



House of Lords
House of Commons
Joint Committee on
Human Rights

The Human Rights of Older People in Healthcare

**Eighteenth Report of
Session 2006-07**

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Joint Committee on Human Rights

The Joint Committee on Human Rights is appointed by the House of Lords and the House of Commons to consider matters relating to human rights in the United Kingdom (but excluding consideration of individual cases); proposals for remedial orders, draft remedial orders and remedial orders.

The Joint Committee has a maximum of six Members appointed by each House, of whom the quorum for any formal proceedings is two from each House.

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The current staff of the Committee are: Dr Mark Egan (Commons Clerk), Bill Sinton (Lords Clerk), Murray Hunt (Legal Adviser), Angela Patrick and Joanne Sawyer (Committee Specialists), Jackie Recardo (Committee Assistant), Suzanne Moezzi (Committee Secretary) and Robert Long (Senior Office Clerk).

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Contents

Report	<i>Page</i>
Summary	3
1 Introduction	5
Our inquiry	5
Terms of reference	5
Structure of our report	6
Evidence and visits	6
Specialist adviser	7
2 Treatment of older people in hospitals and care homes	8
Scale of the problem	8
Elder abuse	10
Neglect or carelessness	11
Dehydration and malnutrition	12
Medication	13
Lack of privacy, dignity and confidentiality	14
Hospital discharge	16
Discrimination	19
Age discrimination	20
Discrimination against vulnerable groups	22
Root causes	24
3 Understanding how the Human Rights Act applies to older people in healthcare	27
The transformative purpose of human rights	27
What does the Human Rights Act add?	28
4 Department of Health's leadership	34
Department's responsibility	34
Political leadership	34
Policy leadership	36
5 Implementation of the Human Rights Act by providers of services	40
Responsibilities of public authorities under the Human Rights Act	44
Positive duty to respect human rights	45
The problem with private care homes	47
6 Health and social care inspectorates and NICE	50
Health and social care standards	50
Healthcare standards	50
National Minimum Standards for Care Homes for Older People	52
National Institute for Health and Clinical Excellence (NICE)	55
Discrimination on grounds of age	55

7	The role of staff in protecting human rights	58
	Training	59
	Hospital staff	59
	Care home staff	59
	Human rights training	59
	Qualifications	64
	Reporting abuse	64
8	Empowering older people	67
	Barriers to voicing concerns	67
	Complaints	71
	Low awareness of rights	73
	How to make rights accessible to older people	75
	Annex: Human rights laws and standards in healthcare	80
	Common law principles	80
	Human Rights Act 1998	80
	Convention rights	80
	Public authorities under the HRA	81
	Legal responsibilities under the HRA	82
	Conclusions and recommendations	92
	Formal Minutes	100
	List of Witnesses	101
	List of Written Evidence	102
	Reports from the Joint Committee on Human Rights in this Parliament	103

Summary

In addition to its scrutiny of parliamentary Bills and policy documents for human rights implications, the Committee examines areas where human rights concerns arise, such as the treatment of older persons in health care.

In this Report the Committee examines how human rights principles can be applied to ensure that older people in hospitals and care homes are treated with greater dignity and respect (paragraphs 1 - 8).

The Committee heard that, while some older people receive excellent care, there are concerns about poor treatment, neglect, abuse, discrimination and ill-considered discharge. It considers that an entire culture change is needed. It also recommends legislative changes and a role for the new Commission for Equality and Human Rights (paragraphs 9 - 65).

In the Committee's view there is a significant distinction between a "duty to provide" under care standards legislation and a "right to receive" under human rights legislation. It recommends that the Government and other public bodies should champion understanding of how human rights principles can help transform health and social care services (paragraphs 66 - 95).

While welcoming the recent acceptance at senior levels in the Department of Health of the importance of human rights in healthcare, the Committee recommends adoption of a strategy to make the Human Rights Act integral to policy-making and social care across the Department (paragraphs 96 - 124).

The Committee regrets the failure of the Department of Health and the Ministry of Justice to give proper leadership and guidance to providers of health and residential care on the implications of the Human Rights Act. It recommends measures to strengthen human rights obligations and duties and to bring private and voluntary care homes within the scope of the Human Rights Act (paragraphs 125 - 161).

The Committee recommends improved guidance and standards on human rights compliance in healthcare and that the forthcoming merged inspectorate for health, social care and mental health should adopt a human rights framework for all its work. It also recommends that the National Institute for Health and Clinical Excellence should take clearer account of the Convention rights of any patients affected by its decisions on clinical practice (paragraphs 162 - 198).

The Committee advocates better staff training in human rights principles and their inclusion in health professionals' qualifications as well as a duty to blow the whistle on abuse (paragraphs 199 - 232).

The Committee makes recommendations relating to protection against eviction for care home residents, improved defence of their human rights and more robust complaints procedures. It also recommends promotional work to improve the image of human rights and spread awareness of older people's rights (paragraphs 233 - 288).

1 Introduction

Our inquiry

1. The number of older people in the UK is growing and people are living longer than they ever did. The Government estimates that by the middle of the century, twice as many people will be aged 80 or over as there are today.¹ Older people are the main users of the NHS. Two thirds of general and acute hospital beds are occupied by people aged 65 and over.² A recent survey found that 72% of care home residents were immobile or reliant on assistance, 62% were confused and forgetful and 24% were confused, immobile and incontinent.³ As older people live longer, their health care needs become more complex, and their dependency and frailty increase. These changes inevitably have consequences for the health service and the social care sector, including an increased pressure on resources (both human and financial). Older people in healthcare, especially those with complex needs, are dependent on others for many if not all of their basic needs, such as food, personal care and medication. They may have, or feel that they have, little or no control over what happens to them.

2. Whilst human rights principles apply to everybody, we chose to limit our inquiry to focus on one particular group, namely older people and their receipt of healthcare services in hospitals and care homes. Victimisation or neglect of older people within the healthcare system raises important issues of substantive human rights law under the Human Rights Act 1998 (HRA), the European Convention on Human Rights (ECHR) and other international law obligations such as the prohibition of ill-treatment, the right to respect for private and family life, physical and psychological integrity and the prohibition on discrimination (including the provision of healthcare on equal terms with the rest of the population). It is also potentially in breach of common law principles such as dignity, humanity and equality and, in particularly serious circumstances, the criminal law. At their most severe, poor treatment could lead to an infringement of the right to life.

Terms of reference

3. Our terms of reference called for evidence in particular on how human rights principles could be applied, by healthcare providers and inspectorates alike, to ensure that older people are treated with greater dignity and respect when being cared for. It sought evidence on the following questions:

- What are the main challenges to the human rights of older persons receiving treatment in hospitals and residential care homes? Do the same problems arise in both settings?
- Are there discriminatory restrictions of the rights of older persons to access healthcare without adequate justification, for example in relation to criteria used for sharing or rationing of finite healthcare resources?

¹ Communities and Local Government, *Discrimination Law Review – A Framework for Fairness: Proposals for a Single Equality Bill for Great Britain*, June 2007, para 9.10.

² Department of Health, *National Service Framework for Older People*, March 2001, p 1.

³ Continuing Care Conference Survey of 32,000 care home residents, 2006, quoted in Age Concern, *The Age Agenda in 2007*, February 2007, p 32.

- What barriers face older people, and their families, seeking to voice their concerns about possible abuse, neglect or discrimination in healthcare?
- Could older people in healthcare be better informed about human rights principles? If so, how could better information and involvement be achieved?
- What examples are there of healthcare professionals or other workers, or advocates for older persons, using human rights principles to secure the dignity of older persons undergoing treatment for physical or mental illness?
- What are the main practical, management and resource considerations facing those working in healthcare settings, including residential homes, when seeking to protect the human rights of older persons in their care?
- Do NICE and the Healthcare Commission take sufficient account of the human rights of older persons in their work?

4. Our inquiry does not consider palliative care, the meaning of “public authority”⁴ or domiciliary care.

Structure of our report

5. In Chapter 2, we set out the evidence we received of the nature and scale of the human rights problem affecting older people in healthcare and its root causes. Chapter 3 explains our understanding of the application of human rights standards to the treatment of older people in healthcare and its benefits. In the following Chapters, we consider the role of the Department of Health (Chapter 4), providers of services (Chapter 5), health and social care inspectorates and NICE (Chapter 6) and staff in protecting human rights (Chapter 7). In Chapter 8, we consider the barriers to older people raising human rights concerns and complaints and the role that human rights have to play in overcoming these problems. Finally, in Chapter 9, we set out our principal conclusions and recommendations. An analysis of the applicable human rights standards is contained in the Annex to this Report.

Evidence and visits

6. We received written evidence from many organisations and some individuals, for all of which we are grateful. Most of this evidence is published in full in a separate volume to this Report. The transcripts of the oral evidence sessions are also published in a separate volume.

7. In May 2007, we visited hospitals and care homes in North London where we met and talked with councillors, managers, staff, residents, patients and their families. Denmark and Sweden are often cited as examples of best practice in the field of health and social care and in March 2007 we visited Copenhagen and Malmö where we had discussions with central and local government, the relevant inspectorates and visited hospitals and residential care homes. We are most grateful to all those who assisted us in the course of our inquiry.

⁴ Ninth Report of Session 2006-07, *The Meaning of Public Authority Under the Human Rights Act*, HL paper 77/HC 410.

Specialist adviser

8. We record our particular thanks to Frances Butler, our specialist adviser on this inquiry, for her assistance.

2 Treatment of older people in hospitals and care homes

“The home always looked attractive with flowers and pictures in the foyer but this masked the quality of the care.”⁵

9. The care of the elderly, frail and sick can be immensely demanding both physically and mentally. At the outset of our Report we pay tribute to the many private individuals and professional staff who do this with dedication, setting high challenges and standards for the rest of us. They deserve the full support of society as a whole, not least in ensuring that the necessary resources are available. Our Report is highly critical of where in institutional care things go wrong. We seek to point no fingers of blame. Our analysis and recommendations, although sometimes hard hitting, are made in the hope that they will help to strengthen best performance. As we explain, a recognition of the significance of human rights is a vital way of underpinning that performance. We emphasise that ensuring the dignity and self-respect of the vulnerable, which is central to the fulfilment of human rights, is a task for us all.

10. In this Chapter, we set out the evidence we received of the quality of treatment that older people receive in hospitals and residential care homes.

Scale of the problem

11. During the course of our inquiry, we received a considerable volume of evidence about the quality of treatment that older people receive in hospitals and residential care homes. We have heard examples of both good and bad practice. Witnesses stressed that some older people received an excellent service in hospitals and residential care. Comments included

There are many residential and nursing home environments out there that are providing very good quality care.⁶

And

We do not see systematic problems across the whole of the NHS. In fact, what we see is a lot of very, very caring activity going on. There are patches of problems and when those come to light they really are a betrayal of values so that you do need the reserve for when that happens.⁷

And

We will always in our society hear the bad news, the bad stories, the evidence of bad practice and often will not hear about some fantastic practice that takes place. There is far more good practice than there is bad.⁸

⁵ Ev 194, para 2.

⁶ Q 211.

⁷ Q 140.

⁸ Q 285.

12. However, many witnesses, including the inspectorates, providers and organisations supporting older people, expressed concern about continuing poor treatment of older people in healthcare. Their principal concerns related to:

- Malnutrition and dehydration (Articles 2, 3 and 8 ECHR)
- Abuse⁹ and rough treatment (Articles 3 and 8)
- Lack of privacy in mixed sex wards (Article 8)
- Lack of dignity especially for personal care needs (Article 8)
- Insufficient attention paid to confidentiality (Article 8)
- Neglect, carelessness and poor hygiene (Articles 3 and 8)
- Inappropriate medication and use of physical restraint (Article 8)
- Inadequate assessment of a person's needs (Articles 2, 3 and 8)
- Too hasty discharge from hospital (Article 8)
- Bullying, patronising, and infantilising attitudes towards older people (Articles 3 and 8)
- Discriminatory treatment of patients and care home residents on grounds of age, disability and race (Article 14)
- Communication difficulties, particularly for people with dementia or people who cannot speak English (Articles 8 and 14)
- Fear among older people of making complaints (Article 8)
- Eviction from care homes (Article 8).

13. Below we explore in more detail some of the recurring issues which emerged in our inquiry. Difficulties experienced by older people in making complaints are dealt with in Chapter 8. Many of the concerns are overlapping and inter-related. Whilst some of these issues may not appear, at first glance, to be obvious healthcare issues, all of the problems, in our view, seriously affect people's experiences of the overall care that they received in hospitals or care homes.

14. According to the Commission for Social Care Inspection (CSCI), since the introduction of the National Minimum Standards in 2002-03, the percentage of social care services meeting the standards for privacy and dignity has increased from 82% to 91%.¹⁰ CSCI also reports that residential services for older people met 79% of the National Minimum Standards in 2006, compared with 59% in 2003.¹¹ Nevertheless, we note that this means that, more than three years after the standards were introduced, 21% of care homes are still failing to meet the minimum standards required of them.

⁹ See definitions of "elder abuse" at paragraphs 16 and 17.

¹⁰ Commission for Social Care Inspection, *State of Social Care Report 2005/06* (December 2006), p 140.

¹¹ *Ibid*, p X.

15. The Department of Health, in its written evidence to our inquiry, does not explicitly acknowledge any of the problems identified by other witnesses, but instead focuses rather defensively on the financial investment made into the NHS and the many initiatives launched by government in relation to older people.¹² These include the Dignity in Care campaign¹³ and, as recently announced by Ivan Lewis MP, the Minister for Care Services, a national action plan to tackle the issue of older people and nutrition which will be published in the summer.¹⁴

Elder abuse

“An 80 year old woman [...] was seriously sexually assaulted by another resident in 2004. It was reported in the log book but no action taken [...] It was only reported to the resident’s daughter in July 2005. She reported the matter to the police.”¹⁵

16. According to Department of Health guidance, “Abuse is a violation of an individual’s human and civil rights by any other person or persons”.¹⁶

17. More particularly, elder abuse has been defined as, “A single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person”.¹⁷

18. According to Age Concern, 500,000 older people are subject to abuse at any one time in the UK, although not all of this abuse occurs in healthcare. Almost four-fifths of the abuse is perpetrated against people over the age of 70, and 16% affects people over 90.¹⁸ Based on telephone calls to their helpline, Action on Elder Abuse identifies five categories of abuse: physical (19% of calls), psychological (34%), financial (20%), sexual (3%) and neglect (12%). It highlights the high number of allegations of multiple abuses (44% of callers report more than one type of abuse occurring simultaneously). The majority of abusers are related to their victim (46%).¹⁹ The next highest category of abusers is paid workers (34%). Of the one third of abuse which is perpetrated by two or more people acting together, 62% is perpetrated by paid staff “that is, through abusive practices that are institutional and passed from one worker to another”.²⁰ 23% of reports to the helpline concern care homes (where less than 5% of the older population live) and 5% concern hospital settings.²¹

19. Reporting on elder abuse in 2004, the House of Commons Health Committee found that abuse of older people was a hidden, and often ignored, problem in society, and was a violation of their human rights.²² It concluded that, unlike child abuse, whose profile had

¹² Ev 105-122.

¹³ Launched 14 November 2006.

¹⁴ Launched 13 February 2007.

¹⁵ Ev 194, para 3.

¹⁶ Department of Health, *No Secrets – Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*, March 2000, para 2.5.

¹⁷ Action on Elder Abuse, *Hidden Voices: Older People’s Experience of Abuse* (September 2004), p 2.

¹⁸ Age Concern, *Rights for Real*, May 2006, p 35.

¹⁹ *Hidden Voices*, *op cit*, pp 2-5.

²⁰ *Hidden Voices*, *op cit*, p 3.

²¹ *Hidden Voices*, *op cit*, pp 4-5.

²² Health Committee, *Elder Abuse*, Second Report of Session 2003-04, paras 13 and 107.

been dramatically raised in the past few years, abuse of older people remained hidden. Witnesses to our inquiry agreed²³ and suggested that it was difficult to determine the scale of abuse due to under-reporting²⁴ and the lack of resources focused on the issue,²⁵ although some suggested that there was now greater awareness of elder abuse.²⁶

20. In our view, elder abuse is a serious and severe human rights abuse which is perpetrated on vulnerable older people who often depend on their abusers to provide them with care. Not only is it a betrayal of trust, it would also, in certain circumstances, amount to a criminal offence.

Neglect or carelessness

“A lady of 89 had been in a care home for 18 months as a self-funder. She was taken to hospital with severe pressure sores and dehydration. The hospital criticised the quality of care she had been receiving and said that she should have been receiving nursing care. On discharge she returned to the care home and was placed in the nursing wing.

When the lady’s son asked staff in the residential section (where she had been living before) why she had been allowed to deteriorate prior to her admission to hospital, why the pressure sores and dehydration had been allowed to develop and why her needs had not been reassessed, they replied that it was not their job to do that and that the district nurse should have been informed and called upon to do it. They did not acknowledge that it should have been their responsibility (or at least the home’s) to call her in if this was the case.”²⁷

21. Witnesses complained that older people in healthcare were sometimes neglected and that staff failed to show them appropriate and adequate care. Neglect is one aspect of elder abuse. By “carelessness”, we mean treatment that is less severe than neglect, but which implies a lack of thought by staff about the effect of their actions on patients and residents. Examples of neglect or carelessness that we heard of included:

- Lack of hygiene, which at its most severe led to ill health and death such as the outbreak of *clostridium difficile* in Stoke Mandeville Hospital which, according to the Healthcare Commission resulted in the “avoidable deaths in hospital of at least 33 patients, who were mainly elderly people”.²⁸
- Problems with personal care, including people being left in their own waste.²⁹ This not only causes distress to individuals, but may also lead to health problems such as the development of bedsores.

²³ Ev 155.

²⁴ Q 7.

²⁵ Qs 4-7.

²⁶ Q 213.

²⁷ Ev 195, para 6.

²⁸ Ev 144, para 2.3.

²⁹ Ev 144, para 2.3; Ev 160, para 1.2.

- Rough handling of patients and residents by staff, for example when changing their clothes.³⁰
- Older people being left with their spectacles, hearing aids or false teeth out of reach.³¹
- Patients being repeatedly moved from one ward to another for non-clinical reasons, sometimes at night.³²
- Hearing and visual problems not being addressed, and conditions remaining undiagnosed and untreated until they became critical.³³
- Patients being left for hours in hospital reception without medication, food or water whilst awaiting transfer to another hospital or residential care.³⁴

22. It is now a criminal offence for a person providing care to someone who lacks capacity to ill-treat or wilfully neglect them.³⁵ A similar offence, of longer standing, exists for anyone being treated for mental disorder in a hospital, mental nursing home, independent hospital or care home.³⁶

Dehydration and malnutrition

“She grew very thin and it was obvious to visitors that, although she has always had an excellent appetite, she found great physical difficulty in feeding herself and using a cup. Visitors would have been only too willing to help her but they were discouraged from staying during meal times. She appeared to be slowly starving to death.”³⁷

“A woman reported that her mother, Dorothy, who is 92 and suffers from dementia, was admitted to hospital but not given the help she needed to eat. On many occasions Dorothy’s food was left untouched on her bedside table and taken away at the end of mealtimes by the catering staff. Her food also needed to be pureed but often this was not done.”³⁸

“Often nurses firstly do not have the time to be able to do this type of work well, but I think we are also seeing no clear understanding of whose job it is. Typically, what a carer will report to us is ‘I asked the nurse if she would be able to help my mother with eating her dinner’ and she said, ‘Ah, no, that is really the job of a care assistant, find a care assistant’.”³⁹

³⁰ Ev 195, para 7.

³¹ Ev 104, para 1(e).

³² Ev 98; Ev 143, para 2.2.

³³ Ev 92; Ev 153.

³⁴ Committee visit.

³⁵ Section 44 Mental Capacity Act 2005.

³⁶ Section 127 Mental Health Act 1983 as amended by the Care Standards Act 2002, section 116, Sch 4, para 9.

³⁷ Ev 104, para 1(c).

³⁸ Age Concern, *Age of equality? Outlawing age discrimination beyond the workplace* (2007), p 23.

³⁹ Q 214.

23. A number of witnesses expressed concern about malnutrition and dehydration of older people in healthcare.⁴⁰ In 2006, Age Concern reported that 60% of older people in hospital were at risk of malnourishment or of their situation getting worse during their hospital stay.⁴¹ Hospital meals may be taken away before patients can eat them and insufficient help is given with eating and drinking. On occasion this can lead to preventable deaths.⁴² The same year, the Healthcare Commission published a survey of 80,000 adult inpatients. Of those needing help to eat meals—a fifth of those surveyed—almost 40% said that they either never (18%) or only sometimes (21%) received help. On 7 March 2007, the Healthcare Commission announced that it would be investigating and reporting on dignity in the care of older people in hospitals.⁴³

24. The Minister accepted that there was a problem of malnutrition in some healthcare settings but stated:

We talk sometimes about the way that nutrition is organised in hospitals we end up with the *Daily Mail* saying thousands of people are being starved in this country. They are not, but are we satisfied with the way that nutrition and people's access to food is dealt with in hospitals and care homes? Often we are not.⁴⁴

25. Some good practice exists. For example, some organisations use red trays to identify patients who have difficulty eating without assistance.⁴⁵ Others ensure that meal times are not interrupted. These practices help to preserve the dignity of older people and are examples of positive steps that organisations can take to ensure that the rights of older people to life and not to suffer ill-treatment are protected.

Medication

“[The caller’s] mother suffers from mild dementia and in recent months had tended to wake at night. At the new home, the staff who sleep in overnight did not like being disturbed during the night because, the manager said, they had day jobs elsewhere to go to during the day. She (the manager) said she had to pay them extra each time they had to get up. The manager suggested that the daughter would have to cover these extra costs.

The home thought that sleeping medication might solve the problem of her wakefulness and the GP prescribed this without seeing the lady or her daughter.”⁴⁶

⁴⁰ Ev 85, para 1(i); Ev 122-123.

⁴¹ Age Concern England, *Hungry to be Heard: the scandal of malnourished older people in hospital* (2006) referred to in Ev 130.

⁴² Ev 163, para 1.25, Ev 144, para 2.3.

⁴³ Healthcare Commission press release, 7 March 2007.

⁴⁴ Q 379.

⁴⁵ Ev 163, para 2.6.

⁴⁶ Ev 195, para 8.

26. A number of witnesses expressed concern about the inappropriate use of medication on older people, including the over or under-use of medication and the use of medication as a means of controlling patients and residents. Action on Elder Abuse cited the misuse of medication as one type of abuse which frequently comes to its attention.⁴⁷ This is a particular issue in care homes.

27. Again, witnesses accepted that there was good practice in this area,⁴⁸ but that this was not universally implemented. Witnesses raised a particular issue of medication being inappropriately used to keep residents docile.⁴⁹ As the Alzheimer's Society's said:

The response to aggression in dementia is often to prescribe powerful sedative neuroleptic drugs that can help to calm the person. However, these treatments have very damaging side effects. Medications such as Haloperidol, Risperidone and Olanzapine are being routinely prescribed to people with dementia in hospitals and care homes. A recent study found that 40% of people with dementia in care homes are being prescribed neuroleptic drugs.⁵⁰ Neuroleptics are not licensed for use in dementia care but have become a convenient staple as part of routine treatment, despite known evidence on the risks which such 'treatments' pose to quality of life and the increased risk of death.⁵¹

28. The concerns of witnesses accord with the findings of the Health Committee that medication was "in many cases, being used simply as a tool for the easier management of residents".⁵² The National Service Framework for Older People requires that all people over 75 years should normally have their medicines reviewed at least annually and those taking four or more medicines should have a review every six months.⁵³ In 2006, *Living Well in Later Life* noted that "the management of medicines needs to be addressed, as many older people taking more than four medications are still not receiving a review every six months".⁵⁴ CSCI found that, in 2005-06, only 59% of care homes met the National Minimum Standard (Standard 9) for medication.⁵⁵ The Alzheimer's Society agreed that there is a very poor record of medication in care homes.⁵⁶

Lack of privacy, dignity and confidentiality

"I went to visit my husband on the first day and he is a very private person, he doesn't like anything to embarrass him and when I went in he was almost in tears which is not my husband. He said 'please, please go and get a bottle I am nearly wetting myself'. I rushed out I got a bottle and I said to him 'Well why didn't you just

⁴⁷ Ev 222.

⁴⁸ Q 219.

⁴⁹ Ev 195, para 8; Ev 173, para 16.

