some saw induction as an opportunity to pass on the values of the organisation to new home care workers – as well as practical information – and ensure that workers understood that these were intrinsic to their role. One provider has a six-day induction which includes service users and informal carers talking about how receiving care affects them and their lives. We consider that this sort of practice needs to be rolled out across the sector to ensure that care workers are properly equipped and supported to do their job.

Output-driven commissioning

As we have detailed in Part 3c, our evidence tells us that good commissioning is central to ensuring a human rights-based approach to service delivery, and that local authorities can go a long way to satisfying their obligations to promote and protect human rights if they get commissioning right – for example, by:

- ensuring commissioning plans incorporate a human rights approach
- using service specifications that require practices and outcomes aimed explicitly at promoting and protecting human rights
- involving older people using services in the commissioning process
- proactively monitoring contracts to see that human rights are respected, and taking action when they are not.

Unfortunately, as there is no independent regulation of social care commissioning it is difficult to check whether this is happening. Although there was some evidence of good commissioning, we received a lot more that pointed to commissioning practices that do not promote and protect human rights. We think this is largely due to the general lack of awareness about the practical implications of human rights responsibilities among local authorities, which is exacerbated by financial constraints.

‘Time and task’ commissioning

Much evidence indicated a restrictive over-emphasis on a ‘time and task’ approach to commissioning, along with a lack of focus on outcomes.

In some cases, the terms for delivering home care were so tightly defined and inflexible that they could place older people’s human rights at risk. According to our analysis of service specifications and related documents, some local authorities specify how many different care workers people can have in any given period. The intention may be to limit the numbers, but the actual numbers permitted in the specifications (up to 10 a week in some cases) are significantly higher than older people are likely to find acceptable – potentially jeopardising their right to respect for private and family life under Article 8 of ECHR. Similarly, several specify quite narrow time bands for meals or help with daily activities such as getting up and going to bed, which obviously places significant restrictions on choice and autonomy for older people. As mentioned before, home care workers themselves experienced frustration at being unable to depart from an inflexible list of tasks to fit in with the individual needs of an older person.

Re-ablement services provide short-term support – often for people who have just left hospital. We were informed that many local authorities take a more user-driven approach to these services, with a focus on assisting older people to identify and achieve their own aspirations. This approach could valuably be incorporated more widely into the delivery of home care.

Financial constraints on quality

Financial restraint is a reality, and is making the home care system more time and resource poor. However, our evidence shows that, even within current financial constraints, some local authorities are successfully finding innovative ways of doing things differently rather than simply doing less of the same. As Baroness Greengross said on the BBC Radio 4 Today Programme:⁷⁶ ‘Society has to get this right and I do believe that human rights as a tool can help to get it right without additional cost – just a better awareness of what you or I would want if we were vulnerable and frail.’

We also heard from a number of organisations and individuals that the approach of some local authorities in response to financial constraints has been to reduce the amount of time that home care workers spend with each older person. The same tasks had to be delivered in a shorter time which, as illustrated in Part 3b, creates a real risk to the human rights of older people receiving home care. Other local authorities have raised their eligibility criteria, so more older people who need home care now have to pay for it themselves, manage without support or face moving into residential care.

We also heard about a move to reduce the number and frequency of home care visits. A number of older people, home care providers and representative organisations highlighted the impact of these reductions. In extreme cases such as the example below, reductions in visits could lead to a breach of the right to respect for private life under Article 8.

“A lady in her 90s no longer receives the seven evening-time visits to help with personal care and check-up on her safety. Since the council ... reduced her care by 41 per cent in January 2011, she has been scalded attempting to make a cup of tea; has spent a night lying on the floor undetected after a fall; and a skin condition has deteriorated as she is unable to apply the lotion she needs. She now telephones her daughter in the evenings in a state of distress. The reduction in hours saved the council about £62 a week.”

United Kingdom Homecare Association written evidence

There is also a question mark about the sustainability of cost-cutting trends in some areas in the medium and longer term. Some interviewees consider that, although a local authority may make short-term savings, this approach is likely to be more costly in the medium to long run due to extra costs of increased hospital admissions, faster deterioration of medical conditions, urgent reviews of service by social workers and the need for more monitoring. However, many of these costs would be borne by health services rather than local authority social care budgets, so there is less incentive for local authorities to quantify these related financial consequences of their decisions.

“One of the dangers is what I call cut and slash ... cut the home care hours down to 15 minutes ... Yeah it saves money but ... at the end of the day if you don’t meet those needs it’ll cost you more ... If there’s somebody in the community with real complex needs ... they will go into hospital, there’s no two ways about that, that’s where they’ll end up and that will cost ... a hell of a lot more.”

Local authority senior manager



Part 5: How can threats to human rights in home care be brought to light and dealt with?

Our evidence is that some older people endure treatment that is distressing, which in certain cases breaches their human rights. In many cases nobody would have become aware of this treatment if we had not gathered evidence from the older people concerned. Clearly, therefore, the current systems for exposing problems are either insufficient or not operating properly. The significant barriers preventing older people from complaining were largely acknowledged by the local authorities, providers, voluntary sector organisations and care workers who spoke to us.

As we have already noted, public authorities' positive obligations to promote and protect human rights include a duty to respond to human rights breaches, which may include carrying out an effective investigation into credible complaints of human rights violations – whether or not carried out by their own staff. Positive human rights obligations also include a requirement for a legislative and administrative framework to deter conduct that would infringe fundamental rights. In this context, it is important that there should be effective avenues for complaint that allow human rights concerns in home care to be brought to light.

Current avenues for complaint

Currently, the standard ways that may bring problems or areas of concern to light are surveys, complaints, safeguarding boards and whistleblowing.

Satisfaction surveys

Both local authorities and home care providers carry out surveys to find out how satisfied older people are with their home care services. In a recent national survey, 58 per cent of older people receiving home care say they are very, or extremely satisfied with the care they are getting.⁷⁷ Although we recognise there are many committed providers delivering high-quality home care, we believe this figure may not be a completely accurate reflection of satisfaction levels as our inquiry also found that many older people do not have high expectations and are reluctant to raise concerns.

Voluntary sector organisations and home care providers also told us that the paper-based questionnaires generally used may not be the most effective way of overcoming older people's reluctance to raise concerns.

Some providers use other methods, for instance involving service users, including older people with learning difficulties, and family members in monthly customer focus groups to discuss service issues that concern them.

“It gives (service users) a great opportunity to address any issues ... I think it’s a terrific idea. It gives us a sense of confidence and we are more involved now than we were ever before.”