⁵⁰ Margallo-Lana, M et al, (2001) *Management of behavioural and psychiatric symptoms amongst dementia sufferers living in care environment*. International Journal of Geriatric Psychiatry.

⁵¹ Ev 214, paras 22-23.

⁵² Health Committee, *Elder Abuse*, Second Report of Session 2003-04, para 65.

⁵³ This milestone was set in April 2002.

⁵⁴ *Living Well in Later Life*, p 9.

⁵⁵ *State of Social Care 2005-6*, op cit.

⁵⁶ Q 219.

ring the nurse', in my innocence. 'I have for an hour and a half I've been asking for a bottle'. Well when I went out [and] told the nurse she said 'Oh don't worry we would have changed the sheets'. Now his dignity at that stage would have gone out of the window. There was no dignity." (Older person)⁵⁷

"[...] there are two reception desks side by side, two lines of patients having discussions about the nature of their medical condition. There cannot be confidentiality in that." (British Geriatrics Society)⁵⁸

"I don't know whether people get almost blasé about the fact that they are dealing with people in a vulnerable state all the time and they forget how that person may be feeling about it." (Physio assistant)⁵⁹

"I think that healthcare staff have become so required to focus on technology and targets that they have lost sight of the humanistic aspects of caring." (Royal College of Nursing)⁶⁰

"We have reached the stage where we value care far less than we value cure." (NHS Confederation)⁶¹

29. Witnesses told us of the lack of privacy, dignity and respect for confidentiality afforded to older people in hospitals and care homes. Examples included:

- The continuing use of mixed sex wards.⁶² Whilst some witnesses felt that there were advantages to mixed sex wards (such as companionship),⁶³ others noted the problems they raised for privacy, particularly when people were partially clothed or naked.⁶⁴
- Sensitive confidential medical advice being given to a patient on a ward, where other patients could overhear.⁶⁵
- Problems with personal care such as "neglect of proper hygiene care or continence care resulting in individuals left lying in their own urine or excrement",⁶⁶ people not being allowed to use the toilet in private⁶⁷ and care home residents being fed whilst on the commode.⁶⁸

⁵⁷ Ev 97.

⁵⁸ Q 291.

⁵⁹ Ev 97.

⁶⁰ Q 285.

⁶¹ Q 336.

⁶² Ev 123.

⁶³ Ev 90.

⁶⁴ Ev 160, para 1.5.

⁶⁵ Q 287.

⁶⁶ Ev 160, para 1.2.

⁶⁷ British Geriatrics Society, *Behind closed doors - Using the toilet in private*.

⁶⁸ Ev 160, para 1.5.

- Healthcare staff having conversations between themselves, whilst attending to the intimate care needs of older people.⁶⁹

30. Witnesses complained that some hospitals and care homes appeared to be planned around the staff rather than service users. For example “the elderly are not treated like individuals; they become just another part of the hospital or care home routine”.⁷⁰ The rights of patients are affected by both clinical and non-clinical staff. We heard one example of an elderly woman who was being discharged from an acute to an intermediate care hospital who had to sit and wait for 5 hours in the non-medical discharge lounge without food or water.

31. In a public survey conducted by the Department of Health, respondents stated that one of the characteristics of ensuring that services provided for dignity in care was “respecting basic human rights, such as giving people privacy and encouraging independence”.⁷¹ The Minister told us that they were focussing on “the centrality of dignity and respect of older people in a variety of care settings, again both NHS and social care”.⁷² Recognising the right of older people to privacy, he noted that:

Every individual has a different story, a different background, a different set of life experiences, a different set of fears maybe. None of us is the same, so the ability of the system or of staff to treat people in a very individualised or personalised way is something that is raised with us.⁷³

32. The Healthcare Commission Core Standard C13(c) requires that providers of healthcare services “have systems in place to ensure that staff treat patient information confidentially, except where authorised by legislation to the contrary”. However, Help the Aged commented that the duty to maintain confidentiality could pose risks for a patient or resident who did not have capacity:

The issue of confidentiality is often misunderstood by health staff, particularly in relation to patients who lack the capacity to consent to disclosure of information, such as many dementia patients. As a result, the principle of confidentiality is applied in a very over-restrictive way (Articles 6 and 8) [...] This is a practical problem for carers. We are concerned particularly with older carers, typically the spouse or partner of a person who has lost capacity. This can leave carers deprived of vital healthcare information, including information about effects of medication, which exposes both carer and cared for to unnecessary risks.⁷⁴

Hospital discharge

“[...] the husband was in hospital, the wife had died, and the individual social worker

⁶⁹ Ev 160, para 1.5.

⁷⁰ Ev 140.

⁷¹ Department of Health, *Dignity in Care public survey - Report of the Survey*, October 2006, p 5.

⁷² Q 373.

⁷³ Q 379.

⁷⁴ Ev 162, para 1.20-1.21. *S v Plymouth City Council* [2002] EWCA Civ 388 – Article 8 ECHR (right to respect for private life) includes a procedural requirement to be involved in decision making processes, including on behalf of a family member who lacks capacity (para 40).

was told that she had to get the son to go and visit a care home the following day, and he said he could not do that because he was attending his mother's funeral. The discharge went ahead on the day of this man's wife's funeral, which seems to me grotesque, grotesquely inhuman."⁷⁵

33. Regulations made under the Community Care (Delayed Discharges etc) Act 2003 require social services to arrange a discharge placement within two working days of notification by the NHS Trust that an acute patient is clinically ready for discharge. If the patient cannot be discharged within this time, the local authority may be required to make payments to the NHS Trust.

34. The Department of Health informed us that it is committed to reducing the number of people whose discharge from hospital is delayed. Figures provided by the Department show that between September 2001 and December 2006:

- The number of people over the age of 75 delayed in hospital reduced from 5,673 to 1,651, a reduction of 71%
- Total delays for the same period were reduced from 7,065 to 2,190, a reduction of 69%.⁷⁶

35. In 2006, Professor Ian Philp, National Director for Older People's Services, in his report on progress in implementing the National Service Framework for Older People noted, amongst other things, that "delayed discharge from acute hospitals has been reduced by more than two-thirds".⁷⁷ According to the Department of Health's own statistics, about 16% of patients over 75 years of age are re-admitted to hospitals within 28 days of discharge compared with about 10% of patients aged 16-74.⁷⁸

36. Although witnesses saw the merit in ensuring that patients did not stay longer in hospital than was necessary,⁷⁹ a number of witnesses expressed real concern about the operation of the Delayed Discharge Regulations, particularly regarding the short timescale permitted to arrange a placement, and the implications that this had for an individual's right to respect for his private and family life. Witnesses told us that the application of the current Regulations leads to older people:

- Having no choice on discharge.⁸⁰
- Being put into placements that do not meet their needs.⁸¹
- Having no chance to come to terms with a momentous life changing event (i.e. the possible move for the first time from independent living to residential care).⁸²

⁷⁵ Q 23.

⁷⁶ Ev 113, para 75.

⁷⁷ Ev 108, para 17.

⁷⁸ Ev 116-121.

⁷⁹ Ev 161, para 1.11; Qs 23 & 281 [Dr Dalley].

⁸⁰ Ev 160, para 1.9; Q 27.

⁸¹ Q 227.

⁸² Q 23.

- Being discharged to care homes instead of receiving rehabilitation⁸³ or returning to their homes with community support.⁸⁴
- Being discharged to care that is miles away from friends and family.⁸⁵
- Being discharged without adequate care in place or when they are still unwell.⁸⁶

In addition, we were told that Department of Health guidance that no one should be discharged from an acute hospital bed directly to a care home was “routinely ignored” by people applying delayed discharge criteria.⁸⁷

37. The British Geriatrics Society stated “what we do as geriatricians is to try and thwart some of the attempts to discharge people prematurely”⁸⁸ and “I do not have the words for how stupid and how wrong such a policy is”.⁸⁹ Similarly, the Royal College of Nursing said “it is clearly harmful to discharge someone who is not ready to be discharged and to discharge them before services have been put in place. That is something that concerns us a lot”.⁹⁰ Help the Aged were concerned that the Regulations currently “have the balance wrong”⁹¹ and create a situation that is “so abusive of individual rights”.⁹²

38. We were pleased to hear the Minister’s assurance that “nobody should be discharged from hospital without appropriate arrangements being put in place for their care”⁹³ and his acknowledgement that the operation of the Regulations could have human rights implications. However, although Department of Health guidance sets out a number of principles which it suggests should be applied, including that discharge should be “planned for at the earliest opportunity across the primary, hospital and social care services”,⁹⁴ we are concerned that, for a number of reasons, this is simply not happening in practice. We are also concerned that the premature or inappropriate discharge of older people could lead to their readmission shortly afterwards.

39. When we asked the Minister about this, he stated that “there are lots of reasons and causes for readmission, a lot of which are absolutely nothing to do with the 48 hour part of the guidance”.⁹⁵ However, he added:

On the question of the data that has come to light on the readmissions, I do not think we would want to be defensive about it, we would want to be frank about it, and we

⁸³ Ev 101; Ev 126, para 2.7; Ev 141.

⁸⁴ Ev 214, para 19.

⁸⁵ Q 227.

⁸⁶ Ev 174, para 17.

⁸⁷ Q 27 [Mr Hurst].

⁸⁸ Q 287.

⁸⁹ Q 311.

⁹⁰ Q 281.

⁹¹ Q 23.

⁹² Q 25.

⁹³ Q 446.

⁹⁴ Department of Health, *Discharge from hospital: pathway, process and practice*, January 2003, p 3.

⁹⁵ Q 448.

need to go away, reflect on it, do more work on it, and if we find that this is an unintended consequence of policy then we ought to do something to address it. Personally, I would regret it if we were to move away from a system where we took the pressure away, as was the case at one stage, and as a result of that people ended up languishing in inappropriate hospital beds for weeks, months and in some cases years.⁹⁶

40. Some witnesses recommended that greater flexibility should be introduced into the Regulations to ensure that the rights of older people were respected when discharge was being considered. Suggestions for amending the Regulations included that the time period should be extended from two days to about a week⁹⁷ or a little longer.⁹⁸ One witness described the operation of the Regulations as leading to a “chaotic scramble”⁹⁹ to find appropriate care for an individual whether in intermediate care, in a care home or supported within their own home. From the evidence that we heard, we agree that this can sometimes be the case. **We recommend the Government amend the Delayed Discharge Regulations to allow for flexibility in applying the time period so as to ensure that the Article 8 ECHR rights of older people are respected. We also recommend that the Government issue guidance for hospitals and local authorities on the application of the Regulations to ensure respect for the Article 8 rights of older people.**

Discrimination

41. As we have already highlighted, older people in healthcare are especially vulnerable to ill-treatment because of their dependency on others for their basic needs. The question is whether they receive this poor treatment because of their age and if so in what situations. Some witnesses have suggested that age discrimination still exists in the provision of healthcare in both hospitals and residential care homes.¹⁰⁰ We have also heard evidence that some older people experience discrimination in addition to their age, due to their race¹⁰¹ or disability. However, we note that it is incorrect to talk about older people as one homogeneous group. As one witness stated:

This [susceptibility of older people to human rights abuses] is not actually a problem of age by itself because older people are very diverse. It is by no means all older people who are vulnerable to human rights abuses, but some groups are more vulnerable than others because of ill-health, disability or dementia.¹⁰²

Age discrimination

“[...] an older person in a care home who is expressing difficulty with breathing where the care home response is to ignore it or say, “She will be okay” or “he will be okay”, and there is absolutely no access to a GP for three, four or five days and then

⁹⁶ Q 460.

⁹⁷ Q 23.

⁹⁸ Q 230.

⁹⁹ Ev 214, para 19.

¹⁰⁰ Ev 125, para 2.3.

¹⁰¹ Ev 197, para 13.

¹⁰² Q 11.

the care home will present it as being a sudden deterioration. But it is not a sudden deterioration, it is a denial of access to a GP that would not happen if that was a younger person.”¹⁰³

42. The National Service Framework for Older People states that “NHS services will be provided, regardless of age, on the basis of clinical need alone”.¹⁰⁴

43. Witnesses tended to agree that explicit direct age discrimination has become less common since the introduction of the National Service Framework for Older People.¹⁰⁵ *Living Well in Later Life* put this improvement down to NHS trusts auditing their policies on access to services and social services reviewing their criteria for eligibility.¹⁰⁶ One example of improved practice is that access to cardiac procedures and hip and knee replacements have improved since the NSF was published.¹⁰⁷

44. However, some witnesses told us that direct discrimination has not ceased altogether. We were alerted to a recent study¹⁰⁸ which found that almost half of a sample of 85 GPs, cardiologists and specialists in old age are influenced by age in deciding whether or not to carry out tests. Patients over 65 are less likely to be referred to a cardiologist, given an angiogram (artery scan) or given a heart stress test. Cardiologists are also less likely to recommend operations to open up blocked coronary arteries for older patients, and they are less likely to be prescribed statins to reduce cholesterol. They are, however, more likely to be offered a follow-up appointment and more likely to have existing drugs reviewed.

45. In Age Concern’s recent report on age discrimination,¹⁰⁹ it concluded that age discrimination existed in healthcare. Examples cited included:¹¹⁰

- Treatment for minor strokes is covertly rationed for people over 80 years of age.
- Doctors are less likely to refer angina sufferers to see a specialist or to have tests if they are over 65.
- National priorities for health and social care restrict targets for reducing heart disease, strokes and cancer to people under 75.
- Invitations to breast screening stop for women over 70.
- Older people tend to be excluded from drug trials.

¹⁰³ Q 244 [Mr FitzGerald].

¹⁰⁴ Standard One, 27 March 2001.

¹⁰⁵ Ev 215, para 27; Q 44 [Mr Hurst].

¹⁰⁶ CSCI, Audit Commission and the Healthcare Commission, *Living Well in Later Life*, March 2006, pp 6-7. See also Ev 108, para 16.

¹⁰⁷ *Ibid*, *Living Well in Later Life*, p 7.

¹⁰⁸ Harries, C., Forrest, D., Harvey, N., McClelland, A. and Bowling, A., Which doctors are influenced by a patient’s age? A multi-method study of angina treatment in general practice, cardiology and gerontology, *Quality and Safety in Healthcare* 2007;16:23-27. See also Young, J., Ageism in services for transient ischaemic attack and stroke, *British Medical Journal*, 9 September 2006; 333; 508-9: “whenever a clinical stone is turned over, ageism is revealed”.

¹⁰⁹ Age Concern, *Age of Equality? Outlawing age discrimination beyond the workplace*, May 2007.

¹¹⁰ *Ibid*, May 2007, p 22.

46. In addition, particular concern was expressed by Age Concern and others about the poor provision of mental health services to older, compared with younger, people. We consider this issue in greater detail below.

47. **What became clear to us from the evidence is that an older person’s age is much less likely to be directly taken into account when decisions are taken about his or her healthcare than in the past. However, age discrimination in both hospitals and care homes is now more subtle and indirect.** As one witness told us, “the majority of policies that directly discriminated on the basis of age have now been eradicated, although it has proved harder to challenge embedded ageist attitudes on the part of NHS staff”.¹¹¹ This accords with the findings of the National Director for Older People’s Services, who has said “although overt age discrimination is now uncommon in our care system, there are still deep-rooted negative attitudes and behaviours towards older people”¹¹² and “our existing services were not designed with older people’s needs in mind”.¹¹³ The Royal College of Physicians of Edinburgh said that there is “‘structural ageism’ in the NHS [...] which biases against the multiple pathology of older persons”.¹¹⁴ Given that, according to the NHS Confederation, “the NHS spends 80% of its resources and 80% of its time on people over the age of 65”,¹¹⁵ we find it surprising that this bias against services for older people continues to exist. Examples include:

- Local authorities have lower budgets for their older people’s teams than for teams dealing with younger people.¹¹⁶
- There is a lower financial cut-off point for care packages for older people compared with equivalently disabled younger people.¹¹⁷
- Decisions about whether to refer or treat are made on the basis of “deep seated, underlying attitudes and beliefs about older people”.¹¹⁸

Discrimination against vulnerable groups

48. The most vulnerable older people are particularly susceptible to poor treatment. Older people may face poor treatment not just because of their age, but also for other reasons such as disability or race. We consider two particular groups below.

People with mental health needs

49. According to the Alzheimer’s Society, there are currently 700,000 people with dementia in the UK.¹¹⁹ With an ageing population, these numbers are set to rise steeply in the

¹¹¹ Ev 128, para 4.1.

¹¹² Department of Health, *A New Ambition for Old Age*, 19 April 2006, p 2.

¹¹³ Department of Health, *A Recipe for Care – Not a Single Ingredient*, 2007, p 1.

¹¹⁴ Ev 153.

¹¹⁵ Q 336.

¹¹⁶ Q 58.

¹¹⁷ Q 58.

¹¹⁸ Q 46.

¹¹⁹ Ev 212, para 3.

future.¹²⁰ People with dementia are significant users of social and health care services. A recent report found that direct costs to the NHS and social care of dementia are currently at least £3.3 billion a year in England, although the overall economic burden is estimated at £14.3 billion.¹²¹ One third of people with dementia live in care homes. Two thirds of care home residents have some form of dementia. Approximately one quarter of hospital beds are being used by people with dementia at any one time.¹²²

50. The National Service Framework for Older People requires that “older people who have mental health problems [should] have access to integrated mental health services, provided by the NHS and councils to ensure effective diagnosis, treatment and support, for them and their carers”.¹²³

51. However, the National Service Framework for Mental Health¹²⁴ specifically excluded older people from its reach as it only focussed on adults of “working age”. As reported in *Living Well in Later Life*:

[...] the organisational division between mental health services for adults of working age and older people has resulted in the development of an unfair system, as the range of services available differs for each of these groups [...] Older people who have made the transition between these services when they reached 65 have said that there were noticeable differences in the quality and range of services available.¹²⁵

52. A number of witnesses criticised the poor provision for the mental health of older people, for example:¹²⁶

- Older people do not have access to the range of specialist mental health services, such as talking treatments, available to younger adults despite having the same, and often greater, need.¹²⁷ This inevitably restricts their choice of treatment options.¹²⁸
- Younger people receive higher levels of community services than older people. Older people are moved into residential care even though “a small amount of additional support at home could help someone to maintain their independence in the community for far longer”.¹²⁹

¹²⁰ National Audit Office, Session 2006-2007, *Improving services and support for people with dementia*, HC 604, p 6.

¹²¹ This figure includes both formal and informal costs (i.e. carers' time). National Audit Office, Session 2006-2007, *Improving services and support for people with dementia*, HC 604, 4 July 2007, p 4. The Alzheimer's Society estimate that the total economic burden in the UK is £17 billion, which includes £6 billion of care provided by families (Ev 212, para 3).

¹²² Ev 212, paras. 4-5.

¹²³ Standard 7.

¹²⁴ Department of Health, September 1999.

¹²⁵ *Living Well in Later Life*, p 7.

¹²⁶ Q 44 [Mr Hurst]; Ev 212, para 6; Ev 134, para 1.

¹²⁷ Ev 100; Ev 163, para 2.7.

¹²⁸ Ev 135, paras. 1.2-1.3.

¹²⁹ Ev 215, para 28.

- Some care homes will refuse to take older people with dementia, even though the majority of people living in care homes have a form of dementia.¹³⁰
- Mental health services are not tailored to the needs of older people.¹³¹
- Staff have insufficient training on the specific needs of people with dementia or other mental health problems.¹³²

53. A recent report on dementia concluded that:

People with dementia have not benefited from the developments in mental health services seen for working age adults [...] Overall [...] services are not currently delivering value for money to taxpayers or people with dementia and their families [...] The rapid ageing of the population means costs will rise and services are likely to become increasingly inconsistent and unsustainable without redesign.¹³³

54. As Mind said:

Despite the high prevalence of mental health problems in older people, too often services fail to provide for this group [...] Mind is concerned that as the population gets older, the service people receive for mental distress in older age will get worse unless discrimination in the system is tackled now.¹³⁴

Black and minority ethnic older people

55. Surveys show that black and ethnic-minority people are high users of healthcare services for conditions that may or may not be present in old age such as heart disease,¹³⁵ stroke¹³⁶ and diabetes.¹³⁷ In addition, it is suggested that black and ethnic minority people, and African Caribbean people in particular, fare worse under the mental health system than other people.¹³⁸

¹³⁰ Ev 214, para 20.

¹³¹ Ev 135, para 1.2.

¹³² Ev 217, para 41.

¹³³ *Improving services and support for people with dementia, op cit*, paras. 34-36.

¹³⁴ Ev 135, paras. 1.2-1.3.

¹³⁵ South Asian people are 50% more likely to die prematurely from coronary heart disease than the general population. *Delivering the National Service Framework for Coronary Heart Disease*, NHS, 2004.

¹³⁶ Amongst African-Caribbean and South Asian men the prevalence of stroke was between about 40% and 70% higher than that of the general population respectively after adjusting for age. National Statistics, *Health Survey for England 2003*.

¹³⁷ Men and women of Pakistani and Bangladeshi origin are more than 6 times as likely as the general population to have diabetes, and Indian men and women are almost 3 times as likely. Rates of diabetes among Black Caribbeans were also significantly higher than in the general population. The Health of Minority Ethnic Groups, *Health Survey for England, 1999*, National Statistics.

¹³⁸ African-Caribbean people are much less likely to be referred by their GP to mental health services but twice as likely to be referred by the police and the courts. Healthcare Commission, 2005, *Count me in - results of a national census of inpatients in mental health hospitals and facilities in England and Wales*, London. Black and ethnic minority groups are more likely to be misunderstood and misdiagnosed, have more ECT (electro-convulsive therapy) rather than 'talking treatments', are more likely to stay in hospital longer and less likely to have their psychological needs addressed. Mind, *The Mental Health of the African Caribbean Community in Britain*.

56. Several witnesses told us that black and ethnic minority older people may be especially vulnerable to poor treatment.¹³⁹ As Mind put it:

Many services have a poor record on engaging with older people from black and minority ethnic (BME) communities. The way that mental health services are organised and delivered creates cultural norms and practices different to those of older BME communities, many of whom spent their formative years outside of Britain. Barriers may include language issues, knowledge of what is available, and attitudes and practices of service providers. A lack of translated information about mental health issues and services often results in isolation for individuals and the delivery of inappropriate care or no care at all [...] Furthermore, older people from different communities may share similar experiences of racism and ageism, but the circumstances of (for example) Chinese, African-Caribbean or Asian older people may require very different approaches.¹⁴⁰

57. As we note below, older people face particular barriers in making their voices heard and raising complaints. This is even more acute for people who are not able to communicate with the authorities because they do not speak English or understand to whom to turn. Witnesses told us that language barriers for older people in accessing healthcare are of real concern. As Race on the Agenda said, “it is unrealistic to imagine that people who have reached a certain level of maturity can learn a new language”.¹⁴¹

Root causes

58. The Healthcare Commission highlights a number of common themes in the treatment of older people in healthcare which resonate with the evidence of other witnesses, including “deeply rooted ageist attitudes [...] Standards of nursing care that fall below expected levels [...] A focus on high profile targets [...] Shortcomings in leadership, management, accountability and governance [...] A poor and institutionalised environment.”¹⁴²

59. In our view, these are symptomatic of wider and more general issues of concern for the protection and respect for the human rights of older people. These include, at a very basic level, a lack of sufficient “protection from harm”,¹⁴³ privacy, dignity, respect, confidentiality, independence and autonomy (or as the British Geriatrics Society put it, a “lack of encouragement to older people to make their wishes and desires known to the staff looking after them”¹⁴⁴). **We consider that the power imbalance between service providers and service users and the strong evidence that we have received of historic and embedded ageism within healthcare for older people are important factors in the failure to respect and protect the human rights of older people. These problems require more than simply action at the local level, but an entire culture change in the way that healthcare services for older people are run, as well as strong leadership from the top.**

¹³⁹ Ev 197, para 13; Ev 101.

¹⁴⁰ Ev 138, para 5.6.

¹⁴¹ Ev 198, para 14.

¹⁴² Ev 144, para 2.6.

¹⁴³ Q 281.

¹⁴⁴ Q 280.

The Human Rights Act has an important role to play in moving the culture to one where the needs of the individual older person are at the heart of healthcare services. We discuss this more fully in the next Chapter.

60. We have heard some valuable and useful suggestions on how the deeply unsatisfactory situation we have outlined can be improved, including a new statutory duty on public services to promote age equality (similar to the race, disability and gender duties).¹⁴⁵ Age Concern recommend that an age equality duty would be beneficial as:

It would have a very powerful influence in transforming public services and achieving a culture change [...] users would end up getting far more voice and choice in relation to the services that they needed and involvement in decisions as to how these services were planned [...] not only would all existing policies and services be assessed for their impact on age—they would be age proofed—but also all new policies and initiatives would be assessed for the impact they made on age as well.¹⁴⁶

61. We note that the Minister for Work and Pensions, Barbara Follett MP said the following during the recent Commons debate on age equality:

A positive duty could be particularly effective in ensuring that public service providers take the needs of people of all ages into account when planning and commissioning services and providing staff training. That could play quite a part in the cultural shift that we need to bring in.¹⁴⁷

62. Help the Aged¹⁴⁸ and others also recommend that the existing prohibition on age discrimination in the workplace be extended to the provision of goods, facilities and services.¹⁴⁹ The Discrimination Law Review Green Paper on the need for a single equalities Act states “we are considering whether legislation to prohibit negative age discrimination beyond the workplace would help to ensure that people are always treated with respect in our society, whatever their age.”¹⁵⁰

63. We will consider these proposals for law reform in due course. In the interim, we consider, based on the evidence that we have received, the case in favour of these two legislative changes to be made.

64. We are convinced that the existing legislation does not sufficiently protect and promote the rights of older people in healthcare. We recommend that there should be a positive duty on providers of health and residential care to promote equality for older people. We also recommend that the current prohibition on age discrimination in the workplace be extended to the provision of goods, facilities and services, so as to encompass (amongst other activities) the provision of healthcare.

¹⁴⁵ Race Relations (Amendment) Act 2000; Disability Discrimination Act 2005 and Equality Act 2006.

¹⁴⁶ Q 61.

¹⁴⁷ 10 July 2007, Column 412WH.

¹⁴⁸ Q 62.

¹⁴⁹ Ev 163, para 2.8.

¹⁵⁰ *Discrimination Law Review – A Framework for Fairness*, *op cit*, para 9.4.

65. The new Commission for Equality and Human Rights (CEHR), which opens its doors in October 2007, has a significant role to play in ensuring that older people's rights are promoted and protected.¹⁵¹ The CEHR has a duty to “monitor the effectiveness of the equality and human rights enactments”¹⁵² and to publish periodic reports.¹⁵³ **We therefore recommend that the CEHR monitors the implementation of human rights and equality legislation in healthcare for older people and reports on this in its State of the Nation report.**

66. In the next Chapter, we consider how the application of human rights principles could make a difference in practice to the problems we have identified above.

¹⁵¹ Here we agree with the Health Committee, Second Report of Session 2003-04, *Elder Abuse*, HC 111-1, para 13.

¹⁵² Equality Act 2006, Section 11(1).

¹⁵³ Equality Act 2006, Section 12(4)(a).

3 Understanding how the Human Rights Act applies to older people in healthcare

67. In the Annex to this Report, we outline the various laws and guiding principles which may broadly be described as human rights instruments and which are relevant to this inquiry. The priority, in our view, is to develop greater understanding of the application of the HRA to older people's healthcare. This is because the HRA is a UK statute enforceable by UK courts which sets out the fundamental rights which all people, whatever their age, are entitled to enjoy. This inquiry has sought to explore the difference that human rights principles can make to older people in receipt of health and residential care services. **We were impressed by the commitment to a human rights approach in healthcare shown by everyone who provided evidence to us.** As our inquiry has revealed, however, there are still many people whether they be patients, care home residents or staff who do not know much about the application of human rights to healthcare. **We agree with the British Institute of Human Rights' comment that "the human rights of older people are particularly invisible in society".**¹⁵⁴ Our concern, shared by our predecessor Committee, is that the HRA has not been implemented properly and, as a result, has been insufficiently understood and applied. We see it as part of our function to improve understanding of human rights in society and we therefore set out in this Chapter, by reference to what witnesses to this inquiry told us, our understanding of how the HRA applies to older people in healthcare.

The transformative purpose of human rights

68. In their Report on the case for a Human Rights Commission in 2003, our predecessors noted the transformative purpose of the HRA, which was to develop a culture of respect for human rights:

A culture of respect for human rights would exist when there was a widely-shared sense of entitlement to these rights, of personal responsibility and of respect for the rights of others, and when this influenced all our institutional policies and practices. This would help create a more humane society, and could help to deepen and widen democracy by increasing the sense amongst individual men and women that they have a stake in the way they are governed. For these and other reasons we believe a culture of respect for human rights is a goal worth striving for.¹⁵⁵

69. This analysis, with which we agree, is inspired by the goals of the Universal Declaration of Human Rights, which are the achievement of both protection and social progress for all. These cannot be attained without adherence to the underlying human rights principles of dignity, respect, equality and fairness. We see the purpose of the Human Rights Act, not as an end in itself, but as a tool that can and should be used in law, policy and practice to enable these social justice goals to be achieved. The human rights legislation therefore

¹⁵⁴ Ev 170, para 5.

¹⁵⁵ Sixth Report of Session 2002-03, *The Case for a Human Rights Commission*, HL Paper 67-I/HC 489-I, Vol 1, para 9.

assists in the quest for a decent civilised society where individuals are treated fairly, with equality and with respect for their dignity.

70. It appears to us to be axiomatic that when a human rights culture prevails within a hospital or care home, then not only will the climate be right for people (both service users and members of staff) to bring issues of concern to the notice of the authorities; but it will be less likely to be necessary because the right kind of culture already exists. Race on the Agenda summarised this point in the following way:

[...] to create a human rights culture you need a two-way process. It is what I call “the push and pull effect” [...] where individuals are aware of their rights and they can demand their rights if they need to. But if the culture of human rights is present then they will not have to do that.¹⁵⁶

71. Someone working at an NHS Trust has been quoted by the NHS Confederation giving her personal view of what happens in practice:

If we really had a human rights approach, we wouldn't have reports of old people not being fed or people lying on dirty beds. Something happens both within people's individual behaviour and at organisational level; we don't on a day to day consistently deliver people's human rights.¹⁵⁷

What does the Human Rights Act add?

72. An issue that emerged during our inquiry was, when it is self-evident that nurses and care workers should be treating people in their care properly and decently, what can the Human Rights Act add? We are aware that this view may be held by people who are sceptical about the value of the Act and it may also be held, as some witnesses quoted below told us, by people working in healthcare who simply do not know much about it. We therefore explore this question more thoroughly here.

73. An emphasis on the need to protect the dignity of people, whether they are elderly or other vulnerable adults or children, has recently become more prominent in public debate. Last year the Department of Health launched the “Dignity in Care” initiative to “ensure all older people are treated with dignity when using health and social care services”¹⁵⁸ stating:

[...] we want to create a zero tolerance of lack of dignity in the care of older people, in any care setting. We want to inspire and equip local people, be they service users, carers, relatives or care staff with the information, advice and support they need to take action to drive up standards of care with respect to dignity for the individual.¹⁵⁹

74. The Government's action in this area is clearly significant. Action on Elder Abuse told us “while some have criticised the Government's ‘dignity in care’ campaign as a ‘gimmick’,

¹⁵⁶ Q 273.

¹⁵⁷ Ev 233.

¹⁵⁸ Ev 105.

¹⁵⁹ *About Dignity in Care*, Department of Health website, 29 June 2007.

the reality is that it is addressing the poor experiences of a substantial number of older people and this should be recognised.”¹⁶⁰

75. The increasing use of the word “dignity” in the context of social care has led people to think more about what dignity means. In an issue of the British Geriatrics Society’s newsletter from last year the editor asked “what is dignity anyway? In an ideal world, it should be a matter of common sense and old-fashioned good manners.”¹⁶¹

76. Dignity of course is one of the fundamental principles underlying the ECHR and the concept itself has been the subject of judicial consideration both in our domestic courts and the European Court of Human Rights at Strasbourg (see the outline in the Annex). The question that is being asked is, why do we need the HRA to protect people’s dignity when service providers should see it as part of their existing duty of care? Gary FitzGerald of Action on Elder Abuse told us that “one of the arguments you would hear from the care providers services—and I have heard this—is, ‘Why introduce another layer of terminology of human rights when actually you are asking me to do what I am already being asked to do under the Care Standards Act?’”¹⁶²

77. The Care Standards Act 2000 provided the Department of Health with the power to issue national minimum standards governing the way in which care homes operate. We discuss these in more detail in Chapter 6. These standards do not, however, explicitly set out that residents of care homes have the legal right to be treated with respect for their dignity. Instead they set out the duties of care to which providers of care should adhere. **In our view there is a significant distinction, with implications for users of services, between a “duty to provide” under care standards legislation and a “right to receive” under human rights legislation. We believe that when health and social care workers carry out their function to the best of their ability this should be both because they see it as their job and responsibility to provide certain levels of care and because they understand that the patient has a need, reinforced by the law, to be treated with respect for their dignity.**

78. The Minister neatly elucidated this distinction when describing the effect of the HRA on “best practice” in the provision of health and social care services as follows:

Best practice means that we [...] reform public services [...] to give more power and control to those who are patients or users of services and their family members and carers than has been the case historically in terms of the relationship between professionals and organisations and those who use the services. Does that in reality in many cases require underpinning by legislation based on rights? My argument [...] would be yes [...].¹⁶³

79. An example of how this “power and control” provided by the HRA can be deployed was explored in oral evidence in a discussion between the Committee and the British Institute of Human Rights (BIHR). The BIHR were pointed by the Committee to evidence provided by another witness:

¹⁶⁰ Ev 222.

¹⁶¹ British Geriatrics Society, Newsletter, Issue 8, November 2006.

¹⁶² Q 236.

¹⁶³ Q 377.

We heard [...] about this lady who claimed there was a trail of urine [...] from her mother's bed to the lavatory, and she complained about that sort of behaviour. To me that is not abuse of the Human Rights Act, that should never have happened under any circumstances whether we have the Human Rights Act or not.¹⁶⁴

80. Replying, Katie Ghose of the BIHR said:

The point is we can now use the Human Rights Act to do something about that. I can give you countless examples [...] in reports we have published, where people have directly used the fact that we do have our own domestic law which for the first time gives us positive entitlement to be protected from inhumane and degrading treatment which can be used in a very practical way. You should see what happens when the argument is put and [...] an individual [can] hold an institution by the scruff of its neck and say, "This isn't acceptable".¹⁶⁵

81. When asked whether bringing the HRA into the discussion simply complicated matters and instead it was actually a question of "getting a grip of the care home or the system which is allowing these things to happen",¹⁶⁶ Ms Ghose answered as follows:

I suppose the question there is how do you get a grip on a system? Human rights is not the only answer, I am sure there are lots of answers to these horrible things which happen to people but it is an answer, an approach, and the research which has been done has come back from people saying, whether it be a family member or a nurse on a ward, "We find this stuff useful. This is how we have used it in a practical way. We would like our organisation to do more of it". People are telling us they are finding the human rights ideas, language and practical tools useful and I think we should listen to that, do some more research and find out how it can be put to good use.¹⁶⁷

82. The HRA therefore empowers users of public services who are often in vulnerable circumstances and who would otherwise be powerless in the face of inherently unresponsive systems.

83. We believe that many people, particularly older people in hospitals and care homes, do not want to feel that they have to demand treatment that they should be able to take for granted. One of the Act's purposes is to grant a power to service users to hold public authorities accountable to respect Convention rights. We recognise that there are people who, together with their families and advocates, can make good use of this power. The publication by the BIHR *Changing Lives* gives many examples where ordinary people have done just that and, in particular, without having to go to court to claim their rights. But there are also a large number of people who do not want to have to claim their human rights. Mr FitzGerald of Action on Elder Abuse put it starkly:

The argument we have at the moment in human rights very much reminds me of the argument ten years ago in the community about who provides a bath to an old

¹⁶⁴ Q 275.

¹⁶⁵ *Ibid.*

¹⁶⁶ Q 276.

¹⁶⁷ *Ibid.*

person, is it a social bath or a health bath? I remember one old woman of 80 saying, “Frankly, folks, I do not give a damn what it is, I just want my bath [...] I don’t care what you call it and what label you give it, I just want to be treated right. I want sympathy and understanding and care that matters and makes me feel human. I do not mind whether it is called ‘human rights’ or ‘dignity in care’.”¹⁶⁸

84. There are also of course, as the Alzheimer’s Society pointed out, many people who are not in a position to be able to assert their rights themselves. This is where the other side of the equation (the “push” side) comes in. A fundamental purpose of the HRA is to provide a legal framework for public authorities to use when they are providing public services. By adopting this framework and the accompanying human rights approach to decision-making and delivery of services, the services themselves should be improved for everyone. The essential point is that, under the positive obligations doctrine (explained in the Annex), the HRA requires public bodies to act preventatively to ensure that the right systems are in place rather than, as is the case under common law, seeking to take action after things have gone wrong. The Act therefore provides a framework to encourage high standards of healthcare practice but, because it has the force of law, it also acts as a backstop in helping to make sure that a positive approach to respecting human rights becomes the norm.

85. Best practice and the rights of patients are two sides of the same coin under the HRA, but they are different sides. Best practice is achieved through effective leadership, institutional change and proper training of staff, but rights underpin best practice and allow patients to say, “It is my right to be treated this way”. Many witnesses to our inquiry who are responsible for service provision well understood the role of human rights in healthcare. In the opening remarks of their written submission, the NHS Confederation state “we believe there is an historical bias against vulnerable people in the health service which must be addressed and the Human Rights Act is a valuable framework through which to embed a new culture.”¹⁶⁹

86. The impact of the HRA on the provision of health services was described succinctly by the Royal College of Nursing “[...] human rights [...] can be used as a lever to ensure that older people get the services they need and in that respect I think it is very helpful.”¹⁷⁰ In our view, the areas of healthcare where human rights principles are engaged and which therefore present challenges are reasonably clear. The Royal College of Nursing summarised them as “[...] access to services and the political prioritisation of such services; the general culture surrounding respect and value of older people and the need to ensure adequate provision of quality, person centred care.”¹⁷¹

87. The HRA provides an impetus for finding solutions to these issues within a legal framework. The NHS Confederation expressed more fundamental concerns about the purpose of the NHS in their evidence to us:

¹⁶⁸ Q 233.

¹⁶⁹ Ev 230.

¹⁷⁰ Q 285.

¹⁷¹ Ev 187.

I think that the NHS has a massive problem [...] the biggest issue [...] is the whole culture and attitude of what we believe the NHS is there for. [...] We spend our time talking about things in terms of “cure” – elective surgery, where you take an illness, you cut something out, everybody is happy about it and we all go on – yet 80% of our care is spent on people with multi-system chronic disease. We really have our priorities back-to-front, it seems to me, in terms of thinking about what the NHS is there for. We have reached the stage where we value care far less than we value cure.¹⁷²

88. In our view, the principles underlying the HRA make a valuable contribution to boosting the caring side of health services. Similarly, the fact that there now exists a legal framework underpinning the need to treat people with respect for their dignity should lessen the confusion that can surround the provision of services by overworked (and possibly under trained and underpaid) healthcare workers. The Alzheimer’s Society spoke of the difficulties that can occur:

What people are regularly reporting to us is that they do not see the leadership in hospitals explaining who it is who has responsibility for the welfare of patients. For example, who is it who has responsibility for making sure that someone is properly nourished and hydrated and [...] who is responsible for looking after the continence management. What we have seen [...] is that often nurses firstly do not have the time to be able to do this type of work well, but I think we are also seeing no clear understanding of whose job it is. Typically, what a carer will report to us is “I asked the nurse if she would be able to help my mother with eating her dinner” and she said, “Ah, no, that is really the job of a care assistant, find a care assistant”.¹⁷³

89. If the responsibility for looking after patients was regarded within hospitals not only as a welfare issue but also as a human rights issue, placing the interests of the patient at the centre and requiring clear lines of management and accountability, we believe that these sorts of problems could be reduced.

90. The question whether there is sufficient funding of healthcare is outside our remit but clearly relates to this inquiry. Action on Elder Abuse suggested to us that:

[...] the primary debates in both the health and social care sector have ignored the Human Rights Act and have instead been focussed upon costs, rather than quality of care provision. We are addressing a “mass production” approach toward older people, rather than a “quality approach”.¹⁷⁴

91. The Royal College of Physicians of Edinburgh, however, observed that “looking after older people well is a lot cheaper than looking after them badly.”¹⁷⁵ This observation is reflected in the Human Rights Act’s purpose of acting preventatively rather than curatively.

92. A culture of respect for human rights in society is crucial. The protection of and respect for human rights are the responsibility of all of us in society. People who work for public

¹⁷² Q 336.

¹⁷³ Q 214.

¹⁷⁴ Ev 220.

¹⁷⁵ Ev 153.

authorities, whether they work for the Government or a local hospital, also have a legal duty under the HRA to protect and respect the human rights of the people to whom public services are provided. Service providers should therefore use human rights principles as, to adopt the Royal College of Nursing's phrase, a "lever" to improve their services.

93. The Human Rights Act gives legal force to the concepts of dignity, respect, equality and fairness. It therefore has more teeth than any governmental initiative focusing on the need for dignity in care. The HRA's functions are to provide a legal framework for service providers to abide by and to empower service users to demand that they be treated with respect for their dignity.

94. We recommend that the Government, other public bodies and voluntary organisations should publicly champion an understanding of how the recognition of human rights principles can underpin a transformation of health and social care services. This should lead to a greater understanding of human rights in civil society and more effective implementation of the Act within public authorities.

95. We also recommend that the Commission for Equality and Human Rights in fulfilment of its duty to "promote understanding of the importance of human rights"¹⁷⁶ should ensure that such an understanding is widely disseminated.

96. We now go on to consider how the HRA has in fact been implemented within the Department of Health and other public bodies.

¹⁷⁶ Equality Act 2006, Section 9(1).

4 Department of Health's leadership

Department's responsibility

97. Although the Department of Health does not have governmental responsibility for the Human Rights Act, it is a public authority with legal responsibilities including positive obligations under the Act. In addition, as a government department, it shares in the collective responsibility of ensuring that legislation is implemented effectively. As our inquiry has revealed, the provision of healthcare to older people raises significant human rights issues for health and social care services and it is necessary for the Department of Health to take human rights seriously.

Political leadership

98. We were impressed by the clear commitment to human rights made by Ivan Lewis MP, the Minister for care services, when he gave oral evidence to us in June. When asked about the importance of human rights principles to the provision of health services, the Minister was unequivocal:

I think [human rights are] absolutely central to the message we are trying to send out in terms of a new approach to the way social care works with users, whether those users are older people or disabled people, and the way the NHS treats patients, with great emphasis on fairness, respect, equality, dignity and autonomy for all. With regard to the human rights legislation and the direction of travel in terms of reform or modernisation [...] of public services, I think there is a direct synergy between the two.¹⁷⁷

99. In her foreword to the Department's publication *Human Rights in Healthcare*, published in partnership with the BIHR in March of this year, Rosie Winterton MP, Minister with responsibility for equalities in the Department of Health, said:

Too often human rights are seen as an issue for other countries or a relic of the past century, and not something we need to be concerned with in health and social care. This is not the case. Quite simply we cannot help to improve people's health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an opportunity to make real improvements to people's lives. Human rights can provide a practical way of making the common sense principles that we have as a society a reality.¹⁷⁸

100. We welcome these clear ministerial statements about the importance of human rights to healthcare, but we note that they are very recent. We cannot resist observing that, for example, when Ivan Lewis MP launched the Department's Dignity in Care campaign in November 2006, he did not refer to "human rights" once in his speech. This may partly explain why so many witnesses told us that they were concerned about the lack of political leadership on human rights from the Department of Health.

¹⁷⁷ Q 374.

¹⁷⁸ Department of Health and BIHR, *Human Rights in Healthcare: A Framework for Local Action*, March 2007, p 3.

101. Age Concern referred to “the government’s lack of leadership in promoting a human rights culture” as one of the “structural weaknesses that contribute to human rights problems for older people in hospital and residential care settings.”¹⁷⁹ Help the Aged gave a clear description of the problem as they saw it:

I think there is a failure of leadership from the Department of Health and the managerial strands in local authorities and health bodies. It is very much about understanding that human rights is not just about background, but it contains a principle of positive obligations to ensure that you are securing rights for everyone within your field of practice and seeing it as being a proactive process rather than a reactive process. I think we are miles from that. It is a really important message for the Department of Health to start to promulgate.¹⁸⁰

102. Discussing what is needed for the programme of capacity-building on human rights with NHS trusts, the BIHR told the Committee “we need high level support, we need to see the Department of Health, ministers at the highest level, setting out the relevance of human rights to healthcare and healthcare to human rights, we really need those high level messages.”¹⁸¹

103. The call for political leadership did not come only from the NGO sector. The Royal College of Nursing said “I think there needs to be a real push in terms of leadership. We need strong political leadership [and] we need very strong policy leadership.”¹⁸²

104. The Healthcare Commission confirmed this too:

In order for the Act to become an effective tool for regulatory bodies such as the Healthcare Commission to use, we believe that the following will also need to be in place [...] Greater commitment from government to embed the principles contained in the Act in all aspects of public policy.¹⁸³

105. Challenged about this in oral evidence, the Minister said:

I think the leadership that is being provided in the department is absolutely brilliant. For the department to have produced [the *Human Rights in Healthcare*] document and to have begun to have the debate with primary care trusts and strategic health authorities about the importance of human rights I think it is doing quite well.¹⁸⁴

106. In our view, the political leadership from Department of Health Ministers that has been shown in the last few months (at least since we announced our inquiry) is commendable. But the fact remains that it has come seven years after the Act came into force. The failure by the Department of Health to give a lead has meant that the Government’s job has, of necessity, had to be done by voluntary organisations, often with few staff, no power and scarce resources. Inevitably it has been an uphill struggle

¹⁷⁹ Ev 124, para 2.1.

¹⁸⁰ Q 81 [Ms Gould].

¹⁸¹ Q 253.

¹⁸² Q 283.

¹⁸³ Ev 147, para 3.3.

¹⁸⁴ Q 391.

to make an impact. The BIHR concluded their written evidence with the following remarks:

[...] from the highest societal level downwards, the odds are stacked against efforts to use human rights to improve healthcare for older people. The barriers [that BIHR identify] compound to form a pyramid of obstacles that renders isolated and exceptional those efforts by older people, staff and others to use human rights based approaches to improve the healthcare experience of older people. In other words, examples of human rights being used to improve healthcare practice remain the exception rather than the rule, since they are not supported by a broader societal commitment to human rights or an explicit emphasis on human rights in the healthcare system as a whole.¹⁸⁵

107. We urge the Department of Health to maintain the clear political leadership that it has recently shown on the importance of human rights in health and social care. We recommend that in any constitution or statement of purpose which the Department of Health might draw up next year to celebrate sixty years of the NHS, a statement about the importance of human rights to the provision of health services should be included.

108. We are pleased that the Minister agreed with us that the priority is:

[...] to get over the fact that the Human Rights Act is not just about terrorists and criminals; it is also about ordinary people's rights in the way that they are dealt with by public bodies, and unless we start to talk positively about the rights of people who are in this circumstance disadvantaged as against the huge bureaucracy of the healthcare system and start to empower people by talking more positively about it, then we are not going to achieve that.¹⁸⁶

109. In view of the attacks on the legislation and calls for its repeal or amendment (some of which have come from members of the Government) it is crucial that the Government speaks with one voice on the Human Rights Act. **We therefore urge the Government as a whole to maintain consistent and constructive support for the Human Rights Act and its importance in contributing to the improvement of our public services and the empowerment of people using them.**

Policy leadership

110. We are impressed by the fact that there are ministers and senior officials within the Department of Health who have recently come to understand the importance of human rights in healthcare. The references to human rights in the published policy documents which we have seen are good but we are concerned about whether human rights principles are actually having an impact on policy-making in practice.

111. For example, in the introduction to their further evidence to the Committee, the Department of Health make the following observation:

¹⁸⁵ Ev 173, para 13.

¹⁸⁶ Q 398.