Older man receiving home care, London

Complaints

People can complain to:

- **Their care provider** – most people make their initial complaint to the care provider. Independent home care providers must have a system for receiving complaints and inform people how to use it. In the last 12 months, 42 per cent of home care providers who took part in our survey had received a complaint or been made aware of a human rights-related problem.
- **The local authority** – people receiving publicly funded care can complain to the local authority. All local authorities and health authorities are required to have complaints procedures, which must include a designated complaints manager and a three-stage procedure to deal with complaints (local resolution, investigation and review panel). All but one local authority who took part in our survey had received a complaint or safeguarding referral, or had been made

aware of problems relating to human rights in the past 12 months.

Complaints came from a number of sources including service users, funders, care providers and whistleblowers.

■ The Local Government

Ombudsman – people who pay for their care privately can now complain about their care to the Local Government Ombudsman. They had no external complaints system before the Ombudsman’s remit was expanded in October 2010 to include complaints from self-funders. This was also expected to improve the standard of complaint handling by independent care providers.

- **The CQC** – although intelligence is mainly passed to the CQC by care providers and local authorities, it also collects information directly from older people and care workers (although it does not investigate complaints from individuals). All of this intelligence contributes to decisions CQC makes about regulatory action. We welcome the fact that the CQC has recently updated its website to make it clearer how people can give direct feedback (good and bad), anonymously if they choose. However, more work could be done to raise awareness about how older people and their families can feed information direct to the CQC.

Referrals to safeguarding boards

Local authorities’ Adult Safeguarding policies act as a safety net and aim to prevent abuse of adults at risk. If an adult with health or social care needs appears to be at risk of harm and unable to safeguard

themselves, social services should ensure there is an investigation – although currently there is no legal duty to do this. The government intends to implement the Law Commission recommendation that adult safeguarding boards be given a statutory basis, giving local authorities legal duties to run them and make sure investigations are carried out. This is a recommendation that we strongly support provided that clear lines of accountability are established when other agencies lead investigations.

Whistleblowing

The majority of the home care workers who gave evidence to the inquiry told us that they would report any concerns about suspected abuse of older people to their line manager. Indeed, 51 per cent of local authorities in our survey had received a complaint or been made aware of a problem about human rights through whistleblowers.

For older people who cannot or do not want to complain about their treatment, it is essential that care staff who might be willing to act as whistleblowers can be assured they will not lose their job and that their complaints will be listened to.

We explored the issue of home care staff raising complaints with Public Concern at Work, which operates a free, confidential telephone advice line for workers who have witnessed wrongdoing in the workplace and are not sure whether or how to raise their concern. They told us that 15 per cent of calls come from the care sector, the highest figure from any one sector of employment.

Public Concern at Work analysed 30 of their most recent calls from workers in home care. In over a quarter of these cases the worker said their concerns had been ignored by their line manager. In some cases these were eventually acted on by a more senior manager or reported elsewhere by the caller.

Case study

A home care worker had seen a family member verbally and financially abusing her elderly relative. The lady was bullied, given little food, and she had to beg for her own money to be spent. The family member refused to buy incontinence pads and left her alone and unfed on Christmas Day. The worker raised this with their line manager, who allegedly did not want to rock the boat with the relative as the care company received a lot of money for the lady's care. The worker was then removed from supporting the older woman until staff shortages meant the caller was placed with her again, and had the same concerns. The worker then raised their concerns with the regional care manager, who investigated the matter.

Public Concern at Work

Employment protection for whistleblowers is provided by the Public Interest Disclosure Act 1998 (PIDA). The CQC is named in this Act as a 'prescribed' body, that is an organisation that care workers can raise whistleblowing alerts with if they don't feel confident to do so with their employer. However, we heard that some workers who wanted to raise concerns about poor or abusive practice

had had difficulty making contact with the CQC or finding someone to take up their whistleblowing alert, partly because the CQC does not have a dedicated telephone hotline. Some felt the CQC have not done enough to tell care workers they can disclose bad practice to the CQC.

We therefore welcome the CQC's current review of its whistleblowing procedures in the wake of the abuse revealed at the Winterbourne View private hospital. The review has resulted in new ways of working including a dedicated whistleblowing team at the CQC call centre and revised guidance.

How well can complaints systems protect human rights?

The evidence to this inquiry strongly indicates that complaints systems, although valuable, cannot by themselves provide the necessary protection of human rights. In fact breaches of older people's rights are often not dealt with because older people themselves are reluctant to make complaints. Many are unaware of their rights, and would in any event be fearful of using a complaints system. This is understood and acknowledged by most local authorities, care providers and regulators.

It became clear that the overwhelming preference of older people is for issues to be brought out and resolved without the need for them to make a formal complaint. Therefore the emphasis should be on providing low-level, informal methods of resolving issues quickly. Some providers we interviewed already provide informal methods, such as regularly inviting service users to give feedback on their care. As we

have seen, the local authorities may in some circumstances have positive obligations to respond to human rights breaches. This can mean that they have a duty to use their legal powers to investigate credible allegations of human rights violations – even where complaints have not been raised.

Also, given the importance of the Local Government Ombudsman's role in allowing people who fund their own social care access to independent consideration of their complaints, it seems necessary to support the Ombudsman to take steps to make self-funders aware of their right to redress and how they can use it.

Why don't older people want to use complaints procedures?

Just under a quarter of the older people and family members who responded to the call for evidence told us that they would not have the confidence to make a complaint. Reasons included:

- not wanting to upset care workers or get them 'in trouble' – many had formed a bond with them, or were worried that they would be less friendly in future
- unwillingness to 'make a fuss'
- being afraid of being put into residential care
- fear of retribution
- fear of losing their care, or that it would be badly disrupted
- thinking that complaining would not improve the poor service they received
- previous negative experience of making complaints
- being ashamed of admitting they could not do things for themselves.

Some of those who said they would or had complained stated that they had or needed support from family or friends to do this.

During our interviews with older people, we found many stoically endure poor care without complaint, grateful to receive publicly funded care. Some had low expectations of home care services, seeming to accept poor practice as an almost inevitable part of the package. Several voluntary sector organisations who support older people echoed this.

“I felt that for a number of people I saw, their expectations of help at home were quite low, and that they were grateful for just getting a service.”

Manager voluntary sector organisation

Compounding these factors was a prevalent attitude among many of the older people we interviewed of not feeling it was totally legitimate to feel upset or angry about poor home care services. They were generally apologetic or embarrassed about mentioning things that had gone wrong. Our findings are supported by the experience of Age UK and the British Institute of Human Rights about the barriers that discourage older people from raising human rights concerns with service providers or the local authority.⁷⁸

Empowering older people – how much information and choice do they have?

Many older people didn't know how to complain – around one in five of the older people and family members who responded to our call for evidence – or where to find information about making complaints.

“I worry very much that I may not get any help if I complain. Worry I will be seen as ‘awkward’...[I] Would not allow family to complain either.”

Woman in her 80s receiving home care, South of England

Even when older people knew where the complaints information was they didn't feel they should refer to it. Often the information about how to complain is kept in a file which home care workers write in after visits, and many of the older people we interviewed felt it was the property of the provider organisation. They didn't feel it belonged to them or didn't want to touch it for fear of being seen as a troublemaker.

Older people also mentioned practical obstacles such as:

- not being sure which organisation was responsible for what, between the care provider agency and social services
- a lack of clear information about what to do if they wanted to talk about concerns or make a complaint
- not knowing they had a right to complain – for example, one older man said that if he had serious problems he would just have to stop having care workers, on the basis that the home care service is a matter of ‘take it or leave it’
- mechanisms for raising issues and making complaints that they could not use – one older woman, who is blind, found it impossible to call the agency or local authority as their telephone switchboards rarely led to ‘real’ people, and often involved having to note down other telephone numbers to call:

“At one time I used to do all sorts of things on the phone but now I can’t, I have to feel for the numbers. Everything is getting very difficult at the moment ... You see when you ring up social services, they don’t give you a certain one; you’ve got to have the next one that comes on the phone; I’ve been on that phone yesterday for an hour, it’s like a record ... When you ring up [the agency] they give you a mobile number. I can’t write anything down because I can’t read it back, so if they give me a mobile number it’s too long for me to remember.”

Woman, 78, lives alone, local authority-funded and self-funded care

Information for self-funders

For self-funders, the picture appears even less clear. The Local Government Ombudsman told us that many providers still tend not to mention the Ombudsman in the complaints information they give to service users. They had discovered that, whereas most providers included a reference to the CQC in their complaints procedures, less than 40% included a signpost to the Ombudsman.

The Ombudsman acknowledged the need for greater public awareness of their role.

Informal mechanisms for issues to come to light and be resolved

There is a need to go further than simply distributing ‘how to complain’ leaflets. This is a complex issue, but our evidence and examples of best practice suggest that what works is:

- creating a culture that supports a regular dialogue between providers and service users – e.g. face-to-face meeting with the care provider manager at the start of a home care relationship, leaving a name and phone number to call, encouraging the person to make contact, regular check-in meetings or phone calls
- better and clearer information for older people about their entitlements, including human rights, and on how to raise issues and make complaints
- empowering older people by actively raising awareness of their human rights and explaining what to do if those rights are at risk.

A project run jointly by Age UK and the British Institute of Human Rights worked with older people to put a human rights approach into practice. It supported three groups of older people, empowering them to use human rights principles and standards to press for the improvement of local public services. For example, one group produced a DVD highlighting the issues that older lesbian, gay, bisexual and transgender people can face in residential care, and the impact this can have on their human rights.

Some good practice

Some independent home care providers and local authorities have recognised that a lack of complaints should not be regarded as evidence that there are no issues to be resolved, and have created various proactive means of identifying issues.

One care provider made sure that older people knew how to raise issues of concern and that they had met a manager from the agency so would feel more confident in raising issues with someone they were familiar with. Older people receiving home care from this agency told us that they felt comfortable in raising issues with the agency managers and staff and gave us examples of where they had done this.

Other providers also recognised that older people are more comfortable raising issues with someone they know. Measures to set up an easy dialogue are definitely more likely to capture issues that could develop into human rights risks. Some providers have regular four-weekly consultation meetings with each older person, to share information and hear feedback. We also heard from providers where the manager of care workers has an initial visit with each person receiving home care to establish a relationship.

A local authority had built up a team of ‘citizen assessors’ (mainly older people or relatives of people receiving home care), who are now an integral part of the authority’s quality assurance system. The citizen assessors undertake annual audits of home care services by interviewing home care service users and care providers. This approach is bringing out far more of the older people’s issues of concern or complaint. The citizen assessors, as their peers, overcome older people’s reluctance to raise issues with ‘official’ bodies and also engage them in face-to-face conversations where they felt far more comfortable discussing areas of concern.

We also know from our analysis of local authority home care service specifications that most require providers to give older people clear and accessible information about how to raise issues and complaints, including referring complaints on to local authorities or regulators. Some spelled out that they required providers to take a positive attitude towards encouraging comments or complaints. A few acknowledge the reluctance of older people to complain, and so flag up the need to communicate to them their right to complain without fear of recrimination, and create an open culture welcoming all feedback. Whether or not these requirements always translate into practice seems questionable given what we heard from older people.

Satisfaction with the outcomes of complaints

We heard from a few older people who felt satisfied about how issues or complaints had been dealt with and the eventual outcome.

“I did raise issues with [the private sector agency] occasionally and they were very responsive ... If the agency had not been responsive, I don’t know where I would have gone.”

Step-daughter of older woman with self-funded home care, East of England

Others felt confident about raising issues of concern direct with their home care worker.

“One girl she came one morning and she hadn’t put the gloves on ... I knew they were supposed to put them on and I just said, ‘have you got your gloves?’ ... I didn’t feel embarrassed asking her and she didn’t seem to take any umbrage that I’d mentioned it.”

Older woman receiving home care, North of England

In contrast, many spoke of a bad experience of making a complaint and felt it was pointless complaining again because of that experience.

“Yes [I know how to complain] and no [I wouldn’t make a complaint]. I would know what to do but I felt I have been treated badly afterwards because I felt the need to complain. You get labelled as a troublemaker!”

Woman aged over 75 with part-funded home care

“I consider [complaining] a futile exercise since I have had a complaint against social services since 2009. I speak from experience having been fobbed off for 2 years.”

Wife of 85-year-old man with local authority funded care, Midlands

Even for an assertive and empowered home care user, the systems in place for feedback and complaints can cause frustration. For example, one older woman we interviewed took a keen interest in the quality of the care she got, and felt it was her right as a client to get a service that suited her as well as meeting her needs.

She used her care plan to check what duties care workers performed and to add her own comments for the care agency. She had complained repeatedly to care providers about sending care workers she didn’t know, and changing care workers or the times of visits without letting her know. She had also complained about poor workers, preferring to keep individuals she had formed a relationship with and ‘trained’. The most common problems she had experienced in complaining included:

- being, in her view, ‘fobbed off’ – not being listened to or taken seriously (by the care provider)
- being passed from one person to another; often going round in circles (when pursuing her complaint with the local authority as the care commissioner)
- having to be very determined and persistent – to the point of threatening to write to her local MP – to get things changed.

How well does the legal and regulatory framework protect human rights?