Respect for human rights is central to a modern [...] health and social care system. Not just because it is a legal duty, but because no system can call itself humane that does not respect and promote the human rights of the people who use the service as well as the staff who provide them.¹⁸⁷

112. Following this promising opening, in the subsequent 20 pages of evidence, however, the Department only mention “human rights” again in two contexts: firstly a reference to the role of the Older People’s Champions Network in ensuring that “older people are treated with respect for their dignity and human rights”¹⁸⁸ and secondly in four paragraphs about the partnership with the BIHR and 5 NHS trusts (described below) under the heading “A Human Rights Based Approach.”¹⁸⁹

113. It may seem trivial to count the references but it illustrates the problem well. In a total of 97 paragraphs of written evidence to a select committee inquiry into the human rights of older people in healthcare, the Department of Health refer to “human rights” in only six of them (although the word “dignity” fares rather better, being referred to in 12 paragraphs). The implication is that when discussing the substantive policy in the area of older people’s human rights in healthcare, the Department has neither understood fully the Committee’s inquiry nor has a proper understanding of its responsibilities under the Human Rights Act. There still seems to be a failure to recognise that the need to accord older people respect for their dignity is now underpinned by statute and therefore the HRA should be actively taken into account in policy development. This is despite what Lord Falconer, then Lord Chancellor, has explained as the impact that the legislation has on policy-making:

[It enshrines] in British law, through a framework of fundamental rights, the notion that all human beings should be treated with respect, equality and fairness [...] The Human Rights Act ensures that we look to our own back yard. It means that every piece of legislation complies with human rights legislation and all public services take human rights into account in the way they operate. Not after the event, or in a way that is burdensome – but as part of good business-planning, as an integral part of policy-making.¹⁹⁰

114. **None of the evidence that the Department of Health has provided to us during this inquiry gives us confidence that the Human Rights Act is in fact “an integral part of policy-making” within the Department.** In our view, this can be achieved only by a department-wide strategy on implementation of the Act and, in particular, its role in underpinning the Department’s work on dignity. This omission was highlighted by Action on Elder Abuse, who pointed out:

Although [*“A New Ambition for Old Age”*] states Governmental ambition, “to ensure that older people and their families will have confidence that in all care settings, older people will be treated with respect for their dignity and their human rights”, it

¹⁸⁷ Ev 106, para 1.

¹⁸⁸ Ev 110, para 38.

¹⁸⁹ Ev 112, paras 62-65.

¹⁹⁰ Lord Falconer, Speech to Institute for Public Policy Research, 10 December 2004.

provides no strategic plan to achieve this, and instead focuses upon ‘dignity’ without making the link to human rights.¹⁹¹

115. When we asked the Minister whether the Department of Health has a strategy for implementing the HRA he told us about the interim reporting process to the *ad hoc* inter-departmental meetings chaired by the Lord Chancellor and the recent publication of *Human Rights in Healthcare*. The former activity clearly provides some impetus for action within the Department and the self-described purpose of the latter is to assist NHS trusts. We consider this document in more detail below. We are also aware that the Department has recently published a guide for NHS managers on equality and human rights which states that “equality and human rights is core business for the NHS”.¹⁹²

116. In our opinion, the Guide could provide a better explanation of the purpose and implications of the HRA and anecdotal evidence suggests that it has not reached all the people who need it.¹⁹³ We are also aware that the Department has included “respect for human rights” in the core standards which providers of healthcare must comply with,¹⁹⁴ and we consider this in Chapter 6.

117. The *Human Rights in Healthcare* publication is the product of a joint venture pilot scheme between the Department of Health, the BIHR and five NHS trusts. Its purpose is to provide practical guidance on how to embed a human rights approach in the provision of healthcare services. Launched by the Department’s equalities minister in March 2007, the publication states “neglecting people’s human rights is bad for their health. In contrast, the protection and promotion of their human rights is not only good for individuals’ health; it makes for better services for everyone.”¹⁹⁵

118. Most importantly, the publication goes beyond rhetoric. It gives detailed, comprehensive and practical guidance on how health providers should incorporate the HRA into planning and delivering services. It provides accessible information on the impact of the legislation and case studies from the five trusts participating in the pilot. In our view, it is one of the best pieces of practical guidance on the impact of the HRA on public services that we have seen. In the next Chapter, we highlight some case studies from this pilot. We believe that the framework document should be circulated widely and we were encouraged by the Minister’s comments on what the Department intends to do with it in oral evidence to us:

[...] we only published *Human Rights and Healthcare – A Framework for Local Action* in March, so essentially the challenge is to make sure that in every locality this document is being debated, discussed and implemented, not just at chief executive and middle management level but also in terms of engaging with front-line staff. I do not believe that that will happen overnight. It will happen over a period of time.¹⁹⁶

¹⁹¹ Ev 220.

¹⁹² Department of Health, *Equality and Human Rights in the NHS: A Guide for NHS Boards*, 2006, p 3.

¹⁹³ Visit to hospitals and care homes in North London.

¹⁹⁴ Department of Health, *Standards for Better Health*, 2004.

¹⁹⁵ *Human Rights in Healthcare*, *op cit*, p 4.

¹⁹⁶ Q 402.

119. We hope, however, that this commitment to make the guidance widely available has not been watered down by what the Minister said in his subsequent letter to us “[...] the Department will investigate options for dissemination of the outputs from this pilot.”¹⁹⁷

120. Our concern is that, although the policy developments on human rights referred to above, of which the BIHR initiative is the most significant, are all laudable, they are piecemeal and in danger of lacking impact because what is still missing is a department-wide strategy which can incorporate these actions within it. Without such a strategy endorsed at the highest departmental level, it is all too easy for good pieces of work to end up having little or no impact in practice. We cannot fathom what the Department means when it says it needs to “investigate options for dissemination of the outputs” – why can it not confirm, in plain English, as the Minister did, admirably in oral evidence, that it will make sure the framework document reaches the largest number of people providing healthcare services?

121. There are other ways of making sure that human rights are embedded in health services. One of the people quoted by the NHS Confederation in their supplementary evidence made a suggestion to which we think the Department should give full consideration:

[...] if the Department of Health is serious about a rights based approach to healthcare there has to be more joined up thinking at a national level. For example, there is a requirement for all trusts to become Foundation Trusts but a human rights based approach to health care is not a requirement to gain FT status.¹⁹⁸

122. We recommend that the Department of Health draw up and publish a strategy setting out how it intends to make the HRA integral to policy-making in health and social care across the whole department.

123. We also recommend that the Department of Health publish an evaluation of the pilot project undertaken by the BIHR and five NHS trusts on using a human rights approach in healthcare. Using its normal channels of communication, it should distribute copies of *Human Rights in Healthcare – A Framework for Local Action* to all NHS trusts.

124. The Department should then survey trusts within, say, a year to find out the extent to which trusts are incorporating a human rights approach in healthcare services. The Department of Health should also commit to providing sufficient funding to implement the emerging good practice more widely. This is likely to include capacity building for providers of health services as well as training of staff and provision of information to patients.

125. We now consider the evidence provided to us on the current state of implementation of the HRA among providers of healthcare services.

¹⁹⁷ Ev 121.

¹⁹⁸ Ev 233.

5 Implementation of the Human Rights Act by providers of services

126. In Chapter 2 we set out a catalogue of instances of poor treatment of older people in hospitals and care homes, all of which affect their human rights and some of which may constitute unlawful violations. What is remarkable in our view is that it is the providers of medical, nursing and residential care services, who may be said to share collective responsibility for these problems, who are being so forthright in acknowledging them. We also believe that it is worth commenting that all of the witnesses who gave evidence to our inquiry took it as a given that the HRA and a human rights approach have a significant role to play in helping to prevent ill-treatment occurring and in improving the provision of healthcare services to older people. We do, however, accept that the witnesses were largely a self-selecting group and we bear in mind that not all healthcare providers share the witnesses' level of understanding about the Act. One of the issues explored in our inquiry has been the extent to which the HRA has in fact been implemented by public authorities providing health and residential care services.¹⁹⁹

127. In its survey of 175 public bodies to assess compliance with the HRA in 2003, the Audit Commission found that:

[...] 58 per cent of public bodies surveyed still have not adopted a strategy for human rights. In many local authorities the Act has not left the desks of the lawyers. In health, 73 per cent of trusts are not taking action. Health bodies consistently lag behind other public services. [...] we found that 44 per cent of public bodies have stalled. This was as high as 60 per cent in the health sector.²⁰⁰

128. The Minister told us that the Department of Health did not formally respond to this report because it was seen to be directed towards individual public bodies.²⁰¹ We have already commented on how important it is for the Department itself to show leadership. Without leadership, there may be pockets of activity but the overall picture will be one of inactivity. Shortly after the Audit Commission published its report, our predecessors reported in the following terms:

No evidence has been found to indicate that human rights are being treated as a core activity in health organisations [and] given the scale of the NHS change agenda and the many competing demands on the time of busy NHS executives, implementing the HRA carries a very low priority in most health organisations.²⁰²

129. Our inquiry has taken place four years after these assessments and, bar some notable exceptions to which we refer below, things do not appear to have changed very much. The BIHR told us “we have got quite low awareness about what human rights really are and

¹⁹⁹ We consider the position of private providers at the end of this chapter.

²⁰⁰ Audit Commission, *Human rights: improving service delivery*, 2003, paras 12 & 29.

²⁰¹ Ev 122.

²⁰² Appendices to the Sixth Report of Session 2002-03, *The Case for a Human Rights Commission*, HL Paper 67-III/HC 489-II Vol 2, paras 2.1 & 7.1.

that is something we see across inspectorates and across public authorities.”²⁰³ Age Concern did not “think we have seen a great change or a great understanding of what the Human Rights Act means and how it might be applied, apart from specifically looking at how to avoid falling foul of the law which has been the lens through which it has been viewed.”²⁰⁴

130. It appears that service providers are not opposed to the legislation; it is just that they do not know what the implications are. As Action on Elder Abuse put it in relation to residential care “[...] care providers are not inherently opposed to the Human Rights Act whether they are a public provider or not a public provider [...] there is a lack of understanding within the sector about what that means.”²⁰⁵

131. Comments made to us by most, but not all, of the providers of health and care services whom we met on our visit to hospitals and care homes in North London confirmed these assessments of lack of knowledge and application of the Human Rights Act. **We regret the failure of both the Department of Health and the Ministry of Justice to provide proper leadership and guidance to providers of health and residential care services on the implications of the Human Rights Act since it came into force.**

132. The challenges that this omission have presented are summarised by the BIHR:

- Low emphasis within Government on the abuse of older people’s human rights in healthcare is reflected in the healthcare sector itself.
- Low institutional commitment among healthcare providers to contributing to [a] culture [of respect for human rights] meaning that human rights are not reflected in institutional policies and procedures;
- Low awareness among healthcare staff of their duties to promote, protect and fulfil human rights;
- A perception among staff that it is too costly to promote human rights.²⁰⁶

133. Witnesses had no doubt about what needed to be done to address these deficiencies. The Royal College of Nursing told us “[...] we need senior members of the healthcare professions to demonstrate that human rights is a very important issue that must be adhered to and promoted.”²⁰⁷

134. A good example of senior members of the profession demonstrating the importance of human rights is the British Geriatrics Society’ campaign on privacy in toilet use. The Society launched its campaign entitled *Behind Closed Doors: Using the Toilet in Private* at Westminster in April 2007. It sets out what might be regarded as the obvious standards to be adhered to by all professionals caring for older people whether in hospitals or care homes. An accompanying leaflet, by way of listed examples, explicitly distinguishes

²⁰³ Q 263.

²⁰⁴ Q 80.

²⁰⁵ Q 237.

²⁰⁶ Ev 171-172, paras 8-10.

²⁰⁷ Q 283.

between “best practice which upholds human rights and promotes dignity” and “poor practice which violates human rights and denies dignity”. The leaflet also states that “all health care professionals and workers have a legal duty to protect patients’ Human Rights (Human Rights Act 1998).”²⁰⁸

135. This connection between the provision of healthcare and human rights needs to be made more frequently and more publicly. Leadership is one part of it. Institutional change also needs to occur. The Healthcare Commission said:

We believe that this question of the culture in a hospital is absolutely crucial and it does require leadership from the top of the organisation. It then also requires systematic back-up to ensure that there is training, information and the right emphasis on it and it requires, by the trust and by us, vigilance in relation to key outcomes.²⁰⁹

136. We are grateful to the NHS Confederation for carrying out interviews with individuals working at the NHS Trusts participating in the training and development pilot sponsored by the Department of Health and undertaken by the BIHR. In their evidence, the NHS Confederation told us what some of the NHS trusts involved in the project have been doing about incorporating a human rights approach and what the experience has been within their own organisations. These case studies illuminate both what is meant by a human rights approach and what is required to implement it. We quote from them quite extensively because we believe that they demonstrate these points so clearly.

Case study 1 - Mersey Care NHS Trust

The Trust was formed in 2001 and decided [...] that service users (patients) and carers [should] have the right to be involved in decisions which affect their lives. The upholding of human rights is now one of the 7 strategic objectives of the Trust and there is Board level leadership.

People have traditionally had things done to them rather than being actively involved. Now that service users and carers are involved [...], they say it makes a difference for them, they feel valued, they have interesting things to do, some have gone on to employment. Users and carers [...] also say that involvement makes a difference to staff attitudes, clinical practice, and the kinds of services provided.

Case study 2 - Surrey & Borders Partnership NHS Trust

When the Trust was established in 2005, a board level decision was made to embed human rights into the organisation. The success to date is largely down to the leadership and governance support and the accountability that brings. The Trust has produced a 5-year equality and human rights strategy for 2007-2012 [...] The plan links to the overall strategic direction and objectives of the Trust.

The Trust has made a deliberate attempt to move away from a singleton approach i.e. either looking at race or gender or sexuality one at a time. The human rights

²⁰⁸ British Geriatrics Society, *Behind Closed Doors: Using the Toilet in Private*, 2007.

²⁰⁹ Q 123.

approach is attractive as it is inclusive and covers everyone [...]

However there are barriers. This is new territory and can easily be perceived as being a piece of legislation to comply with – a tick-box exercise. For senior people it can be perceived as a soft area without hard core financial or business purpose so the communication of its benefits must be prioritised. There isn't any promotion across the NHS on human rights and healthcare and a strong national campaign would be a good starting point. The business benefits need to be articulated.

When asked if the human rights approach will make a difference for patients, [the interviewee] said that the starting point is what difference it will make to staff. It will make them better practitioners and drive what they are there to do – deliver better wellbeing, more respect and dignity [...] The impact is that the patient gets better more quickly; they will be less anxious, less tense and develop more trust in the staff. The risk of litigation is also reduced.

Case study 3 - Heart of Birmingham Teaching PCT

The prioritisation of human rights across commissioning and service delivery has been led from the top [...] with strong support from the Chair, Chief Executive and Directors.

The initial stages included the definition of a statement of human rights principles, an assessment of requirements for including human rights in service contracts and the definition of performance indicators to measure the progress and impact of the project.

However a number of issues were identified by the Trust such as low awareness of human rights amongst staff; a lack of human rights knowledge; the need to embed human rights within the working culture of the trust; the need to explicitly highlight human rights issues in areas where the necessary action is already taken; the need to look at patients as humans first and foremost and the degree to which patient consent is informed.

The biggest barrier [...] is probably telling staff yet again that there is a new approach – something else that they have to take into consideration. They hope to convince staff that this is a moral issue and get them onside through training and demonstrating the positive impact through evaluation from patients. Internal communications will be incredibly important in order to avoid the tick-in-the-box approach.²¹⁰

137. These three case studies provide encouraging examples of the difference that a human rights approach can make to organisational culture and quite evidently to the quality of service provision for users. We feel that these provide evidence of the kind of institutional respect for human rights for which we have been calling. The question is how to spread this good practice to other healthcare providers. Will it happen through the actions of the Department of Health and other health care leaders or does it need more support? As we discussed in the previous Chapter, we are concerned about activity that is piecemeal, may

²¹⁰ Ev 232-235.

be regarded as optional and so risks being shunted into the sidings because of other departmental or organisational priorities. **We recommend that the Department of Health and representatives of health and social care bodies provide guidance to hospitals and care homes on implementing a human rights approach in the planning and delivery of public services. Such guidance should emphasise that implementation should not be exclusively legalistic and should avoid being merely a tick-box exercise.**

138. Clearly, there is an important role here for the Commission for Equality and Human Rights.²¹¹ **We recommend that the Commission for Equality and Human Rights ensures that public authorities, particularly in health and social care services, are receiving the right kind of guidance to enable them to implement the Human Rights Act effectively.**

139. **We are concerned, however, by the implication from these case studies that embedding human rights is merely an exercise in best practice rather than a requirement underpinned by statute.** Do public bodies, including the Department of Health, fully appreciate the extent of their legal duties under the Human Rights Act?

Responsibilities of public authorities under the Human Rights Act

140. Section 6 of the HRA requires public authorities to act compatibly with Convention rights. Under Section 6, public authorities also have positive obligations which may require them to take positive steps to safeguard fundamental human rights.

141. In the seven years since the Act came into force, it appears to us that the Government has not properly understood this duty itself and so has not provided sufficient explanation about what it entails to others. The consequence of lack of information about what positive obligation means has been, inevitably, a lack of understanding or implementation of it within public authorities. The sense that the Act is only about minimal compliance has prevailed. We welcome, however, the fact that in recent months, the Government has started to address this deficiency. For example, in a speech earlier this year, Lord Falconer said “[...] the Human Rights Act places a positive obligation on public authorities to consider human rights implications when they are developing policy.”²¹²

142. **We remain unconvinced that public authorities are alert to the significance of ministerial language. The Government needs to do much more to explain in a clearer way what the positive obligation doctrine means.** We have received written evidence from 12 organisations which, for the purposes of the Human Rights Act, are either public authorities providing public services or are representatives of such public authorities.²¹³ In the submissions of only three of them, the Healthcare Commission, CSCI and the Association of Directors of Social Services (ADASS) (and therefore not the Department of Health), are the positive obligations of public bodies referred to. The Healthcare Commission quite correctly, in our view, states:

²¹¹ Under the Equality Act 2006, Section 9(1), the CEHR is required to “encourage good practice in relation to human rights” and section 13(1) grants the CEHR power to provide education and training and to give advice or guidance.

²¹² Lord Falconer, Harry Street lecture, 9 February 2007.

²¹³ British Geriatrics Society, Herefordshire Older People’s Champions Group, Faculty of Old Age Psychiatry of the Royal College of Psychiatrists, Department of Health, Healthcare Commission, Royal College of Physicians of Edinburgh, British Psychological Society, Commission for Social Care Inspection, Royal College of Nursing, National Institute for Health and Clinical Excellence, Association of Directors of Adult Social Services, NHS Confederation.

In line with other public authorities, the Healthcare Commission has a ‘positive obligation’ to respect and protect human rights. As argued in Age Concern’s Report *Rights for Real*, human rights embody a requirement that people be treated with fairness, respect, equality, and dignity and the concept of dignity is key to achieving meaningful equality for older people.²¹⁴

143. The ADASS also demonstrate an understanding of the obligation by their reference to “the duty on public agencies under the Human Rights Act (1998) to intervene proportionately to protect the rights of citizens”.²¹⁵

144. We conclude that Age Concern and Help the Aged are probably right in telling us that there is “limited understanding” about positive obligations and that therefore they are “poorly understood and rarely implemented”.²¹⁶

145. In our view, the doctrine of positive obligations under the HRA is fundamental to the implementation of a human rights approach within public authorities. This is clearly what the Government intended when the Act was passed. We agree with Age Concern’s analysis:

Given the potential of a human rights approach in helping to raise service standards, we believe that public bodies should welcome the opportunity of taking positive steps to safeguard older people’s human rights [...] We would argue that an understanding of positive obligations is central to the creation of a genuine human rights culture.²¹⁷

Positive duty to respect human rights

146. The Audit Commission’s conclusion in 2003 still seems to hold true today:

Despite developments, public bodies continue to struggle to make the connection between human rights, equalities and service improvement. In part, this is because the Act was introduced without any structured guidance and without a statutory duty to positively promote a human rights culture, as is the case for race and [...] disabilities.²¹⁸

147. In its Report on the structure, functions and powers of the Commission for Equality and Human Rights, our predecessors recommended a positive statutory duty on public authorities to promote human rights in the following terms:

We were clear in our report last year [2003] that there is a need for greater focus by public authorities on their positive obligations to protect human rights. We are now persuaded by the evidence that imposing a “positive” or “general” duty on public authorities to promote human rights will be an effective way of advancing this [...] Requiring public authorities to assess all of their functions and policies for relevance to human rights and equality, and in the light of that assessment to draw up a

²¹⁴ Ev 145, para 2.15.

²¹⁵ Ev 223.

²¹⁶ Ev 127, para 3.3; Ev 169, para 8.2.

²¹⁷ Ev 124 & 127, para 1.4 & 3.3.

²¹⁸ *Human rights: improving service delivery, op cit*, para 9.

strategy for placing human rights and equality at the heart of policy making, decision making and service delivery, would be an effective way of achieving the mainstreaming of human rights and equality.²¹⁹

148. In February this year, the Equalities Review issued its final report on the causes of persistent discrimination and inequality in British society recommending the following:

A strong, integrated public sector duty covering all equality groups, with a focus on outcomes and not process, should enable better policy design as well as better service delivery. Government and Parliament should seize the opportunity presented by the [Discrimination Law Review] to simplify and focus a new integrated duty on the outcomes it is intended to achieve [...]²²⁰

149. In June, the Department for Communities and Local Government published a consultation based on the work of the Discrimination Law Review.²²¹ The Green Paper sets out what the Government wants to achieve with a positive equality duty:

By helping public authorities to embed equality considerations throughout their activities, public sector equality duties support the design and delivery of personalised and responsive public services.

The duties are intended to help bring about a culture change so that promoting equality becomes part and parcel of public authorities core business.²²²

150. These ambitions remind us very much of what another department of Government, the Ministry of Justice and its predecessors, have consistently been saying that it wants to achieve with the Human Rights Act. In 2001, Lord Irvine, then Lord Chancellor, explained it in the following way to our predecessors:

What I mean and I am sure what others mean when they talk of a culture of respect for human rights is to create a society in which our public institutions are habitually, automatically responsive to human rights considerations in relation to every procedure they follow, in relation to every practice they follow, in relation to every decision they take, in relation to every piece of legislation they sponsor.²²³

151. We recognise that the concept of positive obligations is inherent in the ECHR and the Human Rights Act. We also recognise that there is inadequate awareness and implementation of those duties. **In our opinion, measures reinforcing the positive obligations doctrine under the ECHR would kick-start the institutional changes that are needed within public authorities. Unless an obligation encapsulating these positive requirements is provided for, we are not confident that public authorities will implement them.** It was the Minister who told us in relation to the HRA itself “[...] if you simply exhorted and talked of best practice without legislative underpinning then

²¹⁹ Eleventh Report of Session 2003-04, *Commission for Equality and Human Rights: Structure, Functions and Powers*, HL Paper 78/HC 536, para 32.

²²⁰ Equalities Review, *Fairness and Freedom: The Final Report of the Equalities Review*, February 2007, pp 113-114.

²²¹ Discrimination Law Review, *A Framework for Fairness*, *op cit*.

²²² *Ibid*, paras 5.2-5.3.

²²³ Lord Irvine, evidence to Joint Committee on Human Rights, Minutes of Evidence, 19 March 2001, Q 38.

inevitably public bodies would find ways not to completely implement their obligations, so an element of legislation is, I think, really important.”²²⁴

152. While recognising that there are problems of legal certainty, we recommend that the Government take the opportunity presented by its commitment to pass single equality legislation in this Parliament to make explicit that public authorities are under a positive duty to take active steps to protect and respect human rights where the Convention imposes a positive obligation to do so.

153. We recommend that the Commission for Equality and Human Rights makes sure that public authorities are fully aware of their positive obligations under human rights law and we anticipate that it will actively participate in debates about including “respect for human rights” in the proposed single equality duty.

The problem with private care homes

154. The implementation of the HRA which we have explored in this Chapter has been confined to “public authorities” as defined under Section 6 of the Act. These include private bodies when providing public functions but, as recent case law has clarified, do not include care homes which are run by private companies or voluntary organisations. In our recent Report on this subject, we expressed concern about “this gap in human rights protection for the most vulnerable people” and called on the Government to take action.²²⁵

155. Our current inquiry into the human rights of older people in hospitals and care homes has thrown into sharp relief the human rights problems experienced by older people in residential care and reinforced our concern about the lacuna in the law. We have found that the same kinds of ill-treatment of older people happen whether they are in hospitals, local authority care homes or private ones. We are left with the unacceptable anomaly of comparable and worrying problems affecting the same group of vulnerable people but under different legal regimes. A large number of older people are affected. In its evidence, CSCI told us that there are 10,671 residential care services providing approximately 358,000 places though not all of them will be occupied at the same time.²²⁶ CSCI also informed us that “in total 77.9% of homes for older people were in the independent sector, with 13% of homes in the voluntary sector” and that “one-third of [users] fund their own care”.²²⁷

156. We are also aware of findings that demonstrate that care in the private sector is not necessarily the best. The national minimum standards apply to all care homes, whether in the private, voluntary or public sector but, as research undertaken by CSCI reveals, compliance with these standards differs between these sectors. As CSCI report:

Care homes for older people run by the voluntary sector have continued to outperform homes in the for-profit and public sectors. On average, in March 2006,

²²⁴ Q 377.

²²⁵ Press Notice No. 24, 28 March 2007. See also Ninth Report of Session 2006-07, *The Meaning of Public Authority under the Human Rights Act*, HL Paper 7/HC 410.

²²⁶ Qs 144 & 145.

²²⁷ Ev 177.

homes in the voluntary sector met 85% of all the standards compared to 81% and 78% of the standards met by council and not-for-profit providers respectively.²²⁸

157. In CSCI's view, a change in the law to bring private and voluntary providers of residential care within the HRA would not kill the market.²²⁹ CSCI told us:

Personally, I do not believe that to be the case because the good providers will want to provide a service which delivers all the qualities that the Human Rights Act offers anyway, and it would be a very poor provider in the current climate that would want to do less than that when starting up their business. Personally, I do not think that would be borne out in practice and I think the best would want to do that.²³⁰

158. CSCI repeated their earlier stated view that all care homes should be subject to the Human Rights Act.²³¹

159. Since our most recent Report on the meaning of public authority and since the evidence sessions in this current inquiry were completed, the House of Lords has delivered its judgment in the case of *YL (by her litigation friend the Official Solicitor) v Birmingham City Council and others*.²³² By a majority of 3 to 2 their Lordships have confirmed that the provision of residential care by a private provider, even where paid for out of public funds, is a private law matter and therefore outside the scope of the Human Rights Act. This was, in our opinion, a very disappointing decision. We agree with the minority view, broadly for the reasons given in their speeches.²³³

160. We therefore welcome the commitment to take action made by Baroness Ashton, then Minister for human rights, in response to a parliamentary question answered on 27 June 2007:

The question is how to enshrine in care home operations the Human Rights Act in an appropriate manner to make sure that people in care are treated with respect and dignity [...] it is possible that we can do it by amendments to regulations very speedily. I am looking both at a short-term solution, which this may well provide, and at a longer-term solution, for which I am sure I shall have the benefit of the expertise of noble Lords on human rights as well as that of people involved with care homes directly.

This is about making sure that, where elderly people are cared for, they have the backdrop of the Human Rights Act to make sure that they are treated properly and certainly with respect.²³⁴

²²⁸ *State of Social Care in England 2005-2006, op cit*, paras 5.15 & 5.16.

²²⁹ Q 172. The Government has previously told us that including private providers within the meaning of "public authority" would have an effect on a range of markets (Thirty-Second Report of Session 2005-06, *The Human Rights Act: The DCA and Home Office Reviews*, HC 278/HL 1716, Q41 [Lord Chancellor]; Nineteenth Report of Session 2006-07, *Counter-Terrorism Policy and Human Rights: 28 days, intercept and post-charge questioning*, HL 157/HC 394, Q 251 [Attorney General]).

²³⁰ Q 172.

²³¹ Qs 168 & 170.

²³² [2007] 3 WLR 112.

²³³ Lord Bingham of Cornhill (paras 1-20) and Baroness Hale of Richmond (paras 36-75).

²³⁴ HL Deb, 27 June 2007, cols 598-599.

161. As we discuss in the next Chapter, the care home regulations are currently being reviewed and there is scope for including human rights requirements. Our present inquiry has highlighted the inequities for vulnerable residents of care homes where those care homes (and this is 93% of all care homes) are outside the Human Rights Act. **We urge the Government to fulfil the welcome commitments it has recently made in Parliament to take action to bring private and voluntary care homes within the scope of the Human Rights Act as soon as possible by regulation in the short-term and by amendment to primary legislation in the longer term. However, we note that, this will not resolve the broader problem of the provision of public services by private providers (as referred to in our recent Report).**

162. We now turn to consider the regulatory regime governing hospitals and care homes.

6 Health and social care inspectorates and NICE

163. The Commission for Healthcare Audit and Inspection (known as the Healthcare Commission) was established by the Health and Social Care (Community Health and Standards) Act 2003. It has the general function of encouraging improvement in the provision of health care by and for NHS bodies. The Commission is also the independent healthcare regulator for England and is responsible for assessing and reporting on the performance of NHS and independent healthcare organisations to ensure they are providing a high standard of care.

164. Established under the Care Standards Act 2000, what is now known as CSCI is the single inspectorate and regulator for social care in England. The Commission's primary function is to promote improvements in social care for the benefit of the people who use care services. It has a statutory duty to report on the performance of social care services, which it does annually.

165. Nearly 19,000 separate adult care homes (with 441,335 places) are regulated by CSCI (of which approximately 4,000 are nursing homes and 14,000 are care homes).²³⁵

166. The two commissions have a statutory duty to cooperate with each other and the other inspectorates. One example of this is *Living Well in Later Life*, the report of a joint review of progress on the National Service Framework for Older People by the Audit Commission, Healthcare Commission and CSCI, which was published in 2006. It found evidence of ageism across all services, from patronising and thoughtless treatment to the failure of some mainstream services to take seriously the needs and aspirations of older people. It noted that a failure to treat vulnerable older people with dignity is “an infringement of their human rights”.²³⁶

167. The intention to merge the two commissions (together with the Mental Health Act Commission) was announced in the Chancellor's Budget statement in 2005.²³⁷ In this section, we consider and compare the care standards under which they inspect service providers and their implementation of the HRA in the light of the forthcoming merger.

Health and social care standards

Healthcare standards

168. Standards for all healthcare organisations providing NHS services are set out in the *Standards for Better Health* published by the Department of Health.²³⁸ They are divided into “core” and “developmental” standards. Core standards need to be met at all times and

²³⁵ Ev 177.

²³⁶ Healthcare Commission, Commission for Social Care Inspection and the Audit Commission, *Living Well in Later Life*, 2006, p 7.

²³⁷ Chancellor of the Exchequer, Budget Statement, 16 March 2005.

²³⁸ Department of Health, *Standards for Better Health*, 2004, updated 2006.

healthcare organisations are expected to show progress towards meeting developmental standards. The Healthcare Commission is responsible for assessing performance against these standards.

169. Under their annual health check, NHS trusts must comply with 24 core standards. Some of these explicitly refer to human rights or human rights principles. For example healthcare organisations are required to:

- Challenge discrimination, promote equality and respect human rights (C7e).
- Have systems in place to ensure that staff treat patients, their relatives and carers with dignity and respect (C13a).
- Have systems in place to ensure that patients’ individual nutritional, personal, and clinical dietary requirements are met, including where necessary help with feeding and access to food 24 hours a day (C15b).
- Provide healthcare services in environments that promote effective care and optimise health outcomes by being supportive of patient privacy and confidentiality (C20b).²³⁹

170. The accompanying material makes reference to the need for NHS trusts to comply with equality legislation and the HRA in meeting these standards. The Healthcare Commission reports that of the trusts which declared (under the self-assessment procedure) that they did not have assurance that they were “promoting respect for human rights” (C7e), the two most commonly cited reasons were:

- Lack of information (at board level) to determine that human rights are respected across their services; and
- Lack of training for staff on equality, diversity and human rights.²⁴⁰

171. We do not find this ignorance surprising since neither the Department of Health nor the Healthcare Commission has issued guidance to NHS trusts on what promoting human rights means in practice. The senior managers at the NHS trusts to whom we spoke during our visit to hospitals in North London confirmed this. We note that in the original consultation on the standards, the Healthcare Commission did include guidance on what these standards required but it was omitted when the standards were finally agreed.²⁴¹

172. The Healthcare Commission conceded to us that what was needed was to get the “legislation to live”²⁴² and wisely observed that “the more the board can understand the implication of a piece of legislation absolutely on the front line, the more likely that piece of legislation is to be taken seriously by the board and therefore systems will be put in place.”²⁴³

²³⁹ *Ibid.*

²⁴⁰ Ev 150.

²⁴¹ Reported in Butler, F., *Improving Public Services: Using a Human Rights Approach*, IPPR, 2005.

²⁴² Q 101.

²⁴³ Q 102.

173. Although the requirements in the healthcare standards to “respect human rights” and treat patients with “dignity and respect” are welcome, they lack specificity and we recommend that the Healthcare Commission provides guidance to NHS trusts on what is required of them to meet these standards in practice.

National Minimum Standards for Care Homes for Older People

174. The National Minimum Standards for care homes for older people were set by the Department of Health in 2002 (two years before the equivalent standards for health).²⁴⁴ There are a total of 38 standards covering choice of home, health and personal care, daily life and social activities, complaints and protection, environment, staffing and management and administration.

175. Unlike the core standards for health, the standards for care homes do not explicitly mention “human rights”, although they do require that services be provided in accordance with the human rights values of dignity and respect. For example, the introduction to the National Minimum Standards states “the principles on which the home’s philosophy of care is based must be ones which ensure that are residents are treated with respect, that their dignity is preserved at all times, and that their right to privacy is always observed.”²⁴⁵

176. The outcome set for Standard 10 is that “service users feel that they are treated with respect and their right to privacy is upheld”.²⁴⁶

177. As we have observed elsewhere, it is not sufficient just to refer to dignity and respect. What these principles mean, and the fact that they are now underpinned by legal requirements set out in a UK statute, needs to be made clear too. We hope that the revised standards will do that. CSCI told the Committee:

The national minimum standards for care homes are currently under review [...] the drafts that we have seen are much more explicit in each standard about human rights specifically, and we have seconded somebody into the Department of Health to help with the review of those standards.²⁴⁷

178. In order to avoid the unfortunate impression that the human rights of people in care homes are less important and less enforceable than the human rights of patients in hospitals, we recommend that, following the current review, the human rights of residents be more explicitly spelt out in the care home standards.

179. Because of the court decision which we noted in the previous Chapter that private care homes are not public authorities under the Human Rights Act, we recommend, as an interim measure before legislation is passed, that the care standards regulations be amended to require, as the health standards do, that care homes respect residents’ human rights in accordance with the Human Rights Act.

²⁴⁴ Department of Health, *Care Homes for Older People – National Minimum Standards*, 2002, 3rd edition 2003.

²⁴⁵ *Ibid*, p 6.

²⁴⁶ *Ibid*, p 11.

²⁴⁷ Q 159.

180. We also recommend that when the health and social care inspectorates are merged, that the standards applicable to quality of care and other issues engaging the human rights of users of services should be the same for both NHS trusts and care homes. The unified standards should expressly require compliance with human rights standards by hospitals and care homes and state that patients and care home residents have the legal right to respect for and protection of their human rights. The newly established inspectorate should provide guidance to providers of services on the implications of such requirements.

Using a human rights framework

181. The Healthcare Commission and CSCI are influential in providing leadership, guidance and scrutiny of the public services under their jurisdiction. It is not only the health and care standards that are important, but also what the commissions say and do. In our opinion, they play an important role in the implementation of the Human Rights Act. Some NGOs were critical of the low priority given to human rights by the inspectorates in their work. The BIHR commented that “low visible commitment to human rights amongst healthcare providers in both the public and voluntary sectors is compounded by low emphasis placed on human rights by the inspectorates tasked with improving health and social care practice.”²⁴⁸

182. In their evidence, the Healthcare Commission ambitiously stated:

The Healthcare Commission believes that the Act has the potential to become a cohesive framework for improving the care older people – and other vulnerable groups – receive in hospitals and other settings and that the adoption of a human rights based approach would drive significant improvements in care and in the relationship older people have with service providers.²⁴⁹

183. We agree with this sentiment but are disappointed to learn that:

The Healthcare Commission would not claim that, at present, the Human Rights Act is explicitly used as the principal frame of reference for its regulatory work with healthcare organisations. It is one of a large number of sets of regulations and national standards which the Commission is expected to take account of in its work.²⁵⁰

184. In our opinion, the Healthcare Commission should not view the Human Rights Act as “one of a large number of sets of regulations” to which it is subject. Instead it should regard the framework created by the Act as over-arching and fundamental to all its work. We recommend that the Healthcare Commission ensures that the HRA is explicitly used in its regulatory work. We also recommend that the forthcoming merged inspectorate for health, social care and mental health adopt a human rights framework for all its work.

185. Similarly, we very much welcome what CSCI said about the organisation’s approach:

²⁴⁸ Ev 171, para 8.

²⁴⁹ Ev 146, para 3.2.

²⁵⁰ Ev 146, para 3.

The human rights legislation [...] underpins a great deal of the values which we certainly hold and the people who we inspect on behalf of hold as well. From an inspectorate's point of view, it means that we are able to raise the profile of the issues which are in the articles of the legislation [...] this adds extra impetus and extra weight [...] We think that [it] empowers service users [...] gives them effective feedback, and to have it in a human rights context is even more powerful."²⁵¹

186. CSCI has, however, missed opportunities to reinforce these important points. The recently published annual report on the state of social care makes only one reference to human rights in the whole report (in relation to the human rights of carers).²⁵²

187. In their submission, CSCI said, "we have [...] adopted a human rights approach to our work."²⁵³ The Residents & Relatives Association, however, were of the view that "inspectors have not, it appears, been trained in adopting this [human rights] approach."²⁵⁴

188. Gaps in implementation of a human rights approach throughout both organisations' work remain, although we believe both bodies are genuinely committed to such an approach. In our view, lessons can be learned from the more systematic approach pioneered by the Mental Health Act Commission (MHAC). We are aware of the recent publication on implementing human rights by the MHAC in partnership with the Department of Health and what was then the Department for Constitutional Affairs. MHAC state that their purpose was to "[...] incorporate a human rights framework fully in the work of the MHAC, so that it becomes a recognised part of regular activity across the organisation."²⁵⁵

189. The MHAC publication contains accessible and practical information on the steps that it took to complete the project and it identifies what people working within the commission learned from it. We are encouraged by the fact that the MHAC is to be merged with the Healthcare Commission and CSCI and urge that the highest common denominator should prevail. **We recommend that the forthcoming merged inspectorate for health, social care and mental health adopts a human rights framework with the intention that the framework informs all of the inspectorate's work and so makes it more effective in fulfilling its statutory duties.**

190. We are impressed by the Audit Commission's 2003 report on compliance with the HRA across a range of public bodies including the health services. In our opinion, there would be value in a similar exercise being undertaken again. **We recommend that the newly established health and social care inspectorate surveys providers of health and social care services and reports on their levels of understanding of and compliance with the Human Rights Act within three years of the new commission starting operations.**

²⁵¹ Q 164.

²⁵² *State of Social Care 2005-06, op cit.*

²⁵³ Ev 176.

²⁵⁴ Ev 193, para 5.

²⁵⁵ Mental Health Act Commission, *Making it Real: A Human Rights Case Study*, 2007. Leaflet on *Making it Real*, p 2.

National Institute for Health and Clinical Excellence (NICE)

191. NICE is responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. It produces guidance in three areas of health, one of which is clinical practice, described as the appropriate treatment and care of people with specific diseases and conditions within the NHS.

192. In their evidence, NICE note that they have taken advice from their lawyers, and that their procedures are human rights compliant, paying particular attention to equalities. They also state that human rights allegations (through NICE's appeals process) are "not common" and "it is less common still for the appeal panel to agree that the [human rights allegations] should be upheld, but the mechanism is in place to detect and respond to any infringement of the HRA".²⁵⁶ Although these statements may be accurate, they do not, in our view, reflect a complete understanding of the responsibilities of a public authority under the Human Rights Act.

193. **In particular, we are not convinced that NICE are fully taking human rights into account in their decision-making.** For example, the *Social Value Judgements Guidelines*,²⁵⁷ which describe how NICE incorporates social value judgements into the development of its guidance and the principles that should be applied when developing individual items of guidance, make no mention of human rights. Age Concern told the Committee:

There is not any evidence that NICE takes human rights into consideration at all in the work we have seen [...] and the directions that set NICE's work, and also in the frameworks that they have developed. There does not seem to be any recognition there that human rights are part of their responsibility or any demonstration of how they might have been applied in their work. Certainly, when they did their work about social value judgements [...] that would have been an ideal place in which to raise the issue of human rights and how they might be used and developed in NICE's work, but it was completely absent from that work.²⁵⁸

194. In their consultation on draft guidance on dementia, NICE refers to the ECHR and some of the related Articles in general terms, for example "Article 2 asserts that everyone has the right to life".²⁵⁹ There is, however, no reference to NICE's responsibility to consider these rights as part of their duty as a public authority under the Human Rights Act.

Discrimination on grounds of age

195. The National Service Framework for Older People requires that "NHS services will be provided, regardless of age, on the basis of clinical need alone."²⁶⁰ Although this requirement governs the provision of all NHS services, NICE's function is to make what are usually difficult decisions about the availability of treatment in a context of competing needs and finite resources. Quality Adjusted Life Years (QALYs) were developed by health

²⁵⁶ Ev 205, para 2.4.

²⁵⁷ NICE, *Social Value Judgements: Principles for the Development of NICE Guidance*, December 2005.

²⁵⁸ Q 48 [Mr Hurst].

²⁵⁹ NICE, *Supporting People with Dementia and their Carers*, Consultation, May 2006.

²⁶⁰ Department of Health, 2001.

economists to measure preference for treatment and for the last eight years have informed NICE decisions. They include two basic components: quality and quantity of life. Several witnesses²⁶¹ were concerned that the use of this measurement was inherently disadvantageous and discriminatory for older people. For example, Philip Hurst of Age Concern told us that QALYs:

[...] appear to us to be age discriminatory in the sense that by definition older people will have fewer years to live and therefore the cost of each life year is inevitably higher. In the way that NICE works, that would work against older people.

Chairman: Can that be justified in any circumstances?

Mr Hurst: If you do use QALYs at all, you have to use a range of other measures to balance out against those but QALYs seemed to rule in terms of the NICE decision-making.²⁶²

196. NICE, however, in their evidence state that “[...] in practice, we have found that estimates of the cost per QALY can be advantageous to older people [...] Older people would only be potentially disadvantaged by QALYs in the event of a hugely expensive, curative procedure whose benefits were lifelong.”²⁶³ During oral evidence, the chief executive of NICE told us quite categorically “I have no experience of QALYs acting in a way that disadvantages older people.”²⁶⁴

197. The controversy about the effect of the use of QALYs has now reached the court room. During 2006 NICE made a decision that drugs for use by people with Alzheimer’s disease were not cost-effective for those in the ‘mild’ stages of the disease, changing its previously published guidance. This decision has been judicially reviewed on the application of the drug company Eisai, the licence holder of donezepil, the drug affected by this decision. Their application is backed by Pfizer, who manufacture the drug, and the Alzheimer’s Society. The case falls within both Houses’ *sub judice* resolutions and therefore the merits of it cannot be explored by this Committee.

198. Regardless of the court case, we would be reluctant in any event to comment on whether the use of QALYs does or does not adversely discriminate against older people and whether in the latter case such discrimination can be objectively justified. This is because it is a complex issue and we did not take sufficient evidence on the subject. In any event, each case needs to be looked at on its own merits. The point that we think needs to be made, however, is that NICE, as a public authority under the Human Rights Act, needs to refer explicitly to relevant Articles of the ECHR such as Article 2 (right to life) and Article 14 (freedom from discrimination) in the context of its decision-making and its legal duties. **We recommend that the National Institute for Health and Clinical Excellence demonstrates in all relevant publications that, in its decisions on clinical practice, it has expressly taken into account the Convention rights of any patients who may be affected, as required by the Human Rights Act.**

²⁶¹ Royal College of Physicians in Edinburgh; Royal College of Nursing; Help the Aged; Age Concern.

²⁶² Qs 51 and 52.

²⁶³ Ev 207-8, paras 4.7- 4.8.

²⁶⁴ Q 184.

199. We consider, in the next Chapter, the extent to which staff have a role to play in ensuring the promotion and protection of the human rights of older people in their care.

7 The role of staff in protecting human rights

200. As we have already identified, leaders in healthcare (in the Department of Health and the inspectorates, as well as in service providers) have an influential and important role to play in ensuring that the human rights of older people in healthcare are protected and respected. Without their leadership, the change that we advocate for creating a culture of respect for the human rights of older people will not be achieved. However, the role of staff in achieving this change should not be underestimated. They are the people with whom older patients and residents interact every day and upon whom they rely for their basic care, provided with compassion and skill. They are also the only people who can really bring about this change in culture on the ground, in hospital wards and care homes up and down the country.

201. In this Chapter, we are concerned with clinical and non-clinical staff, as both have a vital role to play in shaping the culture of their working environment and the experiences of older people. Healthcare for older people is sometimes referred to as the “Cinderella” of medicine. When asked about the main practical, management and resource considerations facing those working in healthcare settings, when seeking to protect the human rights of older persons in their care, the British Geriatrics Society forcefully replied:

- The failure to recognise the increasing complexity, frailty and dependency of older persons in the hospital and care home settings over the last five to 10 years.
- The failure to provide staff with appropriate skills and in sufficient numbers to meet these changes.²⁶⁵

202. Often people caring for older people have low status²⁶⁶ and, particularly in the care sector, are poorly paid. However, whilst witnesses accepted that there were on occasions links between under-resourcing, staffing levels and poor treatment (such as when one care assistant had to choose between helping someone to the toilet, or helping another person to eat), they did not agree that low pay necessarily led to poor performance or abuse. As one witness said “where I would be very wary is to say that abuse is related to somebody’s pay or wage, because it is not. We see people very, very poorly paid providing very, very high quality care.”²⁶⁷

203. Some witnesses referred to the poor morale and high stress levels of staff within the sector.²⁶⁸ Given the many and competing demands on healthcare staff, if cultural change is to be achieved, it is vitally important not only that staff understand what human rights principles mean and how they apply, but they also recognise and support the positive benefit they can bring to their working lives and to the lives of the patients and residents they serve. Appropriate and accessible training of staff therefore has a vital role to play. We

²⁶⁵ Ev 94.

²⁶⁶ Ev 94.

²⁶⁷ Q 225.

²⁶⁸ Ev 87, para 4(a).

note that the new Prime Minister and the Secretary of State for Health have jointly announced a review of the NHS which will “undertake an unprecedented process of engagement and consultation with NHS staff”²⁶⁹ and we hope that it will include a review of how a human rights approach can be embedded in the working practices of all NHS staff.

Training

Hospital staff

204. The NHS Knowledge and Skills Framework (KSF) is designed to identify the knowledge and skills that all staff working for the NHS²⁷⁰ need to apply in their post. It is intended to help guide their development and provide a fair and objective framework on which to base review and development for all staff.

205. One of the six “core dimensions” of this framework is “equality and diversity.” Staff are assessed as being at level 1 if they “act in ways that support equality and value diversity” and at level 4 if they “develop a culture that promotes equality and values diversity.” The term “human rights” is not mentioned in the framework document but the NHS Confederation states that “the current NHS Knowledge and Skills Framework is being further refined and developed and in the process will take human rights principles further into account”.²⁷¹ They recommend that “the right training needs to be provided for all employees to ensure the Act is part of the way the service thinks and works, rather than being viewed as an issue for the legal department.”²⁷²

Care home staff

206. Under the national minimum standards for care homes for older people at least half of the staff providing care services must have qualifications at NVQ level 2 or equivalent.²⁷³ In addition, care home management must ensure that there is a staff training and development programme which meets what is now the Sector Skills Development Agency workforce training targets.²⁷⁴ In their evidence, ADASS state in general terms “there are many good examples of training programmes to address the key areas of dignity. Some examples are generic through ongoing NVQ training; others are specific which focus upon dignity and equality.”²⁷⁵

Human rights training

207. In its 2003 report on human rights in public services, the Audit Commission recommended that human rights training should be provided for all frontline staff

²⁶⁹ Department of Health press release, 4 July 2007.

²⁷⁰ Except doctors, dentists and some senior managers who are subject to separate review arrangements.

²⁷¹ Ev 232.

²⁷² Ev 230.

²⁷³ Department of Health, National Minimum Standard 28.

²⁷⁴ Department of Health, National Minimum Standard 30.