Not all home care is delivered through a local authority contract, so not everything could be picked up by local authority monitoring, however effective. It is therefore important that the system for regulating the home care sector is fit for purpose, and that there is a sufficiently robust legal framework for protecting service users from human rights abuses and age discrimination.

Evidence from our inquiry suggests that the legal and regulatory systems are not strong enough to ensure the protection of human rights for older people receiving home care, because:

- The CQC is under-resourced for its important regulatory role and its approach to human rights needs to be enhanced.
- The Human Rights Act (HRA), which in any case only provides a minimum irreducible standard of human rights protection, does not extend to home care services provided by private and voluntary organisations.
- Legislation has not yet been introduced to outlaw age discrimination in services.
- Social care legislation is not explicitly underpinned by human rights standards.

Are human rights embedded into the regulation of social care?

As we have seen, local authorities have a key role in monitoring the home care services that they commission from private and voluntary sector providers. However, as the regulator of this sector, the CQC has an equally important role in picking up on potential threats to human rights from qualitative information supplied by local agencies and other sources, as well as older people themselves. Because of the HRA, the CQC must carry out its statutory role so as to comply with the European Convention on Human Rights (ECHR). It may also have to take active steps to promote and protect the human rights of home care service

users – including those who fund their own care in some circumstances.

As discussed in Part 1, all care providers must be licensed with the CQC and must meet its essential standards, set out in a series of regulations. Although these regulations do not refer specifically to human rights, the CQC has recognised that a human rights approach is consistent with its own values. However, human rights are more likely to be expressed in terms of privacy, dignity and independence than to be explicitly referred to in CQC documents. For example, Outcome 1 under the heading ‘Respecting and involving people who use services’ states: ‘People using the service have their privacy, dignity and independence respected.’ As noted in the Equality and Human Rights Commission’s Human Rights Inquiry report, it is important to use explicit human rights language. This emphasises that human rights are enforceable under the HRA rather than being merely aspirational. For the CQC, this approach would help show how specific human rights are relevant to particular situations and would also encourage an awareness of its own positive obligations to promote and protect human rights.

In September 2011, CQC and the Equality and Human Rights Commission published joint guidance for CQC inspectors on equality and human rights. This gives practical information linking human rights to each of the essential standards, with the aim of ensuring a more consistent understanding of human rights and increased response to human rights issues across their large workforce of inspectors.

Home care is a challenging sector to regulate

The complexities inherent in regulating home care – which by definition is delivered behind closed doors, by a wide range of providers, care workers and personal assistants, and decreasingly funded by the public purse – were acknowledged in our evidence.

There was general recognition that the CQC does not have the resources to tackle this challenging task. A number of individuals and organisations were concerned about the diminishing number of CQC inspections and that the human rights of older people receiving home care may be going unchecked. A large private sector provider told us:

“I honestly hold out little hope that the CQC will be able to do much more than enforce action against the worst providers in the coming years. Their resources are already at breaking point.

Some local authorities told us that the reduction in inspections made the job of maintaining provider standards more difficult. Although they tried to fill the gap by monitoring providers, they expressed frustration about not having the status to do so adequately.

Over a period of time, CQC’s role in the regulation of home care appears to have reduced, with the responsibility of monitoring falling more onto commissioning departments in local authorities. As much as commissioning needs to monitor, it is essential that this is supported by any regulatory bodies who can take actions if human rights are not being protected by home care providers.”

Local authority responding to survey

The need to capture older people’s voices

Our evidence also told us that the risk-based model used by the CQC did not seem able to pick up qualitative intelligence effectively enough. Although the CQC can hear directly from care workers and older people, in reality this does not happen very often, partly because people don’t know they can contact the CQC but also because of older people’s reluctance to raise issues.

The CQC does not rely solely on self-assessment. However, the reliance on providers self-assessing by using questionnaires was seen as inadequate because it could be completed as a ‘tick box exercise’. Although this is based on a model used in hospitals, the evidence indicates that it is not sufficiently probing for regulating home care.

We welcome the new regulatory approach being piloted by the CQC which we understand will make sure each home care provider (there are approximately 6,000) is inspected at least once a year, with inspections being more frequent where essential standards are not met. While we strongly welcome this development, we believe that the systems for capturing the voices of older people need to be more effective. Paper-based surveys may not elicit such evidence-rich information as face-to-face contact. They also increase the risk of excluding people with visual impairments – a common situation for older people – and may exclude people whose comprehension of written language is affected by cognitive impairment. We understand CQC is starting to test better ways of capturing service user views; these include questionnaires, face-to-face

interviews with older people, intelligence from local organisations and involvement of ‘experts by experience’ (who have used or cared for someone using home care services).

We suggest the CQC take into account the limitations of paper-based surveys that we have identified above.

One or two providers that we interviewed believed that some CQC inspectors did not have all the relevant expertise to pick up on threats to older people’s human rights, particularly for older people with dementia.

Monitoring commissioning

A number of organisations and individuals voiced their concern that the CQC no longer monitors the commissioning practices of local authorities. The United Kingdom Homecare Association (UKHCA) felt that this change has come at a time when local authority commissioners are under particular stress due to constrained budgets, which they believe has led to some ‘deteriorating commissioning practice’. Some organisations view the fact that the regulator will not be overseeing commissioning practice as a serious gap and inconsistency in the system, as the CQC can no longer comment on poor commissioning, but only on the quality of care services which result from those commissioning practices.

The English Community Care Association (ECCA) fear this gap ‘will lead to inequity in the system’ as some issues which shape the quality of care provided are controlled by commissioning bodies so they are outside the influence of care providers

(for example, very short care visits and time- and task-focused commissioning).

“Local authorities are commissioning large tranches of care and yet they are not being called to account for commissioning 10- or 15-minute domiciliary care visits. Unless CQC is able to regulate the whole system, much of its outputs will be useless.”

The English Community Care Association

In its evidence to the inquiry, the CQC told us that it ‘recognises the frustration that many domiciliary care providers voice’ around poor commissioning practices. It hopes that organisations such as Think Local Act Personal (TLAP), health and wellbeing boards, clinical commissioning groups, and the NHS Commissioning Board ‘will each seriously consider their roles in leveraging positive change in this area’. The CQC also envisages that HealthWatch could feed in their experience and knowledge of local home care providers, and how services are commissioned locally, to HealthWatch England, who could then pass on any concerns to the NHS Commissioning Board.

While some of these organisations may have an important role to play in relation to home care services, and should be supported in this, we consider that – given the central importance of commissioning in promoting and protecting the human rights of older people – a single regulatory body should oversee this function.

Gaps in the coverage of the Human Rights Act

When care is provided to service users in their own homes, this may increase the risk of human rights breaches going unchallenged. Our inquiry has identified a great reluctance on the part of older people to raise any areas of concern about their treatment. However, they also face a major legal barrier to complaining about any violations of their human rights by home care service providers. Our evidence supports the case for closing this ‘human rights loophole’.

As explained in the introduction to Part 1 of this report, the HRA applies both to public authorities and to other organisations when they are performing public functions. However, in the 2007 case of *YL*,⁷⁹ the House of Lords held that private and third sector providers of residential social care under contract to local authorities fell outside the scope of the HRA as they were not performing ‘public functions’. Although the court did not expressly make a ruling on other areas of social care, its reasoning almost certainly applies to independent home care providers too. Legislation has since been put in place, partly reversing the effects of this decision, to give direct HRA protection to residents of private and third sector care homes whose places are arranged by local authorities.⁸⁰ Any of these residents whose human rights are violated can use the HRA to get legal redress against the care home provider.

With regard to home care, the *YL* decision almost certainly places private and voluntary sector providers outside the scope of the HRA – even when their

services are commissioned by local authorities. This leaves the majority of home care users without the direct protection of the HRA: the diversification of provision is such that 84 per cent of publicly funded care is now delivered by the private and voluntary sectors.⁸¹ The HRA also gives no direct legal protection to individuals paying for their own home care (‘self-funders’) should they experience human rights breaches by private or third sector providers.

In 2000, when the HRA came into effect, many more older people using social care would have had human rights protection. At this time, 44 per cent of care was provided directly by local authorities and 56 per cent by private and third sector providers.⁸²

It does not seem that Parliament foresaw this lack of HRA protection for users of home care services. During parliamentary debates on the passage of the HRA, the former Home Secretary made it clear that bodies delivering privatised or contracted-out public services were intended to be brought within the scope of the Act by the ‘public function’ provision.⁸³ In its 2007 report on the definition of public authority under the HRA, the Joint Committee on Human Rights concluded that disparities in human rights protection created by case law were ‘unjust and without basis in human rights principles’.⁸⁴

The human rights protection of home care users has also been weakened by the decision of the Supreme Court in the case of *McDonald*.⁸⁵ By a majority, the court decided that it was lawful for the local authority, given its limited resources, to withdraw Ms McDonald’s night-time

care and require her to use incontinence pads instead.

The McDonald Case

Human rights arguments were central to a case on home care services decided by the Supreme Court in July 2011. Elaine McDonald, former principal ballerina with the Scottish Ballet, was disabled by a stroke and had a bladder condition. The Royal Borough of Kensington and Chelsea, her local authority, had awarded her a home care package that included a care worker to help her use the toilet during the night. Subsequently, the authority decided to withdraw night-time care on the basis that Ms McDonald – who is not incontinent – could use incontinence pads instead. The Supreme Court did not agree that requiring Ms McDonald to use pads was a breach of her rights under Article 8 (the right to respect for private life). Even if this decision had interfered in her Article 8 rights, the court took the view that the interference was proportionate and justified. The local authority only had limited financial resources and was entitled to strike a balance between the competing interests of an individual and the community as a whole. But Lady Hale, who dissented from the decision, commented: ‘We are, I still believe, a civilised society. I would have allowed this appeal.’

After this judgment, the Equality and Human Rights Commission expressed concern that local authorities would find it easier to justify withdrawing care,

putting older people’s human rights at serious risk. Ms McDonald is now taking her case to the European Court on Human Rights in Strasbourg, a process that could well take at least two years.

Lack of legal protection from age discrimination

Human rights are universal – they should not be conditional on age or any other status. However, our findings suggest that age discrimination is one of the factors explaining why older people face risks to their human rights in home care services. We came across worrying examples of differential practices related to age in the funding and provision of home care services.

While age discrimination was banned in employment and vocational training several years ago,⁸⁶ it has not yet been outlawed in services and public functions – including home care services.

Legislation is badly needed to establish a clear benchmark for the acceptable treatment of older people. The Equality Act 2010 contains provisions to put this ban in place, but this part of the law has yet to be introduced. The government has not committed itself to a firm implementation date – although it has indicated that commencement should take place in 2012. Our findings suggest that the ban should be implemented as a matter of urgency.

When it comes into effect, the new law will recognise that some age-based rules and practices are seen as acceptable or beneficial. As with age discrimination in employment, it will be possible for some

age-differentiated treatment in services and public functions to be ‘objectively justified’ in particular circumstances.⁸⁷ The new law will also include exceptions, making some age-based rules and practices automatically lawful – for example, in the financial services sector.

We welcome the fact that there are no planned exceptions for health and social care services. This means that age-differentiated treatment in home care will only be lawful if it can be objectively justified. If services that are targeted or limited by age can satisfy the objective justification test, the new law will allow them to continue but it will not be possible for harmful age discrimination to be justified in this way; for example, ignoring older people’s dignity and wellbeing in the delivery of care. Neither will it be lawful to offer unjustifiable differences in levels or types of home care for older people and adults of working age.

The Equality Act 2010 has also introduced in a new, integrated public sector equality duty (PSED), which came into effect in April 2011. The PSED, which covers seven protected characteristics including age, consists of a three-way general duty to have due regard to the need to (1) eliminate discrimination, (2) advance equality, and (3) foster good relations between groups. In relation to age, the first limb of the duty is significantly weakened because unlawful age discrimination does not yet extend to services and public functions. This underlines the importance of implementing the ban on age discrimination in these sectors as soon as possible.

Underpinning social care legislation with human rights principles

The effect of the HRA is that public authorities with responsibility for designing, commissioning or delivering social care must perform these functions in a way that is compatible with ECHR rights. The NHS constitution requires providers and commissioners of NHS care to respect individuals’ human rights.⁸⁸ In contrast, the statutory framework for social care makes no express reference to human rights obligations.

At present, the reform programme for adult social care is high on the political agenda. To help make the social care system more coherent, the Law Commission has recommended a single statutory scheme to replace the current ‘complex and confusing patchwork of legislation’.⁸⁹ The report of its review proposes a three-layer structure, consisting of a statute setting out core powers and duties, together with regulations and a code of practice.

The Law Commission suggests that ‘promoting or contributing to the wellbeing of the individual’ should be the overarching statutory purpose of adult social care. Rather than having a precise definition of wellbeing, the statute would have a checklist of factors underpinning individual decisions. These might include:

- assuming that the person is normally the best judge of their own wellbeing
- where possible, achieving a balance with the wellbeing of others
- safeguarding adults from abuse and neglect, and

- using the least restrictive solution when it is necessary to interfere with the individual's rights and freedoms.