²⁷⁵ Ev 227.

involved in the delivery of services to the public (such as social care, health, education, housing and asylum) and that it should be ongoing and integrated with existing training programmes.²⁷⁶

208. Four years on and the verdict from a range of witnesses is that this kind of training has not yet happened or, if it has happened, staff do not know how to apply it in practice. The joint publication of the Healthcare Commission and others, *Living Well in Later Life*, spoke of there being “little evidence of staff [in acute wards] receiving training to help them challenge ageist attitudes”.²⁷⁷ As one medical witness said “training and knowledge of human rights [by those working in healthcare settings] is poor”.²⁷⁸ This resonated with our experiences at most of the hospitals and care homes that we visited in North London. None of the care home staff we met seemed to have received any human rights training. Some of the hospital staff we met had received training on the duty of care (described by one member of staff as “doing the best for the patient at all times”), whilst others appeared to have some understanding of how human rights related to their work. The Association of Directors of Adult Social Services provided us with examples of training programmes focussing on “dignity”.²⁷⁹ Whilst they are commendable, these programmes do not make an explicit connection with human rights requirements to protect dignity.

209. Further, human rights principles are not included in the criteria for professional training or in codes of practice for health professionals or social care workers such as:

- The General Medical Council’s guidance for Tomorrow’s Doctors;²⁸⁰
- The General Medical Council’s “Good Medical Practice”;²⁸¹
- The Nursing and Midwifery Council’s Code of Conduct;²⁸²
- The curriculum for trainees in geriatric medicine;²⁸³
- The NHS Knowledge and Skills Framework (which applies to all NHS staff except doctors);
- The General Social Care Council’s Code of Practice for Social Care Workers and Code of Practice for Employers of Social Care Workers (September 2002).

210. Where training has been provided, it has often been a one-off event which has not sufficiently focussed on improving staff understanding of how human rights principles

²⁷⁶ *Human Rights: Improving Public Service Delivery*, *op cit*, para 19.

²⁷⁷ *Living Well in Later Life*, *op cit*, p 26.

²⁷⁸ Ev 101.

²⁷⁹ Ev 228-229.

²⁸⁰ Q 305 [Professor Crome].

²⁸¹ Although it requires doctors to “show respect for human life” and “treat patients as individuals and respect their dignity”.

²⁸² The Code is currently under consultation. It states that registered nurses, midwives or specialist community public health nurses “are personally accountable for ensuring that you promote and protect the interests and dignity of patients and clients, irrespective of gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs”, p 5.

²⁸³ Q 305 [Professor Crome].

affect what they do on a daily basis.²⁸⁴ More than one witness spoke of the prevailing idea within healthcare that human rights was something to be confined to the legal department, or concerned simply with damage limitation to avoid the service provider facing a legal challenge.²⁸⁵ In our view, this focus only on the litigious aspects of human rights risks losing the real benefit that human rights can bring to improving healthcare across the board. Bemoaning the lack of training, Action on Elder Abuse suggested that “this contributes to a cultural approach that denies seeing an older person as an equal within society”.²⁸⁶

211. Witnesses told us that training needed to “target staff who have direct responsibility for the healthcare of older people”²⁸⁷ and be supported by managers, including those at the highest level.²⁸⁸

212. Ensuring that staff understand human rights principles has benefits at many levels. Firstly, explaining human rights principles and how they relate to the specific work that the staff member does, takes the question of human rights out of the “legal” or “defensive” box and moves it into the mainstream. Witnesses have told us that this resonates with healthcare staff performing many different roles. As BIHR told the Committee:

What we found was when we took a step back and said, “This is how human rights is relevant to you as a healthcare worker”, had a discussion with them, gave them some information and gave them some practical training, they then said, “Hang on, this is what we came to the health service to do. These are the things we care about.” And I think that is one of the reasons why we saw such a positive response from the trusts we worked with²⁸⁹.

213. Witnesses disagreed that human rights would be seen by staff as a chore. Instead, based on her experience as a human rights trainer, one witness observed “I find that rather than seeing human rights as yet another regulatory burden social workers on the ground are enormously excited once they start to see what it could mean. It very much resonates with the care professionals’ idea of what their job is all about.”²⁹⁰

214. Secondly, it provides staff with an opportunity to reflect on the care they provide and its impact from a broader perspective. As the British Geriatrics Society observed “staff taught about Human Rights were able to look at things differently and stopped thinking just about protecting themselves but about care from the resident’s as well as the families’ perspective.”²⁹¹

215. Thirdly, it provides a methodology to assist staff in making some of their difficult decisions. The BIHR, which provides training to a range of public sector workers, reports a

²⁸⁴ Q 282.

²⁸⁵ Ev 171-2.

²⁸⁶ Ev 221.

²⁸⁷ Ev 186, para 8.4.

²⁸⁸ Qs 258 & 259.

²⁸⁹ Q 252.

²⁹⁰ Q 81 [Ms Gould].

²⁹¹ Ev 94.

sea change in the approach of staff following their human rights training sessions “on countless occasions we have facilitated staff to come up with their own human rights based solutions to seemingly intractable problems.”²⁹²

216. In their publication *The Human Rights Act – Changing Lives*, the BIHR provide the practical example of a carer supervising a man with learning difficulties while he bathed. According to the BIHR, during one of their human rights training sessions, his carer commented “I knew in my heart he was being treated without dignity and now I recognise that his human rights are perhaps being violated”.²⁹³

217. It is right to note that human rights training is not a panacea. Staff do not just need training on human rights, but also require support more generally (for example training on dementia care) and a strong lead from their managers, supervisors and mentors on appropriate caring attitudes. The Royal College of Nursing told us:

One practical consideration is the need to ensure an appropriate degree of compassion and understanding with those who work with older people in all settings. A need for education and training opportunities is fairly obvious but there is also the need to develop and maintain appropriate attitudes and values when working with older people. Staff working in such environments will need to feel supported in their workplace, care standards can be improved by access to continuing professional development, provision of adequate resources and adequate training for staff about human rights.²⁹⁴

218. Organisations may be put off training staff if they do not see the benefit to their core business or if they fear that it will cost too much. However, as the BIHR pointed out:

Training does cost money but I think you have got to look at the costs of not training people in these matters [...] the Committee has heard from previous witnesses just what happens when people are not treated properly, the human cost of that, but also the cost to the organisation in terms of being sued and so on, so we probably need a cost benefit analysis. The early signs we have got are that it does not have to be particularly costly, particularly if you make human rights part of other training which is already going on in the organisation²⁹⁵.

219. The Minister accepted that the Audit Commission’s recommendation had not been effectively implemented, but noted that the Department was looking at how to mainstream “awareness of human rights legislation” as part of staff training.²⁹⁶ He told us:

We have to change the way we look at entry level training into some of these jobs, continual professional development, and that has to apply not just to highly skilled, highly paid clinical staff; it also has to apply to all members of staff, and therefore the logic of that statement is that, going forward, awareness of human rights legislation

²⁹² Ev 172, para 10.

²⁹³ British Institute of Human Rights, *The Human Rights Act—Changing Lives*, April 2007, p 7.

²⁹⁴ Ev 189.

²⁹⁵ Q 262.

²⁹⁶ Q 421.

and its implications should have a much greater priority in terms of the way staff are trained.²⁹⁷

220. The Minister told us that they were currently looking at “how we are going to embed human rights in the training and induction programmes for staff across health and social care”,²⁹⁸ to include clinical and non-clinical staff. We welcome this development. The Minister also stated that:

If you are trying to persuade frontline public service professionals of the virtues of human rights, you have to make a correlation between the legislation and what they should want to do in terms of improving the lives of the people they are there to serve. If you do not do that it will just be more guidance and it will be pretty meaningless in terms of transforming either health services or social care services.²⁹⁹

221. We can see real benefit for older people in healthcare, especially the most vulnerable, of greater awareness of human rights within the organisations that care for them. Human rights should certainly not remain in the legal department, but instead need to be understood and embedded in the culture of hospitals and care homes. This will only happen if staff throughout the organisation are part of that cultural change. We are pleased to hear the Minister’s recent assurance that human rights training of staff should be a priority for the future, and in particular that it will include both clinical and non-clinical staff. However, we are disappointed that, almost seven years after the HRA came into force, such a commitment should still be necessary.

222. In our view, human rights training should have been provided throughout hospitals and care homes and other public service organisations from 2000. We recommend that all staff working in healthcare (both clinical and non-clinical) receive targeted and regular training in human rights principles and positive duties and how they apply to their work. This could be incorporated into existing training programmes (such as ethics or equality and diversity) rather than operate as stand alone sessions.

223. We commend the Department of Health and the BIHR for their pilot³⁰⁰ on introducing human rights principles in healthcare and have made recommendations on its future development and expansion in Chapter 5. **We recommend that the Department of Health review, within three years, the extent to which training has taken place within healthcare and the effects of that training. We also recommend that the Department of Health produce guidance, building on its pilot with the BIHR, including case studies and examples as appropriate, of best practice in training different groups of healthcare staff on human rights principles as they apply to their day to day work.**

224. **We also recommend that the reports on individual healthcare providers by the newly merged health and social care inspectorate should include details of the human rights training that has been provided to staff. Further, we recommend that the Commission on Equality and Human Rights monitors the extent to which hospitals and care homes include human rights principles in their staff training.**

²⁹⁷ Q 422.

²⁹⁸ Q 399.

²⁹⁹ Q 429.

³⁰⁰ *Human Rights in Healthcare – A Framework for Local Action, op cit.*

Qualifications

225. Some witnesses, including the representative bodies of nurses and doctors working with older people, have also suggested to us that human rights principles should be included in qualifications, accreditation and re-licensing for health professionals.³⁰¹ The Royal College of Nursing saw a wider imperative:

I think there is clearly a need to ensure that all nurses are educated around the implications of human rights [...] The reason why I think we do need to work with the Human Rights Act and to use it as a lever is because we have decades of examples of challenges in terms of trying to get society in the UK to view aging in a positive way [...] the first thing is legitimising speaking out when things are not right. There is something relatively straightforward that could be done around nurse education, pre-registration and post-registration, in terms of an introduction to the essential aspects of human rights.³⁰²

226. Not only would a greater understanding of human rights help to overcome “ageist attitudes”, it would also provide healthcare workers with ammunition to persuade their managers of a need to change working practices or obtain more resources if they saw that they were unable to properly respect the rights of the older people in their care. **We recommend that a basic understanding of how the Human Rights Act requires the protection of basic principles such as dignity, fairness, respect and equality be included in qualifications, accreditation and re-licensing for health professionals.**

Reporting abuse

227. We accept that training only goes so far to improving the care and experience of older people in healthcare. Whilst the majority of people working in healthcare are dedicated professionals, striving to provide the best service to all those within the care, there will inevitably be those who cannot or do not meet acceptable standards of care. On our visit to Sweden, we were informed about Lex Maria and Lex Sarah, two laws which require all employees in residential care settings or hospitals to report suspected abuse.

228. We were told in evidence that, in the UK, doctors and nurses are already under a professional duty to report poor treatment.³⁰³ The issue is whether such a duty should be extended by legislation to everyone caring for older people in healthcare institutions. Several witnesses³⁰⁴ have supported the introduction of such a law. For example, the Alzheimer’s Society saw it as a way of raising the debate about abuse and neglect “if you introduce that type of obligation then necessarily you [...] expand people’s knowledge about what abuse is and not just [...] violent, aggressive forms of abuse which people might talk about but also the neglect, so that would be incredibly helpful.”³⁰⁵

³⁰¹ Q 291.

³⁰² Qs 294 & 304.

³⁰³ Q 358.

³⁰⁴ Action on Elder Abuse (Q 243), NHS Confederation (Q 358), ADASS (Qs 357 & 358), Royal College of Nursing (Q 299), and British Geriatrics Society (Q 300).

³⁰⁵ Q 243.

229. Witnesses noted the difficulties faced by whistle-blowers³⁰⁶ and suggested that staff, whilst protected by the Public Interest Disclosure Act 1998, needed to know that it was legitimate to speak out when things were not right.³⁰⁷ Further, some witnesses, such as Action on Elder Abuse, whilst supporting the proposal, offered a word of caution about how effective such a duty would be “the caution I would give [...] is mandatory reporting exists in America and the best estimate is one in five cases is actually reported and we need to be aware that there are limitations of that.”³⁰⁸

230. From the provider side, ADASS noted that staff had a moral obligation to report abuse and agreed that this duty should also form part of an employee’s contract of employment. However, a key issue for staff would be to see that effective action was taken at a management level when suspicions were brought to their attention:

From a social services’ perspective, our view is that there is a moral duty and it should be custom and practice that that is the case. The key thing, though, is that, if we are to ensure that it is a moral duty and it is custom and practice, that requires strong leadership and it requires people like ourselves sitting around this table and others to make sure that we can demonstrate that we take action against those perpetrators, particularly of abuse.³⁰⁹

231. The Minister was not sure whether a statutory duty was required, although he stated “I am not saying I would rule it out forever”.³¹⁰ He pointed to existing professional standards and registration, stating:

Every professional who works in health and, as we register the social care workforce, in social care will have professional standards that are non-negotiable, and part of those professional standards, as well as the guidance that will operate in any care setting in any part of the country, will be that if somebody is being abused you have a responsibility as part of your professional code of practice, as part of the policies that apply in your workplace to report that [...] we have recently gone through a process of registering social workers. We are moving on to domiciliary care staff and we are moving ultimately to people working in residential and nursing care settings, and as part of that registration they have to meet certain professional standards, including reporting abuse, so we are on a journey in that respect in terms of those who work in residential and nursing homes. I am not sure that the Chairman’s fears would be allayed as a consequence of having a law.³¹¹

232. Whilst we do not want to increase the burdens on healthcare staff, we are conscious that they have a vital role to play in ensuring that all patients and residents with whom they come into contact are treated with dignity and respect and are not subjected to abuse. They do this in two ways. Firstly, they are responsible for their own conduct and ensuring that they act in accordance with human rights principles and their

³⁰⁶ Q 300.

³⁰⁷ Q 304.

³⁰⁸ Q 243 [Mr FitzGerald].

³⁰⁹ Q 357.

³¹⁰ Q 385.

³¹¹ Qs 380 & 384.

positive duties. Secondly, they are the eyes and ears of the outside world. They will be the first to notice if someone is being ill-treated. Older people with mental health problems or who do not have visitors are especially vulnerable. **A duty to report suspected abuse is more than merely a moral duty and we consider that such a duty should be a requirement for all staff working in the NHS and in care homes. We therefore recommend that the Government include a requirement in both the Care Standards for Better Health and the National Minimum Standards for Care Homes for Older People (or, as we have already recommended, preferably in one set of integrated care standards) that hospitals and care homes should have a policy requiring all healthcare workers to report abuse or suspected abuse, with protection for whistle-blowing and confidentiality.**

233. We now go on to consider whether older people, their relatives, advocates or carers, have sufficient information to safeguard their rights and ensure that service providers meet their responsibilities, and the difficulties they encounter in raising concerns and complaints.

8 Empowering older people

234. Throughout the course of our inquiry we have been constantly reminded of the particularly vulnerable situation in which some older people in healthcare find themselves. Of course, it would be wrong to generalise and suggest that this was uniformly the case, in the same way as some of the ill-treatment that we have outlined is not a problem in every healthcare environment in the UK, or that all of the problems are limited to older people. However, it is true that some older people, including those without family or friends, with mental health problems or from black and minority ethnic communities are particularly vulnerable. If the human rights approach is to have any impact, then it needs to reach out first and foremost to those who are the most marginalised and excluded within our society. One of the issues of which witnesses frequently told us, was the difficulties that some older people have in accessing information about their rights and the barriers they face in raising concerns or complaints with the authorities who should be looking after them. We deal with these issues in this Chapter.

Barriers to voicing concerns

“Older people are often in a situation where they are trying to preserve an ongoing relationship with a care home or long stay hospital and it makes it very difficult for them to have the confidence to complain or assert their rights and they often feel very anxious about their position were they to do so.”³¹²

“There are a number of cases, far too many to just be the odd coincidence, where people face eviction from care homes because a relative has complained. There is one case I know of where a relative complained once simply that her mother’s bed was very rarely made and her mother faced eviction as a result of that. I have another case here where a caller’s mother had been asked to leave her residential care home because she complained about a member of staff who would not attend to her at night. She had wanted to go to the toilet, so she rang the buzzer, but the staff member did not come for half an hour by which time it was too late and the care worker left her in wet nightclothes, took the buzzer from her and threw it across the room.”³¹³

235. A fundamental issue for older people in healthcare is the relationship that they have with their care provider. A number of submissions³¹⁴ described the “power imbalance”³¹⁵ which exists between older people and those who care for them. This imbalance is one of the key factors contributing to the poor treatment of some older people in healthcare and one which leads, as many witnesses told us, to a reluctance by older people in healthcare to complain. Other factors include a lack of confidence in asserting their rights; a failure to identify themselves as people with (human) rights; a reluctance to “make a fuss” on their own behalf (not wishing to cause trouble, fear of recriminations); lack of security of tenure and fear of eviction; internalised ageism in the individual him or herself (i.e. lower

³¹² Q 11.

³¹³ Q 12.

³¹⁴ Ev 137, para 4; Ev 140; Ev 172, para 12; Ev 198, para 14; Ev 221.

³¹⁵ See paragraph 59 above.

expectations of what is fair) or lack of family support. The Department of Health agreed that fear of complaining was a problem:

There is the question of people feeling able to complain without retribution. We are constantly told by people, “I do not like to say anything because maybe they will hold it against me, and anyway the staff are wonderful”. It is a sense of feeling that if you can be secure and confident it is perfectly legitimate to register concerns without there being retribution or without suggesting that the whole system is flawed³¹⁶.

236. These barriers to raising concerns are present in both hospitals and care homes. The Healthcare Commission bears this out in relation to hospitals. It told us that “our inspections repeatedly highlighted reluctance by older people to complain due to fear that this would affect the treatment that they or their relatives received.”³¹⁷

237. As for care homes, it is no wonder that older people in some homes are scared to express concerns. We were shocked by the number of witnesses who told us of people who had faced eviction from care homes because they or their relative or carer had complained.³¹⁸ Care home residents, unlike ordinary tenants, do not have security of tenure. This is different from the situation of older people in residential care in Denmark and Sweden, where older people in residential care are accommodated in individual flats and have secure tenancies. As demonstrated by the examples at the beginning of this Chapter, sometimes the complaints can be about very minor things which should be very easily resolved at a local level. Sometimes residents or their relatives will be told that they can no longer be cared for in the home and that they must leave, often at short notice. Whilst this may be true for some people (e.g. where their nursing needs have become too complex for the home to handle), we got the impression that there are likely to be occasions where this excuse was used to get rid of residents who were regarded as too difficult or troublesome. Such residents are usually the most vulnerable and likely to be suffering from dementia or other mental illness which affects their behaviour.

238. During our visit to Sweden and Denmark, we were impressed that people in residential care could continue to be accommodated in the same care homes, and, as their needs increased, so did the care that was provided. This meant that people were not moved around when their needs became more complex and instead received continuity of care, in an environment and with staff with whom they were familiar.

239. The Minister accepted that people should be able to complain without retribution. Dealing with the issue of people being evicted because of making a complaint, he said:

The commissioning relationship between a local authority and a home or, indeed, a PCT and a home should make that kind of thing impossible because if I was doing business with a private provider who behaved like that I would stop doing business with them.³¹⁹

³¹⁶ Q 379.

³¹⁷ Ev 145, para 2.12.

³¹⁸ E.g. Residents and Relatives Association provide several examples of older people being given notices to quit their care homes after making complaints (Ev 194-196).

³¹⁹ Q 440.

240. However, whilst this might help residents who are in homes which receive some publicly funded residents, this is of no assistance to self funders. Nor would CSCI intervene (for reasons which we outline further below).

241. We were alarmed and concerned by how little protection care home residents appear to have against eviction, as compared to ordinary tenants in rented accommodation who have the protection of housing legislation, and suggest that rectifying this anomaly be considered as a matter of urgency.

242. In addition, people do not know how to raise their concerns, or doubt that any good will come of it. Help the Aged mentioned institutional and systemic barriers, including there being “no clear or accessible mechanism for raising issues of concern”³²⁰ including about violations of their Convention rights. They pointed out that care home residents have minimal contact with social workers and annual reviews “tend to be a cursory and bureaucratic exercise”.³²¹

243. In our view, in order to ensure greater protection of an individual’s human rights, an individual (or his or her relative or carer) must have a real and effective means of raising concerns with service providers and, if they are not able to deal satisfactorily with the issue, a third party to which he or she can address complaints. We deal with this in more detail below. Such mechanisms go to the very heart of ensuring that the human rights of patients and residents are respected in practice.

244. For people with mental health difficulties or language difficulties, the problem of raising concerns is even more acute.³²² As the Alzheimer’s Society said:

The challenge of promoting human rights for people with dementia is even more pronounced than for older people as a whole. As someone develops symptoms in dementia, their ability to communicate their wishes and challenge human rights violations falls [...] This makes people with dementia especially susceptible to abuse [...] Reporting of distress is far more likely to happen if the person with dementia has someone such as an articulate relative who can speak out for them and when the care providers encourage feedback.³²³

245. Partly to overcome this problem, the Alzheimer’s Society suggests the use of independent advocates and recommends “more emphasis on these types of support”.³²⁴ A number of witnesses supported the suggestion that greater use should be made of independent advocates to help older people to express themselves, raise concerns and stand up for their rights.³²⁵

246. In addition, witnesses suggested that whether or not people had mental health problems, some “older people may need additional support and advocacy to understand

³²⁰ Ev 164, para 3.7.

³²¹ Ev 164, para 3.7.

³²² Ev 125 & 129, paras 2.4 & 5.1.

³²³ Ev 213 & 215, paras. 10 & 32.

³²⁴ Ev 217, para 40.

³²⁵ Ev 125, para 2.6; Ev 135-136 para 2.3; Ev 182-183, paras. 3.6-3.7; Ev 188.

the options available to them and to overcome the power imbalance”.³²⁶ Recognising how opaque the healthcare system can be, providers also saw the wider benefits of advocates to older people:

It is incredibly important that people get the right information, but written and conveyed in such a way that it makes common sense, rather than the sort of language that a lot of us in the professions tend to talk; then giving people time to understand it, and to be given some assistance in thinking through some of the choices that might be available to people. Those choices might be limited but they are still choices that people ought to be helped to think through [...] In my authority we spend a significant amount of money on advocacy services, because we recognise that, when people need to make important and difficult choices, they should have independent help with that.³²⁷

And to staff “[...] who find older people having access to advocacy services [...] make a real difference to everybody concerned.”³²⁸

247. Some witnesses recommended that consideration should be given to the use of ethnic minority advocates “as a matter of general good practice”.³²⁹ In addition, witnesses recognised that, in order for advocates to successfully speak up to protect the rights of older people, the advocates themselves would need to be trained in human rights. However, as BIHR, who have trained advocates of older people, pointed out:

What [advocates] tell us is this stuff is not complicated but it gives them a language and confidence because what they start from is not the needs of the institution but the human being and the absolute right to be protected from inhumane treatment or the positive right to have a family life.³³⁰

248. We are pleased to note that the Minister accepted that advocacy had an important part to play saying “you also have to put in place advocacy and other support systems to make control, power and choice a reality.”³³¹

249. We conclude that older people, especially those who are the most vulnerable, would greatly benefit from the assistance of independent advocates in order to secure their human rights on the same basis as the rest of society. As the Alzheimer’s Society Ealing suggests, and we agree, “the key principles of advocacy promote human rights – independence, inclusion, empowerment and citizenship”.³³² Advocacy for vulnerable individuals is also required as part of the positive obligations of public authorities to ensure respect for human rights. **We welcome the Minister’s support for independent advocates and recommend that he ensures that the Department provides sufficient independent**

³²⁶ Ev 137, para 4.1,

³²⁷ Q 354 [Ms Owen] & Q 355.

³²⁸ Q 306.

³²⁹ *Hidden Voices, op cit*, paras 4.4 and 9.4. This accords with the recommendation of the Health Committee that “advocates on elder abuse drawn from black and minority ethnic communities should be identified, trained and deployed” (*Elder Abuse, op cit*, para 10.28).

³³⁰ Q 274.

³³¹ Q 379.

³³² Ev 142.

advocacy services to older people, with particular priority being given to older people with mental health problems or who are unable to communicate in English. These advocates should have an understanding of human rights principles and the positive duties of service providers towards older people.