The new statute would also set out a single, clear duty to assess a person, with a low qualifying threshold, and the code of practice would specify a minimum level of services.

The review's proposal to unify the statutory framework has clear attractions, and the Equality and Human Rights Commission supported this model when responding to the Law Commission's consultation. Our response also argued that the new statute should be specifically underpinned by human rights principles. We believe that the findings of this inquiry support this approach, which would have the effect of putting local authority social care on the same footing as NHS services.

We note that our inquiry findings lend support to many of the Law Commission's detailed recommendations on the reform of adult social care legislation. In particular, our evidence supports the recommendation that decision-makers be required to respect an individual's autonomy by following their 'views, wishes and feelings wherever practicable and appropriate' and to ensure that 'decisions are based upon the individual circumstances of the person and not merely on the person's age or appearance'.⁹⁰ Likewise, our findings support the Law Commission's call for local authorities to be placed under a statutory duty to provide information, advice and assistance services in their area and to stimulate and shape the market for services.⁹¹ We also welcome their recognition that services should be

outcome-focussed, an approach which is supported by our own findings.⁹² Earlier in this Part of our report, we have indicated our support for the Law Commission's recommendation that adult safeguarding boards be placed on a statutory footing.



Part 6: Conclusions and recommendations

Our key conclusions

We drew the following key conclusions from the inquiry evidence:

- Many older people are very happy with the home care service they receive and value the autonomy it gives them to carry on living the lives they want.
- However there were many instances of home care which caused us real concern, where human rights were breached or put at risk because of the way care was delivered.
- Many of these problems could be resolved by local authorities using opportunities to promote and protect older people's human rights in the way they commission home care and the way they procure and monitor home care contracts. However it appears that commissioning is not being consistently used to protect human rights effectively. Indeed some commissioning practices make the negative experiences that some older people described more likely to happen.
- There is a general lack of awareness among public authorities with responsibility for home care about what complying with the Human Rights Act (HRA), including their positive human rights obligations, actually means. Only around a quarter of local authorities train all elected members with lead responsibility for social care about their important role in protecting and

promoting human rights. Our survey responses show that many local authorities commissioning home care would welcome practical guidance on human rights.

- There are acknowledged difficulties in regulating this sector which by definition is delivered in the home.
- Older people are very reluctant to make complaints, even when they are aware of how to do so. Therefore more sophisticated ways are needed to create an easy dialogue and flow of information between older people, care providers, local authorities and regulators so that any threats to human rights can be picked up and resolved as early as possible.
- The majority of older people using home care services lack the protection of the HRA.

A number of other interlinked factors are contributing to the human rights risks identified in our findings:

- Age discrimination is reflected in ageist attitudes towards older people, and there are indications that less money is spent on their care compared to other age groups, with care packages unlikely to include support for activities outside the home.
- A lack of suitable information on the different processes and options for obtaining care and on the quality and different specialisms of care providers,

so as to allow older people to make informed choices. Many older people and self-funders in particular require more guidance on local care providers.

- There is little or no advocacy or age-appropriate brokerage support on offer to assist older people interested in self-directed personalised home care in some areas.
- There is a lack of investment in care workers, influenced by commissioning practice and the workforce being predominantly female and part time, leading to low pay and status, in sharp contrast to the level of responsibility and skills required to provide quality home care. Poor pay and conditions also affect staff retention, causing a high turnover of care workers visiting older people.

Recommendations

We are therefore making the following recommendations which include actions for the Commission as the independent regulator of equality and human rights.

To address gaps in the current legal and regulatory framework:

1. The definition of ‘public function’ under Section 6(3)(b) HRA 1998 should be extended to include the provision of home care by private and voluntary sector organisations, at least when this is publicly arranged. This would bring home care into line with residential care services.
2. As there is no longer an independent regulatory body inspecting or monitoring adult social care commissioning, the oversight framework introduced in October 2010 to uphold standards should be evaluated by government no later than September 2012 to assess its effectiveness in promoting and protecting the human rights of older people receiving home care.
3. The government should implement the provisions in the Equality Act 2010 outlawing age discrimination in services and public functions by no later than by April 2012, recognising the adverse impact of age differentiated treatment in social care and the link between negative ageist attitudes and human rights abuses of older people.
4. The CQC risk-based approach to the regulation of home care needs to place more reliance on inspection of care providers and obtaining the unconstrained voices of service users. We believe it is essential that the CQC inspects each care provider location at least once a year, as proposed by the Care Quality Commission (CQC) itself. These inspections should be complemented by a broad and fully inclusive range of methods of capturing information from users and their representatives – including by capitalising on the intelligence available from Local HealthWatch organisations.
5. Given that the CQC has no regulatory remit over personal assistants who are not supplied by a care provider, local authorities should develop ways of supporting those who employ their own personal assistants, to ensure older people’s human rights are protected. This could include steps such as funding advocacy and advice

services and facilitating voluntary registers for personal assistants.

6. The Law Commission's proposal for a single statutory scheme for adult social care, an approach that we broadly support, should be implemented as soon as parliamentary time is available. The new statute should be expressly underpinned by human rights principles, putting social care on the same footing as NHS services.
7. In fulfilling its commitment to implement the Law Commission's recommendation that adult safeguarding boards be placed on a statutory footing and led by local authorities, the government should ensure that there are clear lines of accountability when agencies other than local authorities conduct investigations. As part of this legislative change, consideration should also be given to strengthening and broadening the role of Directors of Adult Social Services in relation to adults not receiving publically funded community care services who may be at risk of harm.

To address the lack of awareness among local authorities about what human rights obligations mean in practice:

8. Local authorities should mainstream human rights into their decision-making processes and business plans to ensure compliance with the HRA, including their positive obligations to promote and protect human rights. Human rights considerations should be at the centre of assessment,

procurement and commissioning of home care, for example incorporating human rights requirements into care provider service specifications.

9. Before October 2012 local authorities should review their policies and practice in the light of this inquiry's findings as to the causes of potential breaches of human rights in home care. As a minimum this should include examination of the following:
 - the effectiveness of systems to overcome barriers that older people experience in raising concerns or making complaints
 - the design and operation of Resource Allocation Systems with a view to identifying and removing any age-related bias that may exist
 - the extent to which differential treatment linked to age is present in care planning and support for community participation
 - whether the diverse needs of older people are being met through commissioning practices
 - the extent to which their commissioning supports the delivery of care by a sufficiently skilled, supported and trained workforce.

10. The Ministry of Justice, the Department for Communities and Local Government and the Department of Health should collaborate on producing guidance for local authorities on their duties under the HRA, including their positive obligations to promote and protect human rights, to provide a framework

for operating more responsively to the needs of their communities when the Localism Bill is brought into force.

11. To enhance the leadership of local authority elected members, training and guidance should be provided on using their scrutiny function and their roles on Health and Wellbeing Boards to maximise the promotion and protection of the human rights of older people.
12. Through their guidance and training to HealthWatch Local organisations, HealthWatch England should adopt a proactive role in disseminating understanding of obligations under the HRA and the value of a human rights approach to home care.
13. To ensure maximum human rights protection, consideration should be given to incorporating HRA obligations into local authorities' contracts with providers, to include clauses giving service users 'third party' rights to challenge the care provider for any breach of their human rights for which the care provider is directly responsible.
14. Commissioning practice needs to balance allocation of resources against assessed home care needs that must be met, to ensure contracted providers can pay at least the National Minimum Wage to care workers, including payment for time spent travelling.

15. The Commission will work with the Association of Directors of Adult Social Services to produce voluntary national standards and guidance for

elected local authority members and local authority officers with responsibility for commissioning home care or assessing home care needs (a) on their obligations under the HRA, including positive human rights obligations, and (b) on the value of applying a human rights approach to home care services.

To address the lack of awareness about human rights and care entitlements amongst older people and their families:

16. Much more consumer information should be compiled and made accessible about the quality of care providers and their specialist areas to enable home care users to make an informed choice, including by means of:
 - the development of in-depth provider profiles on the CQC website
 - support for a consumer feedback website
 - steps by local authorities to draw together and provide relevant information on care providers in their area
 - increased information sharing between the Local Government Ombudsman, local authorities and providers.
17. We welcome the steps being taken by the Social Care Institute for Excellence, Skills for Care, National Centre for Independent Living, Social Care Association and others to develop tools such as voluntary personal assistant (PA) registers in order to support those older people using direct

payments looking for a better understanding of the workforce. However, in order that more older people can, if they choose, benefit from the greater autonomy inherent in personalised home care, an increased focus is needed by government and local authorities on developing advocacy, guidance and brokerage schemes.

18. The Commission will work with stakeholders including UKHCA to produce guidance for older people and their families about how their human rights should be protected in home care, however funded, and what to do if those rights are at risk – including the option of legal redress as a last resort.

To ensure there are better arrangements in place to detect threats to human rights in home care:

19. The CQC, local authorities and providers should develop more flexible ways of ensuring systems for exchanging information are designed to detect threats to human rights, including through the CQC and ADASS protocol.
20. The Local Government Ombudsman should take steps to increase public awareness of their role to investigate complaints about home care from self-funders.
21. The CQC should take steps to ensure maximum awareness by care workers of the protection available to whistle-blowers under the Public Interest Disclosure Act, and the CQC's own role in responding to whistleblowing alerts.

22. To ensure that threats to human rights are detected as early as possible, the CQC should take all available steps to facilitate feedback by any reasonable means from older people, their families and others. CQC should ensure that such intelligence is fed into their compliance monitoring and early warning risk assessments and acted upon where risks to human rights are indicated.

23. With support from the Social Care Institute for Excellence and other organisations such as UKHCA, home care providers should share good practice that embraces a human rights approach to home care for older people.

To address the status of home care workers:

24. Skills for Care, the National Care Forum, the UKHCA, the Social Care Association, the English Community Care Association, the Health Professions Council, trade unions and other partners should work together to consider what steps will best enhance the status and skills of care workers, particularly those related to promoting and protecting human rights.

25. The Commission strongly endorses the recommendation of the Low Pay Commission that commissioning policies of local authorities should reflect the actual costs of care, including at the very least the National Minimum Wage.

Appendix 1: Glossary of terms about home care

Advocacy	supporting an individual to say/communicate what they want, secure their rights and/or services.
Assessment/needs assessment	the assessment by a local authority of a person's need for community care services in order to maintain their life at a certain standard. Local authorities have a duty to assess any person in their area who appears to need such services (Section 47 NHS and Community Care Act 1990).
Block contract	a contract which guarantees a certain amount of business between the local authority and a social care provider, e.g. a set amount of time, in a particular location, for a set price.
Brokerage services	support given to individuals to help them identify what support package will best meet their needs and preferences within available resources, and organise and manage this support. Brokerage services should be provided by third parties other than the local authority, and can include advocacy, organising a care package and managing a personal budget including staffing and pay-roll services.
Call cramming	over-booking home care visits on a care worker's rota making it impossible for them to spend the allotted time on each visit.
Care Quality Commission (CQC)	the independent regulator of all health and adult social care in England.
Carer	a person who provides unpaid support to a family member or friend who could not manage otherwise.

Carer's assessment

an assessment of the help needed by a carer looking after a friend or relative to continue caring and to help maintain the carer's health and balance within their life, work and family commitments (Carers and Disabled Children Act 2000).

Care worker

a person employed to deliver home care by a local authority, private agency or voluntary sector organisation.

Commissioning

authorising external providers to deliver services on behalf of a public body. Local authority commissioning of services involves a strategic overview of the needs of the local population, setting policies to decide how those needs will be met in the most effective and cost efficient way, procuring the services and monitoring them to ensure that they meet requirements.

Direct Payments

a personal budget paid directly to a person (or to a third party acting on their behalf) who chooses to make their own care arrangements by employing their own personal assistants rather than receiving services provided by the local authority.

Eligibility criteria

criteria used by local authorities to determine whether a person is eligible for services provided by them. The government has issued guidance to promote fairness and consistency in the assessment process and each authority sets its own eligibility criteria based on this national guidance.

Home care

help with personal care which may include bathing, dressing and undressing, getting into and out of bed or on and off the toilet, preparing meals, taking medication, housework, managing money, going to the doctor, shopping, making phone calls, writing letters and keeping in touch with family and friends.

Human Rights Act 1998

the statute which makes the European Convention on Human Rights (ECHR) part of our law. It requires public authorities to act compatibly with the ECHR and allows individuals whose human rights have been infringed by a public authority to bring a case in our own courts.

Human rights approach

provides a legal and ethical framework, underpinned by the HRA, which has been shown as effective in raising standards in the design and delivery of public services including social care. This approach uses human rights principles such as dignity and autonomy as the starting point for clear expectations about the treatment of service users – for example, zero tolerance of abuse, respecting individuals, supporting independence and control, alleviating isolation and encouraging complaints without fear of retribution. A human rights approach can also assist staff faced with difficult decisions involving competing rights and interests.

Independent sector provider

private sector, voluntary sector and social enterprise home care agencies /organisations.

Local Adult Safeguarding Board

Multi-agency partnership which provides strategic leadership for the development of safeguarding policy and practice relating to adults at risk of harm.