Complaints

“The caller’s mother-in-law had been living in a care home for six years funded by the local authority where she had previously lived. Her daughter first made a mild complaint that her mother’s bed was often left unmade late in the day. The care worker’s response was to suggest that she might like to move her mother to another home. The daughter made a further complaint about this reaction which was investigated by the manager who wrote to the daughter denying that the home was at fault, claiming they had handled the complaint fairly and gave her mother four weeks notice to quit.”³³³

250. The National Minimum Standards for Care Homes for Older People (Standard 17) require that “service users [...] are enabled to exercise their legal rights directly”. CSCI state that inspectors should assess whether “residents have access to a robust, effective complaints procedure”.³³⁴ However, witnesses told us that CSCI’s complaints procedure is misleading to users because it suggests that CSCI can help with complaints. In fact, with the exception of severe abuse, which will be referred to the police, CSCI refer complainants back to their care home provider. Alternatively, if residents are publicly funded, CSCI may refer the investigation of their complaint back to the local authority.³³⁵

251. The Residents & Relatives Association outlined the conundrum:

In the first instance if a relative or resident complains to the Commission for Social Care Inspection they are advised to go back to the home and resolve it through the home’s own complaints procedure and, of course, relatives and residents are loath to do that because of fear of victimisation, they are complaining to a complaints procedure which is run by the very people they are accusing of behaving badly to them [...] [CSCI] are inspecting the quality of the home as a whole and they are not pursuing the interests of individual residents.³³⁶

252. CSCI noted the practical effect of the problem as follows:

We do not have the powers to investigate or handle complaints [...] each care home has to have a process for handling complaints in place and those procedures have to be exhausted [...] When complaints are made to us we do register those [...] and we will consider whether we need to go and inspect [...] We act on the general issue, although we do not have the powers to deal with the specific issue [...] if you are a resident placed in a care home by a local authority, that authority has the duty to investigate concerns and they will also have a contract and commissioning

³³³ Ev 194, App. 1 para 4.

³³⁴ Ev 179.

³³⁵ Qs 12 & 18.

³³⁶ Qs 18 & 19.

responsibilities for the establishment concerned to ensure good standards are maintained. However, where you are a person who is paying for yourself and you may have placed yourself in a care home, you do not have that protection and you do not have the escalation protection through the local authority or through a different appellate process, nor do you, in those circumstances, have access to an ombudsman. We would say in those circumstances that what we are seeing is two different classes of resident: with one group of residents who may be more exposed because there is no public framework to oversee the placement that they have made [...] We would agree [that it is pretty unsatisfactory].³³⁷

253. The fact that CSCI cannot investigate complaints means, as HTA noted, that individuals do not have “an immediate and accessible remedy”.³³⁸ They state that even if an individual complains to CSCI, this may lead to an inspection of the care home, but not investigation of the complaint itself. Whilst publicly funded residents may have their complaint investigated by the local authority, this leaves self-funding individuals in particular without a remedy, as local authorities would not investigate their complaint.

254. The Department of Health’s Core Standard C14 requires healthcare organisations to:

- Have systems in place to ensure that patients, their relatives and carers:
 - Have suitable and accessible information about, and clear access to, procedures to register formal complaints and feedback on quality of services;
 - Are not discriminated against when complaints are made;
 - Are assured that organisations act appropriately on any concerns and, where appropriate, make changes to ensure improvements in service delivery.

255. Unlike CSCI, the Healthcare Commission has a duty to investigate individual complaints where a patient is dissatisfied with the response of a trust.³³⁹

256. ACE suggest that:

Complaints should operate in such a way that whichever agency receives the complaint has a duty to ensure that there is a response even if they do not regard it as their role to investigate the complaint themselves. Department of Health guidance on NHS and Social Care complaints supports such an approach, but inquiries from relatives and older people received by Age Concern raise doubt as about whether this is happening in practice.³⁴⁰

257. The Government’s consultation paper on the proposed merger of the inspectorates states “the new regulator will focus on assessing whether organisations have appropriate systems and processes in place, rather than handling individual cases of complaint”.³⁴¹ The Minister noted that there was a difference in the way that CSCI and the Healthcare

³³⁷ Qs 148 & 149.

³³⁸ Q 68.

³³⁹ Ev 144, footnote 59.

³⁴⁰ Ev 130, para 5.1.

³⁴¹ Department of Health, *The future regulation of health and adult social care in England*, 2006, para 3.24.

Commission dealt with complaints. However, he was not able to guarantee that when the complaints processes were merged, the approach of the Healthcare Commission would prevail (i.e. that it would itself investigate individual complaints rather than refer the matter back to the body being complained about). He said:

There are two different systems and part of what we have got to decide in terms of merging the systems is where the ultimate right of appeal goes in relation to individual complaints, but we have not made that decision yet [...] We have to look at what is the most effective way of ensuring people, first of all, feel able to complain, secondly, feel that their complaint is taken seriously and, third of all, that there is an element of independence and objectivity about the system³⁴².

258. We welcome the Government's consultation on the merger of the inspectorates, although we are concerned that the consultation suggests that the new inspectorate will not handle individual complaints. We were alarmed that the Minister was unable to guarantee that the new inspectorate would be able to investigate individual complaints at the appropriate point in the process. We are convinced that complaints, including those raising human rights concerns, need to be investigated by an independent third party, rather than by the organisation against which the complaint is made and where the older person may continue to live. We therefore recommend that the newly merged inspectorate be empowered to investigate individual complaints, as the Healthcare Commission is currently able to do.

Low awareness of rights

259. In 2006, the Patients Association conducted a survey among 188 patient/health advocates asking for their views on patients' rights within the NHS, including such issues as the ability of patients to exercise their legal rights within the NHS and how a patients'-rights-based system could be managed and/or enforced. The survey apparently generated one of the best response rates ever attained from a poll of patient/health advocacy groups in the UK, suggesting that the topic of patients' rights is regarded as important by the patient advocacy community in England and Wales.³⁴³ Despite this, witnesses told us that older people generally had a low awareness of their healthcare rights,³⁴⁴ including how to complain and how to navigate the complaints system.³⁴⁵

260. As Age Concern³⁴⁶ and others noted, this was partly due to a lack of information from the Department of Health and the inspectorates about the standards that people can expect in healthcare. They explained:

There has been no attempt to publicise the existence of [the health] standards to the public at all. That appears to us to be a huge gap in enabling older people to understand what they and their relatives have the right to expect and to challenge

³⁴² Qs 438 & 439.

³⁴³ Patients Association, *Should the NHS take more account of patients' rights? A survey of health campaigners in England and Wales*, November 2006.

³⁴⁴ Ev 140.

³⁴⁵ Ev 125, para 2.4.

³⁴⁶ Ev 125, para 2.4.

any failure to provide that. It is something that we have consistently challenged the Department of Health on. In setting out these standards, unless you tell people they exist, in effect they do not exist.³⁴⁷

261. Noting the gap between rhetoric and reality, the Minister said:

I also believe that this is not just about the State; I think it is also about the awareness and the confidence of citizens and communities to assert their rights. I think that is why the Government increasingly understands that reforming public services is not just about changing structures; it is also about empowering those people who use services and, more broadly than that, communities and society³⁴⁸.

262. Whilst we are pleased that the Minister accepts that older people need to be aware of their rights, he misses the point when he says that “this is not just about the State”. Given the particular vulnerabilities of people in healthcare, there is an onus on the State to ensure that service users are provided with information about their rights and the standards that they can expect whilst in receipt of healthcare services. Empowering older people relies in part on overcoming some of the barriers to raising concerns which we mentioned above, and in tandem, ensuring that older people, or their carers or advocates, are sufficiently well informed about their rights and the State’s responsibilities.

263. According to our witnesses, older people also have a low awareness of their *human* rights. As one witness put it “human rights are misunderstood, not just by service providers and those who plan services, but also by older people themselves as the end users of those services.”³⁴⁹

264. As the National Pensioners’ Convention said “we are aware that the Human Rights Act has relevance to older people but believe that there is widespread ignorance about exactly how it can be used.”³⁵⁰

265. This ignorance about human rights should not be confined merely to older people, but is part of the bigger problem of the failure of Government to promote a positive concept of human rights with the general public. Recent research by Age Concern involved researchers meeting with older people to explore their understanding of human rights. Age Concern found that “when exposed to the themes of the HRA, people could see ways in which it might help them, their family or their friends. However, prior to being exposed to the HRA, the tenor of discussion had been very hostile to ‘human rights’.”³⁵¹

266. This chimes with the findings of the BIHR when healthcare workers received training in human rights (see above). Age Concern found that people did not want information about the different provisions of the HRA, but simply wanted to know that they had a firm legal right to be treated decently and to know how to assert that right. However, poor awareness of human rights is not simply a matter of distrust of the concept of human

³⁴⁷ Q 77 [Mr Hurst].

³⁴⁸ Q 406.

³⁴⁹ Q 73.

³⁵⁰ Ev 103.

³⁵¹ Age Concern, *Rights for Real*, May 2006, Annex 1.

rights. As Action on Elder Abuse told us, it is also a question of information and terminology:

What is the point of a human right if I do not know I have got it? That is the first question. The second, what is the point of a human right if I cannot access it? I think we need to address both those things, people need to understand their human rights in whatever terminology we use and wrap it up, that they understand I have a right to be treated with respect and dignity and the right to ask questions and get responses, and if I am not happy, I have a right to complain.³⁵²

267. The issue of terminology was echoed by the Alzheimer’s Society which suggested that human rights were seen as alien and legal:

Human rights principles do not come easily to older people who often view the Human Rights Act as a legal tool that is used and abused. It is also perceived as being a legalistic approach and this discourages people from making use of human rights arguments. Beyond the populist reaction, human rights also seem alien to people unless particularly violent forms of abuse such as physical or sexual abuse take place.

A question in this context would be whether it is useful to frame the discussion in terms of “human rights” if seeking to encourage older people to make more use of their rights? Typically the Alzheimer’s Society seeks to inform and encourage people to make use of their ‘rights’, rather than ‘human rights’. The term ‘rights’ seems to have more immediate meaning for people with dementia and their families.³⁵³

268. In addition to terminological problems, witnesses considered that there might be some “difficulties in communicating information about human rights to the very people who are most vulnerable to human rights abuses”³⁵⁴ and therefore advocated targeting human rights information to a wider audience beyond older people themselves.

269. There is clearly some important promotional work which needs to be carried out to improve the image of human rights within the population generally, including older people. We commend the former Minister for Human Rights and the former Lord Chancellor for the steps that they have taken, as part of the Government’s *Common Values, Common Sense* campaign. We urge the new members of the Government, in particular the new incumbents in the Ministry of Justice, to be steadfast in their support for the Human Rights Act and its real importance for many ordinary people, including older people receiving health and care services.

How to make rights accessible to older people

270. Despite concerns about terminology, witnesses have nevertheless told us that they see great benefits to older people and their carers or advocates of equipping them with information about human rights principles and their practical application to them. As Age Concern explained, it would be one way of addressing the power imbalance and overcoming the powerlessness that older people complain of when trying to challenge poor

³⁵² Q 237.

³⁵³ Ev 216, paras 37 & 38.

³⁵⁴ Ev 131, para 6.2.

treatment.³⁵⁵ It would also provide them with a new language to help them to “advocate more strongly for themselves”.³⁵⁶ However, the BIHR sounded a note of caution:

The responsibility for making sure that people’s rights are respected should never fall on one frail individual in a residential care home but, at the same time, that frail individual should at least have the opportunity to know what their rights are and for those rights to be respected.³⁵⁷

271. Race on the Agenda agreed that consumers of public services need to have enough knowledge to enable them to challenge the system when the service is poor, that they should be consulted to “identify the best methodologies in using the principles underlying the Human Rights Act” but that such a process “should not over-burden individuals”.³⁵⁸

272. It is important that older people and their advocates or carers have sufficient information about their rights, to ensure that they can claim them from service providers if they wish to do so. However, this should be a matter of last resort. Given the power imbalance between older people and service providers, and their resulting reluctance to complain, we do not consider that it is either realistic or appropriate to expect older people to shoulder the burden for ensuring that service providers treat them with respect for their human rights. The primary responsibility for the protection of human rights, as we have repeatedly said in this Report, falls on providers of public services. We have already recommended in Chapters 4, 5 and 6 what the Department of Health, providers of healthcare services, inspectorates and other healthcare agencies should be doing to ensure that older people’s human rights are protected in hospitals and care homes.

273. Witnesses agreed that, in addition to better education of the general public, specific targeted information aimed at older people, their carers and advocates was required. Information needs to be “accessible and meaningful”,³⁵⁹ and staff should be trained to support people in accessing this information. Help the Aged noted the need for independent quality advocacy services to ensure that older people are informed and involved and that “access to qualified legal advice is also essential”.³⁶⁰

274. Some witnesses commented on the role of voluntary and community organisations in communicating the message of human rights to the public,³⁶¹ and they recommended that the new Commission for Equality and Human Rights produce similar general and targeted information.³⁶² The BIHR told us this about their guide on human rights for older people:

³⁵⁵ Ev 131, para 6.1.

³⁵⁶ Ev 157, para 8.

³⁵⁷ Q 274.

³⁵⁸ Ev 200.

³⁵⁹ Ev 188.

³⁶⁰ Ev 166, paras 4.3-4.5.

³⁶¹ Ev 125, para 2.5.

³⁶² Ev 174, para 19.

We produced a plain English guide for older people about human rights and it has flown off our shelves. It has been the most popular guide of the four guides we produce. I think it shows there is an appetite there for information.³⁶³

275. The National Pensioners Convention told us about their leaflet, *Older People and the Human Rights Act*.³⁶⁴ However, Action on Elder Abuse felt that the emphasis should be on changing institutional culture:

In our opinion, the strategy to move this situation forward is less about producing leaflets or posters telling older people about their human rights, but is more about influencing the institutions that provide health and social care so that a human rights culture is “mainstreamed” into the thinking, planning and delivery; but also to make human rights accessible through mechanisms other than the judicial system.³⁶⁵

276. We consider that a dual approach is required: firstly, older people need information about their human rights; and secondly, institutions need to mainstream human rights within their work. We recommend that the Department of Health, the inspectorates, healthcare policy-makers and every provider of healthcare services make a public commitment to: (a) embed a human rights approach in hospitals and care homes across the country and (b) make sure that accessible information on human rights and how to use them are provided to patients, care home residents, relatives, carers and advocates, and the public as a whole.

277. In addition, we recommend that the Commission for Equality and Human Rights, in partnership with organisations representing older people, assesses the quality of the information available to older people, their families and carers on the application of human rights principles to their lives and makes sure that the best information is widely disseminated. Independent advocates and advisors have a crucial role to play in assisting people to understand and apply these concepts.

278. During the evidence session with the Healthcare Commission, it was revealed that although the care standards require hospitals “to respect human rights”, this requirement is not made clear to patients:

Chairman: You do not say to patients and relatives, “Do you realise that human rights include X, Y and Z?”?

Ms Walker: No, we do not do that. That would be another way of coming at it. Our relationship with the patient fora is in its infancy in the sense that we introduced the annual health check for the first time last year.³⁶⁶

279. Under the National Minimum Standards, care homes are required to make the following information available to residents:

The registered person produces and makes available to service users an up-to date statement of purpose setting out the aims, objectives, philosophy of care, services and

³⁶³ Q 274.

³⁶⁴ Ev 103.

³⁶⁵ Ev 223.

³⁶⁶ Q 106.

facilities, and terms and conditions of the home; and provides a service users' guide to the home for current and prospective residents.³⁶⁷

Each service user is provided with a statement of terms and conditions at the point of moving into the home (or contract if purchasing their care privately).³⁶⁸

280. A number of witnesses, including providers, recommended that older people should be informed about their rights and responsibilities, as well as what the service provider was and was not able to do, when entering the hospital or care home.³⁶⁹ The Royal College of Nursing suggested that there was work to be done in putting together:

[...] something very simple for patients and for healthcare staff so that they understand what that actually means, so that patients understand what they have a right to expect and so that healthcare staff also have the right in understanding what they have a right to expect and what they should do if they cannot meet those expectations.³⁷⁰

281. On our visit to a North London hospital, we were given copies of leaflets provided to patients on admission about the services that they could expect. These included information on care and treatment, how to make a complaint and what happens on discharge. In one of them, *Our promise to you*, the NHS Trust states “we will deliver our services in a way which is fair and safe, recognising the individual needs of our patients and the potential of our staff”.

282. There is no reference to the fact that patients have “rights” as well as “needs” or that the providers have a legal duty under the Human Rights Act. It was thought by those present, however, that a bald reference to “human rights” could be “off-putting” for patients. **We recommend that information on human rights be presented by the NHS in an appropriate way to older people.**

283. For care homes, information could be provided as part of the information that homes are required, under the national minimum standards, to make available to residents.

284. The Minister agreed that individuals should be informed of their rights and responsibilities when entering healthcare and that ideally this should be done not by giving the older person a document, but by having a conversation with them.³⁷¹

285. Some witnesses advocated a bill of rights for older people in healthcare.³⁷² This is supported by a survey by the Patients' Association.³⁷³ The British Geriatrics Society suggested that:

³⁶⁷ *National Minimum Standard: Care Homes for Older People* (Standard 1).

³⁶⁸ *National Minimum Standard: Care Homes for Older People* (Standard 2).

³⁶⁹ Qs 305 [Professor Crome] & 361.

³⁷⁰ Q 304.

³⁷¹ Q 437.

³⁷² Ev 94; Ev 155; Ev 239.

³⁷³ Patients Association, *Should the NHS take more account of patients' rights? A survey of health campaigners in England and Wales*, November 2006.

Older persons receiving treatment in hospital or in residential care could be better informed about human rights principles [...] This could be achieved by a public information campaign and/or a Bill of Rights for older frail persons entering hospital or a care home.³⁷⁴

286. As part of its evidence, the British Geriatrics Society appended, as a good practice example, US Federal law requirements for nursing homes which state that “Federal law requires a nursing home to care for its residents in a way that promotes their quality of life.”³⁷⁵

287. The listed rights under US law are comparable in content to those contained in the Department of Health’s national minimum standards but the difference is that they are contained in primary legislation.

288. We recommend that information on the human rights of older people and the duties of service providers as “public authorities” under the HRA be provided to older people, in an accessible form, on entry to the care home or hospital. The applicable care standards for hospitals and care homes should be revised to require that service providers make specific reference to an individual’s human rights and the avenue for making a complaint.

³⁷⁴ Ev 94.

³⁷⁵ Ev 95, 42 USC para 1395i-3.

Annex: Human rights laws and standards in healthcare

1. The way in which older patients and care home residents are treated is not simply a healthcare standards issue, but also a human rights issue. In this Annex, we set out the applicable human rights standards deriving from common law, UK statutes and international treaties, of which the most important is the Human Rights Act 1998.

Common law principles

2. Under the common law, the state is required to treat people humanely.³⁷⁶ In addition, the courts recognise a common law principle of equality.³⁷⁷ The corollary of the principle of equality is the requirement not to discriminate either directly or indirectly without objective and reasonable justification. These long standing common law principles are now also embodied in human rights and equality legislation.

Human Rights Act 1998

3. The HRA, which came into force in October 2000, brings the main rights and freedoms (known as Convention rights) guaranteed by the ECHR 1950 into UK law.

Convention rights

4. Since the Act came into force, everyone in the UK is entitled to respect for and protection of their Convention rights. They are also able to enforce their Convention rights in the courts in the case of a breach by a public authority.³⁷⁸

5. Convention rights which are particularly important for older people in hospitals and care homes are:

- Respect for private and family life, home and correspondence (Article 8);
- Prohibition on inhuman or degrading treatment (Article 3);
- Right to life (Article 2);
- Enjoyment of Convention rights must be guaranteed without discrimination on any ground (Article 14).

6. We consider each of these rights in more detail below. The following rights may also be relevant to older people's experiences in hospitals and care homes, depending on their circumstances:

- Right to liberty (Article 5);

³⁷⁶ *R v Eastbourne (Inhabitants)* (1803) 4 East 103, 102 ER 769 at 770.

³⁷⁷ *Matadeen v Pointu* [1998] 3 LRC 542 at 552; [1999] 1 AC 98 at 109, *M v Secretary of State for Work and Pensions*, [2006] 2 AC 91 at para 136.

³⁷⁸ Human Rights Act 1998, Section 7.

— Freedom of thought, religion, expression and association (Articles 9–11).

7. Some rights, like the right to life (Article 2) and freedom from degrading treatment (Article 3), are absolute, which means that they cannot be qualified or limited. Others, like the right to respect for private and family life (Article 8) and freedom of thought, religion, expression and association (Articles 9, 10 and 11), are qualified. These rights may be restricted by public authorities, provided the restriction is proportionate (the minimum necessary to achieve the justification sought), is “necessary within a democratic society,” and is set out clearly in law.

Public authorities under the HRA

8. Under the HRA, statutory bodies such as the Department of Health, inspectorates, NHS trusts and primary care trusts, hospitals, local authorities, and local authority run care homes are public authorities with obligations under the Act.³⁷⁹

9. The HRA therefore applies in general terms to the provision of health and social care services in the UK.

Private bodies exercising public functions

10. Private providers of health and residential services are considered to be public authorities when exercising “functions of a public nature.”³⁸⁰ There has been much judicial investigation of this provision with several test cases concerning health and social care. In 2002, a private provider of mental health care was found to be exercising functions of a public nature.³⁸¹ In the same year, however, a well-known charity managing homes for disabled people with resident’s places funded by local social services was found not to be a public authority.³⁸² The recent decision of the House of Lords in the case of *YL*³⁸³ put beyond doubt, so far as the courts are concerned, that care homes run by private companies, even where they have a contract with a local authority for placement of residents, are not, as a matter of current law, to be regarded as “public authorities” for the purposes of the HRA. We have expressed our dissatisfaction with this state of affairs in our recent Report on the meaning of public authority.³⁸⁴

11. Even where providers of residential care services have been judicially determined not to be within the scope of the HRA, the residents of those care homes are still entitled to the protection of their human rights. This raises a question about whether the Government has

³⁷⁹ *Ibid*, Section 6.

³⁸⁰ *Ibid*, Section 6(3)(b).

³⁸¹ *R(A) v Partnerships in Care* [2002] 1 WLR 2610.

³⁸² *Callin, Heather and Ward v Leonard Cheshire Foundation* [2002] 2 All ER 936.

³⁸³ *YL v Birmingham City Council* [2007] 3 WLR 112. *YL* was a resident of a care home run by a private healthcare company. The House of Lords held that, despite her placement being paid for, in part, by the local authority under its National Assistance Act duties, that the healthcare company was not a public authority for the purpose of the Human Rights Act.

³⁸⁴ Ninth Report of Session 2006-07, *The Meaning of Public Authority under the Human Rights Act*, HL Paper 77/HC 410.

provided an “effective remedy” under human rights law for people in this situation as required by Article 13 ECHR.³⁸⁵

Legal responsibilities under the HRA

12. Under the HRA, it is unlawful for any public authority to “act in a way which is incompatible with a Convention right”.³⁸⁶ This means that public authorities have to take Convention rights into account in relation to all of their functions, including the provision of public services to individual users.

Positive obligations

13. Although not discernible on the face of the HRA, public authorities also have positive obligations under the Convention. These duties may require public authorities to do more than merely avoid breaching people’s human rights. Article 1 of the ECHR requires States to ‘secure [the ECHR rights] to everyone within the jurisdiction’. Although the government did not incorporate Article 1 into the HRA, this Article remains an obligation under the Convention and has been reinforced by decisions of the European Court of Human Rights and, since the HRA came into force, decisions of the UK courts. This means that public authorities have an additional responsibility, in certain circumstances, to take reasonable measures to protect people’s rights.

14. These positive obligations may have implications for law and policy. For example, the European Court of Human Rights required the UK to have laws in place that sufficiently protected children from excessive corporal punishment in breach of Article 3.³⁸⁷ Similarly, the European Court held that Article 8 was breached where a 16 year old woman with a mental disorder, and her father acting on her behalf, were both prevented from lodging a criminal complaint in respect of a carer who sexually assaulted her. The court stated “this is a case where fundamental values and essential aspects of private life are at stake. Effective deterrence is indispensable in this area and it can be achieved only by criminal law provisions.”³⁸⁸

15. There may also be a duty in practice to “take effective operational steps to guard against [...] ill-treatment.”³⁸⁹ For example, the state has a legal duty under Article 2 (right to life) which may require the police or other authorities to take reasonable steps to protect an individual whose life is at risk from the criminal acts of others³⁹⁰ and to protect the public from environmental hazards which threaten life.³⁹¹ To take a more recent example, the probation service had a duty under Article 2 to take reasonable steps to protect the public from the risk created by the release of the prisoner, Anthony Rice, a convicted rapist serving a life sentence. As was noted in the recent review conducted by (what was then) the

³⁸⁵ *Ibid*, paras 81-83; Seventh Report of Session 2003-04, *The Meaning of Public Authority under the Human Rights Act*, HL Paper 39/HC 382, para 83.