Local Government Ombudsman

looks at complaints about local authorities and some other public authorities. It also examines complaints about independent adult social care providers, including providers of home care services.

Managed account

a personal budget managed by the local authority in line with the wishes of the person receiving home care, also known as a ‘virtual budget’.

Micro-employer	an individual or very small local enterprise (no more than five paid or unpaid full-time equivalent workers) independent of any larger or parent organisation.
Personal budget	funding given to a person to meet their assessed needs enabling them to choose and control when and where they receive their support, and who will provide it. A person can choose to receive their personal budget as a direct payment, a managed account, or a mix of the two options.
Personalisation	giving people more choice and control over deciding how their social care needs are met including through the use of personal budgets. Also known as self-directed support.
Procurement	the process of identifying and selecting a provider, which may involve, for example, competitive tendering.
Reviews	formal re-evaluation of an individual's assessed risks, needs and personalised care plan at an arranged time resulting in a decision about any changes that might be necessary to a care plan.
Safeguarding	keeping individuals safe who may be at risk of harm, including intervention in a particular situation and prevention before a situation develops.
Self-funder	a person who pays entirely for their own care.
Social care	the delivery of a range of personal care and support services to individuals in their own homes or in a care home.

UN Convention on the Rights of Persons with Disabilities (CRPD)

an international treaty that identifies the rights of persons with disabilities as well as the obligations on states to promote, protect and ensure these rights. Alongside civil and political rights, CRPD contains social, economic and cultural rights which states are expected to progressively realise; these rights have their origin in the International Covenant on Economic, Social and Cultural Rights. The CRPD was ratified by the UK in 2009.

UN Principles on the Rights of Older Persons

these principles, adopted by the UN General Assembly in 1991, were designed to influence and support national government programmes for older people. The 18 principles are grouped under five broad headings: independence, participation, care, self-fulfillment and dignity.

Whistleblowing

disclosure by an employee of genuine concerns about crimes, illegality, negligence, miscarriages of justice, or danger to health and safety or the environment, when these have been ignored or covered up by the employer or by a fellow employee. Rights and protections for whistleblowers are set out in the Public Interest Disclosure Act 1998.

Endnotes

- 1** Laing and Buisson (2011) *Domiciliary Care, UK Market Report 2011*. Laing and Buisson: London. Tables 1.2 and 1.5. In 2009/10, 452,610 older people received home care or home respite through their local authority and 91,625 received direct payments, some of whom may have received home care. In contrast, 167,435 were in a residential home and 81,670 in a nursing home.
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- 3** Action on Elder Abuse (2007) Briefing Paper: The UK study of abuse and neglect of older people. Available at: <http://www.elderabuse.org.uk/AEA%20Services/Useful%20downloads/Prevalence/Briefingpaperprevalence.pdf> and Community and District Nursing Association: Ev64, evidence to the Health Select Committee Inquiry on Elder Abuse. HC 111–11: London: The Stationery Office, March 2004.
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- 8** NHS Information Centre (2011) *Personal Social Services Expenditure and Unit costs England, 2009-10*. Available at: <http://www.ic.nhs.uk/pubs/pss0910exp>
- 9** Equality Act (2006) Sch 2 para 18 A person to whom a recommendation in the report of an inquiry, investigation or assessment is addressed shall have regard to it.
- 10** NHS Continuing Healthcare (Responsibilities) Directions 2009.
- 11** See, in particular, the report of interviews with older people. Sykes, W. and Groom, C. (2011) *Older people's experiences of home care in England*. Manchester: Equality and Human Rights Commission.
- 12** The CRPD includes: the right to equal access to facilities and services (Article 9); equal recognition before the law, including safeguards for people who lack legal capacity (Article 12); freedom from exploitation, violence and abuse (Article 16);

protection of the integrity of the person (Article 17); the right to live independently and be included in the community (Article 19); the right to an adequate standard of living and social protection (Article 28).

- 13** Adopted by the UN General Assembly in 1991, the 18 principles are grouped under five broad headings: independence, participation, care, self-fulfillment and dignity.
- 14** In addition, the Local Government Act 1972 contains provisions that enable local authorities to do things that facilitate the exercise of their express statutory functions.
- 15** *YL v. Birmingham City Council* [2007] UKHL 27.
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- 18** These regulations are set out in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and the Care Quality Commission (Registration) Regulations 2009.
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- 20** An additional 92,000 older people were in receipt of direct payments, some of whom may also have been in receipt of home care but because of changes in recording it is not possible to say how many were in this category.
- 21** NHS Information Centre (2011) Community Care Statistics 2009-10. Social Services Activity Report, England. p.39. Available at: http://www.ic.nhs.uk/webfiles/publications/009_Social_Care/carestats0910asrfinal/Community_Care_Statistics_200910_Social_Services_Activity_Report_England.pdf
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- 24** Equality and Human Rights Commission (2009) *From safety net to springboard*. Manchester: Equality and Human Rights Commission. Available at: http://www.equalityhumanrights.com/uploaded_files/safetynet_springboard.pdf
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- 26 Section 47 NHS and Community Care Act 1990. Under this provision, the local authority has a duty to assess a person in need whether or not they actively request an assessment.
- 27 Legislation relevant to provision of home care services to older people includes S29 National Assistance Act 1948, S45 Health Services and Public Health Act 1968 and S2 Chronically Sick and Disabled Persons Act 1970. Under the latter provision there is a legal obligation to provide services for someone assessed as needing them.
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- 85 *R. (McDonald) v. Royal Borough of Kensington and Chelsea* [2011] UKSC 33.
- 86 The Employment Equality (Age) Regulations 2006 have now been consolidated into the Equality Act 2010.

- 87** The ‘objective justification’ test has two stages: first, does the policy/practice have a legitimate aim – for example, ensuring the wellbeing and dignity of service users or reducing health and safety risks? Second, is this aim being achieved proportionately and using the least discrimination possible?
- 88** All providers and commissioners of NHS care are under a legal obligation to have regard to the NHS constitution in all their decisions and actions. The constitution includes seven key principles, the first of which states that the NHS has a duty to respect individuals’ human rights.
- 89** Section 29 of the National Assistance Act 1948 lists the type of services that local authorities have the power to provide. For home-based care, these powers are complemented by Section 2 of the Chronically Sick and Disabled Persons Act 1970, which sets out the types and range of services that should be available. A number of other statutory sources are also relevant for older people receiving home-based care from local authorities or the NHS. Most home-based care is means-tested, but certain provisions, for example Section 117 of the Mental Health Act 1983 and NHS Continuing Healthcare (Responsibilities) Directions 2009, require services to be provided free of charge.
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