³⁸⁶ Human Rights Act 1998, Section 6.

³⁸⁷ *A v UK* (1998) 27 EHRR 611.

³⁸⁸ *X and Y v Netherlands* (1986) 8 EHRR 235 at para 27.

³⁸⁹ *R (Limbuella) v Secretary of State for the Home Department* (2006) 1 AC 396 at para 92.

³⁹⁰ *Osman v UK* (2000) 29 EHRR 245.

³⁹¹ *Oneriyildiz v Turkey* (2004) 39 EHRR 12.

Department for Constitutional Affairs “there seems to be insufficient recognition that the prison, parole and probation services are themselves subject to a positive obligation under the Human Rights Act to take proper steps to protect the public from dangerous criminals such as Rice.”³⁹²

16. The requirement for public authorities to take action to protect people’s human rights can also arise in less high profile cases, which nevertheless have a significant effect on the quality of people’s lives. In *Bernard v London Borough of Enfield*³⁹³ the court held that the local authority was in breach of Article 8 ECHR having failed to provide suitable accommodation to a severely disabled woman and her family within a reasonable period of time.

17. The state and its agencies may have positive obligations to take action in relation to the acts of private individuals to protect the human rights of one individual from infringement by another. As the European Court of Human Rights stated in *X and Y v Netherlands*:

[Article 8] does not merely compel the State to abstain from . . . interference: in addition to this primarily negative undertaking, there may be positive obligations inherent in an effective respect for private and family life . . . These obligations may involve the adoption of measures designed to secure respect for private life even in the sphere of relations of individuals between themselves.³⁹⁴

18. For example, where private care providers do not have duties under the HRA, local social services departments may have to take action to ensure that the human rights of private care home residents are protected. This point was made clear by Forbes J. in the case of *Johnson v Havering*:

A transfer of the [care] homes to the private sector does not absolve the Council of its duty under Section 6(1) to act compatibly with Convention rights, including the Convention rights of the claimants. Thus, if a transfer does take place, the Council will continue to be obliged to take appropriate steps (for example) to safeguard the lives of the claimants, to protect them from inhuman and degrading treatment and to safeguard their private and family life, home and correspondence. The real and effective protection of the claimants’ rights will continue to be ensured by the Council and, if necessary, by the Courts.³⁹⁵

19. The fact that the positive obligations doctrine is not specified clearly in the UK statute and instead derives from Convention obligations and caselaw has not assisted either understanding or application of it by public authorities in the UK.

Dignity in law

20. We provide outlines of Articles 8, 3, 2 and 14 below but, because each of these Convention rights is dependent upon protecting people’s dignity, this section briefly

³⁹² Department for Constitutional Affairs, *Review of the Implementation of the Human Rights Act*, July 2006, p 27.

³⁹³ *R (Bernard) v Enfield London Borough Council* [2002] EWHC 2282 (Admin).

³⁹⁴ *X and Y v the Netherlands* (1986) 8 EHRR 235 at para 33, *Botta v Italy* (1998) 26 EHRR 241.

³⁹⁵ [2006] EWHC 1714 (Admin) at para 44.

considers the extent to which this fundamental human rights principle has been given the force of law.

Dignity in international human rights instruments and statutes

21. The concept of dignity is prominent in the Universal Declaration of Human Rights 1948:

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Article 1: All human beings are born free and equal in dignity and rights.³⁹⁶

22. Two years later, however, when the ECHR was drafted, dignity was not expressly referred to. This may have been due to a natural reluctance on the part of the British lawyers contributing to the drafting, schooled as they would have been in the more precise tradition of British law-making, to legislate about basic values. As we consider below, any such reluctance amongst legislative draftsmen has diminished since the HRA was passed.

23. The international Covenants that brought the principles of the Universal Declaration into legal effect do, however, refer to dignity as a human right to be upheld. The preambles to both the International Covenant of Civil and Political Rights (ICCPR) and the International Covenant on Economic Social and Cultural Rights (ICESCR) 1966 state:

[...] in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world, *Recognising* that these rights derive from the inherent dignity of the human person.

24. The more recent Charter of Fundamental Rights of the European Union 2005 devotes the whole of its first chapter to dignity.³⁹⁷ That chapter, containing the first five Articles of the Charter, declares that human dignity is inviolable, and asserts the rights to life, to integrity of the person, the prohibition of torture and inhuman or degrading treatment or punishment and the prohibition of slavery and forced labour.

25. Dignity as a human rights concept is being increasingly used by parliamentary draftsmen in the UK. Recent research revealed that 57 statutes in the last five years have referred to dignity as compared to 16 in the previous five (with most of the references concerning the dignity of ordinary humans as opposed to references to the dignities of a particular office).³⁹⁸ For example, regulations on adult placement schemes state:

The registered person shall make suitable arrangements to ensure that the scheme is conducted, and that care or support (including any accommodation) is provided

³⁹⁶ UN General Assembly Resolution 217A (III).

³⁹⁷ Official Journal of the European Communities, 18 December 2000, C364/1.

³⁹⁸ Allen, R., QC., & Moon, G., 'Dignity Discourse in Discrimination Law: a Better Route to Equality', EHRLR 2006, 6, 610-649.

[...] in a manner which respects the privacy, dignity and wishes of service users, and the confidentiality of information relating to them.³⁹⁹

26. More recently, the statute establishing the Commission for Equality and Human Rights (CEHR) imposes on it a general duty to exercise its 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.”⁴⁰⁰

Dignity as interpreted by the courts

27. Although it has been said that “there is hardly any legal principle more difficult to fathom in law than that of human dignity”,⁴⁰¹ the concept is frequently referred to in the jurisprudence of the Convention in the context of Articles 8 and 3 ECHR, not as a legal standard but as a fundamental value.⁴⁰² The European Court of Justice has also held that it must ensure that the fundamental right to human dignity and integrity is observed.⁴⁰³ Courts in the UK have considered the importance of dignity as a principle and value both before and after the incorporation of the ECHR into domestic law, although they have declined to define the concept precisely. For example, as Baroness Hale recognised in *Ghaidan v Godin-Mendoza* “the essence of the Convention [...] is respect for human dignity and human freedom”, along with equal treatment.⁴⁰⁴

28. Recent research has looked at the extent to which British courts are referring to dignity. This research showed that 48 cases which referred to dignity occurred in the last five years, while in the previous five there were only 19 references. It concluded that there has been an “exponential growth in dignity discourse in the courts of England and Wales” and that “judges, advocates and legislators feel increasingly confident in referring to dignity.”⁴⁰⁵

29. In *Airedale NHS Trust v Bland*⁴⁰⁶ a case which explored the moral issues of withdrawing life support (decided before the HRA), Hoffmann L.J. (as he then was) said the principle of dignity reflects:

[...] our belief that quite irrespective of what the person concerned may think about it, it is wrong for someone to be humiliated or treated without respect for his value as a person. The fact that the dignity of an individual is an intrinsic value is shown by the fact that we feel embarrassed and think it wrong when someone behaves in a way which we think demeaning to himself, which does not show sufficient respect for himself as a person.⁴⁰⁷

³⁹⁹ Adult Placement Schemes (England) Regulations 2004, SI 2004/2071, Regulation 21(1)(f).

⁴⁰⁰ Equality Act 2006, Section 3(c).

⁴⁰¹ See Opinion of Advocate-General Stix-Hackl in Case C-36/02 *Omega Spielhallen-und Automatenaufstellung GmbH v. Oberbürgermeisterin der Bundesstadt Bonn (Omega)* at para 74. See also judgment of the European Court of Justice in the same case; 14 October 2004.

⁴⁰² See, for a recent example, *Ahmet Zkan and others v. Turkey* (Application no 21689/93) 6 April 2004 at para 337.

⁴⁰³ See Case C-377/98, *Netherlands v. the European Parliament, and the Council of the European Union*, judgment 9 October 2001 at para 70.

⁴⁰⁴ [2004] 2 AC 557 at para 132.

⁴⁰⁵ Allen and Moon, *op cit*.

⁴⁰⁶ [1993] 2 WLR 316 (CA) (affirmed on other grounds by the House of Lords [1993] AC 789).

⁴⁰⁷ *Ibid*, p 851.

30. Since then, in a recent case, Lord Hoffmann sketched out a definition of dignity when he observed that the jurisprudence shows that dignity is a core value being “the right to the esteem and respect of other people [...]”.⁴⁰⁸

31. The importance of dignity both as a human rights concept and as a fundamental value was emphasised in a case concerning the way in which two severely disabled sisters were cared for by local authority carers in their home. Munby J. said:

True it is that the phrase [human dignity] is not used in the Convention but it is surely immanent in Article 8, indeed in almost every one of the Convention’s provisions. The recognition and protection of human dignity is one of the core values – in truth, *the* core value – of our society [...].⁴⁰⁹

32. The essential characteristics of dignity are beginning to be explored by judges and academics. Professor Feldman, a former legal adviser to our predecessors has observed that dignity operates at three levels, the dignity attaching to the human species, the dignity of groups within the human species and the dignity of human individuals.⁴¹⁰ He notes that dignity of individuals:

requires the right to make one’s own decisions, and to contribute to decisions made by others which affect one’s life [...] But we may be required to respect the dignity of people who lack freedom of choice, such as those in a permanent vegetative state. Such cases present difficult questions about the relationship between dignity and autonomy, and between different kinds of dignity.⁴¹¹

33. There is no question that the concept of dignity and the developing jurisprudence on it is significant to our inquiry on the human rights of older people in hospitals and care homes.

Respect for the person and family life

34. Article 8 ECHR provides:

- Everyone has the right to respect for his private and family life, his home and his correspondence.
- There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

⁴⁰⁸ *Campbell v MGN Ltd* [2004] 2 AC 457 at para 51. As quoted by Allen and Moon, *op cit*.

⁴⁰⁹ *R (A and B) v (1) East Sussex County Council (2) The Disability Rights Commission (Interested Party)* [2003] EWHC 167 (Admin) at para 86.

⁴¹⁰ Feldman D, *Civil Liberties and Human Rights in England and Wales*, Oxford University Press, 2nd edition, p 126.

⁴¹¹ *Ibid*.

35. The right to respect for private life has been interpreted by the European Court of Human Rights as including a right to physical and psychological integrity.⁴¹²

36. Since the HRA came into force, there have been several decisions based on Article 8 involving the protection of vulnerable people, particularly those who are elderly or have disabilities. A local authority has been found liable under Article 8 for failing to carry out meaningful consultation with elderly residents of its care homes following a decision to close them. The Court held that the decision-making process should have taken into account Article 8 and there should have been a careful balancing process to make sure that the council's interference in the residents' rights was 'proportionate'.⁴¹³

37. In the *East Sussex* case, referred to above, which considered the local authority's handling and lifting policy with regard to the care of two sisters with profound disabilities in their home, the court found that Article 8 required protection of the sisters' dignity and this needed the human touch of some manual handling by their carers.

Freedom from inhuman or degrading treatment

38. Article 3 ECHR prohibits torture and inhuman or degrading treatment or punishment. It provides:

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

39. Article 3 is mirrored by Article 7 ICCPR. The prohibition against torture and inhuman or degrading treatment or punishment is absolute and cannot be opted out of in any circumstances. Treatment must attain a "minimum level of severity" to fall within Article 3 ECHR. The assessment of the minimum is relative and depends on all the circumstances of the case such as the nature and context of the treatment that is in issue.⁴¹⁴

40. The European Court of Human Rights has defined inhuman and degrading treatment as:

[...] "ill-treatment" that attains a minimum level of severity and involves actual bodily injury or intense physical or mental suffering [...] Where treatment humiliates or debases an individual, showing a lack of respect for, or diminishing, his or her human dignity, or arouses feelings of fear, anguish or inferiority capable of breaking an individual's moral and physical resistance, it may be characterised as degrading and also fall within the prohibition of Article 3 [...] The suffering which flows from naturally occurring illness, physical or mental, may be covered by Article 3, where it is, or risks being, exacerbated by treatment, whether flowing from conditions of detention, expulsion or other measures, for which the authorities can be held responsible.⁴¹⁵

⁴¹² *X and Y v Netherlands* (1985) 8 EHRR 235.

⁴¹³ *R (Madden) v Bury Metropolitan Borough Council* [2002] EWHC 1882 (Admin).

⁴¹⁴ *Ireland v UK* (1978) 2 EHRR 25 at para 162.

⁴¹⁵ *Pretty v UK* (2002) 35 EHRR 1 at para 52.

41. The UK High Court has held that Article 3 brings out “[...] the enhanced degree of protection which may be called for when human dignity at stake is that of someone who is [...] so disabled as to be critically dependent on the help of others for even the simplest and most basic tasks of day to day living.”⁴¹⁶

Right to life

42. The first sentence of Article 2 ECHR provides:

Everyone’s right to life shall be protected by law.

43. This right is replicated in Article 6 ICCPR. The corollary of the right to life is the duty to protect life. The state has a positive duty to take steps to safeguard the lives of those within the jurisdiction.⁴¹⁷ An issue may arise under Articles 2 and 14 ECHR where the state puts an individual’s life at risk through the denial of healthcare which is available to the general population.⁴¹⁸ The impact of the HRA on the dilemma for the NHS of providing life-saving treatment in a context of limited resources is considered below.

Equality and non-discrimination

44. The ECHR protects against unjustified discrimination in the way that other Convention rights are enjoyed. Article 14 ECHR provides:

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

45. Although there is no clear authority, we proceed on the basis that Article 14 includes age within “other status”. In the enjoyment of any Convention right, the state is prohibited from discriminating without objective and reasonable justification.⁴¹⁹ This is an overarching principle which applies to all ECHR rights. It encompasses both direct⁴²⁰ and indirect discrimination.⁴²¹ Article 2(2) ICESCR contains a similar provision.

46. Unlike the ECHR, Article 26 of the ICCPR provides a freestanding equality guarantee:

All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

⁴¹⁶ *R (A and B) v (1) East Sussex County Council (2) The Disability Rights Commission (Interested Party)* [2003] EWHC 167 (Admin) at para 93 per Munby J.

⁴¹⁷ *L.C.B. v United Kingdom* [1999] 27 EHRR 212 at para 36.

⁴¹⁸ *Cyprus v Turkey* [2002] 35 EHRR 30 at para 219.

⁴¹⁹ *Belgian Linguistics Case (No. 2)* (1968) 1 EHRR 252 at para 14.

⁴²⁰ *Ibid.*

⁴²¹ *Thlimmenos v Greece*(2001) 31 EHRR 15 at para 44; *Zeman v Austria* App. No. 23960/02, 29 June 2006 at para 32.

47. Protocol 12 to the ECHR extends the Convention to provide a freestanding prohibition on discrimination. The Protocol is designed to advance the ECHR's protection of equality beyond the relatively limited guarantee in Article 14. The UK Government has not ratified the Protocol. In previous Reports, we have recommended that the Government should ratify Protocol 12 and include it within the rights protected in the Human Rights Act, in order to provide protection in domestic law equivalent to the equality rights which bind the UK internationally, such as under the ICCPR and the ICESCR.⁴²²

Protection / absence of protection on the grounds of age

48. The CEHR has statutory duties to work towards “the elimination of prejudice against” particular groups and “enabling members of groups to participate in society.” “Age” is listed as one of these groups, along with disability, gender (including gender reassignment), race, religion or belief and sexual orientation. These categories have come to be known as the “protected groups” or the “equality strands.” The groups do, however, enjoy different underlying legal protection from each other.

49. Although older people are now protected against discrimination in employment on grounds of age,⁴²³ they do not, as yet, enjoy comparable legal protection in the following areas:

- Protection from discrimination in the provision of goods, facilities and services, which would include health and social care, by contrast with race, gender, sexual orientation or disability.
- A positive duty on public bodies to promote equality of opportunity, by contrast with race, disability and gender.

50. The recently published consultation from the Discrimination Law Review⁴²⁴ addresses these issues in detail and invites responses on possible law reform.

51. In the international arena, ICESCR General Comment No. 6 on the Economic, Social and Cultural Rights of Older Persons includes age.

52. The new UN Convention on the Rights of Persons with Disabilities (2006) and its Optional Protocol opened for signature on 30 March 2007, and was signed by the UK on the same day. They will provide protection for people with disabilities, including older people. The Convention refers to the right to life (Article 10), freedom from exploitation, violence and abuse (making reference to “age-specific assistance” and “age-specific needs”) (Article 16), respect for privacy (Article 22) and the right to health (Article 25) (with specific reference to older persons).

53. The UN Guiding Principles on Older Persons (1991) (UNPOP)⁴²⁵ encourage Governments to incorporate certain principles into their national programmes “whenever possible”. Of particular relevance to this inquiry are the following principles:

⁴²² Seventeenth Report of Session 2004-05, *Review of International Human Rights Instruments*, HL Paper 99/ HC 264, paras 29-34.

⁴²³ Employment Equality (Age) Regulations 2006, SI 2006/1031.

⁴²⁴ *A Framework for Fairness*, *op cit*.

- Older persons should have access to adequate health care through the provision of income, family and community support and self-help (Principle 1);
- Older persons should have access to health care to help them to maintain or regain the optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness (Principle 11);
- Older persons should be able to utilize appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment (Principle 13);
- Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives (Principle 14);
- Older persons should be able to live in dignity and security and be free of exploitation and physical and mental abuse (Principle 17); and
- Older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability or other status, and be valued independently of their economic contribution (Principle 18).

54. Although the impact of these Principles on the UK Government, in particular on the Department of Health, has been negligible, the Welsh Assembly has embedded the Principles into its strategy for older people⁴²⁶ and the new Commissioner for Older People in Wales is required to have regard to them when considering the interests of older people.⁴²⁷

Healthcare

55. Even though the ECHR does not guarantee a right to healthcare, the cases referred to above demonstrate the application of Convention rights (especially the right to respect for private life under Article 8) where people are receiving health and social care services. The emerging jurisprudence also reflects how Convention rights operate as a “living instrument”⁴²⁸ which changes with the times. Munby J. in the *East Sussex* case observed that “the concept of human dignity may be the same as ever, but the practical standards which require to be met are not. Changes in social standards demand better provision for the disabled if their human dignity is not to be impaired.”⁴²⁹

⁴²⁵ Resolution 46/91, adopted by the General Assembly of the United Nations on 16 December 1991.

⁴²⁶ Welsh Assembly Government, *The Strategy for Older People in Wales*, January 2003.

⁴²⁷ Commissioner for Older People (Wales) Act 2006, Section 25.

⁴²⁸ *Pretty v UK* (2002) 35 EHRR 1 at para 54.

⁴²⁹ *Munby J, R (A and B) v (1) East Sussex County Council (2) The Disability Rights Commission (Interested Party)* [2003] EWHC 167 (Admin) at para 98.

56. This comment should be viewed in the light of the recent findings of the National Audit Office on the increase in the number of people with dementia to which we refer in Chapter 2.⁴³⁰

57. Article 12 of the ICESCR recognises the right of everyone to the “highest attainable standard of physical and mental health”. This takes into account both the individual’s biological and socio-economic preconditions and a state’s available resources (General Comment No. 14, which further defines the right in Article 12). States are required to “progressively realise” this right by the adoption of all appropriate means, including legislation, without discrimination on any ground, including “other status” (Article 2). This could include age (see General Comment No. 6 on the Economic, Social and Cultural Rights of Older Persons). In particular, Article 12 requires the creation of conditions which assure medical service and attention to all who are sick. There is no express reference to the rights of older persons in the Covenant, but its provisions apply equally to all members of society.

58. The right to health is also protected in Article 5(e)(iv) of the Convention on the Elimination of all Forms of Racial Discrimination (CERD) (1966) and Articles 11(1)(f) and 12 of the Convention on the Elimination of Discrimination Against Women (CEDAW) (1979). The EU Charter (Article 35) provides a right of access to preventive health care and the right to benefit from medical treatment “under the conditions established by national laws and practices”.

59. The question of the allocation of a State’s finite resources is one which falls within the discretion given by courts to public authorities. The European Court of Human Rights has shown greater deference to the domestic legislature of member states in areas of economic and social policy⁴³¹ than it would in other areas, such as criminal procedure. Whilst it is inappropriate for the courts to engage in redistribution of resources, principles of non-discrimination and reasonableness of decision-making are relevant even in the area of economic and social policy. For example, in *Nitecki v Poland*, the European Court of Human Rights considered whether the State’s refusal to fund a particular drug was discriminatory. Whilst it ultimately found that it was not, it stated:

The Court recalls that Article 14 only prohibits differences in treatment which have no objective or reasonable justification. However, the Court finds such justification to exist in the present health care system which makes difficult choices as to the extent of public subsidy to ensure a fair distribution of scarce financial resources. There is no evidence of arbitrariness in the decisions which have been taken [...]⁴³²

⁴³⁰ *Improving services and support for people with dementia*, National Audit Office, HC 604 Session 2006-2007, 4 July 2007.

⁴³¹ *Buckley v United Kingdom* (1996) 23 EHRR 101.

⁴³² *Nitecki v Poland*, App. No. 65653/01, 21 March 2002 (Adm.) at para 3.

Conclusions and recommendations

Treatment of older people in hospitals and care homes

1. In our view, elder abuse is a serious and severe human rights abuse which is perpetrated on vulnerable older people who often depend on their abusers to provide them with care. Not only is it a betrayal of trust, it would also, in certain circumstances, amount to a criminal offence. (Paragraph 20)
2. We were pleased to hear the Minister's assurance that "nobody should be discharged from hospital without appropriate arrangements being put in place for their care" and his acknowledgement that the operation of the Regulations could have human rights implications. However, although Department of Health guidance sets out a number of principles which it suggests should be applied, including that discharge should be "planned for at the earliest opportunity across the primary, hospital and social care services", we are concerned that, for a number of reasons, this is simply not happening in practice. We are also concerned that the premature or inappropriate discharge of older people could lead to their readmission shortly afterwards. (Paragraph 38)
3. We recommend the Government amend the Delayed Discharge Regulations to allow for flexibility in applying the time period so as to ensure that the Article 8 ECHR rights of older people are respected. We also recommend that the Government issue guidance for hospitals and local authorities on the application of the Regulations to ensure respect for the Article 8 rights of older people. (Paragraph 40)
4. What became clear to us from the evidence is that an older person's age is much less likely to be directly taken into account when decisions are taken about his or her healthcare than in the past. However, age discrimination in both hospitals and care homes is now more subtle and indirect. (Paragraph 47)
5. We consider that the power imbalance between service providers and service users and the strong evidence that we have received of historic and embedded ageism within healthcare for older people are important factors in the failure to respect and protect the human rights of older people. These problems require more than simply action at the local level, but an entire culture change in the way that healthcare services for older people are run, as well as strong leadership from the top. The Human Rights Act has an important role to play in moving the culture to one where the needs of the individual older person are at the heart of healthcare services. (Paragraph 59)
6. We are convinced that the existing legislation does not sufficiently protect and promote the rights of older people in healthcare. We recommend that there should be a positive duty on providers of health and residential care to promote equality for older people. We also recommend that the current prohibition on age discrimination in the workplace be extended to the provision of goods, facilities and services, so as to encompass (amongst other activities) the provision of healthcare. (Paragraph 64)

7. We recommend that the Commission for Equality and Human Rights monitors the implementation of human rights and equality legislation in healthcare for older people and reports on this in its State of the Nation report. (Paragraph 65)

Understanding how the Human Rights Act applies to older people in healthcare

8. We were impressed by the commitment to a human rights approach in healthcare shown by everyone who provided evidence to us. We agree with the British Institute of Human Rights' comment that "the human rights of older people are particularly invisible in society". (Paragraph 67)
9. In our view there is a significant distinction, with implications for users of services, between a "duty to provide" under care standards legislation and a "right to receive" under human rights legislation. We believe that when health and social care workers carry out their function to the best of their ability this should be both because they see it as their job and responsibility to provide certain levels of care and because they understand that the patient has a need, reinforced by the law, to be treated with respect for their dignity. (Paragraph 77)
10. The Human Rights Act empowers users of public services who are often in vulnerable circumstances and who would otherwise be powerless in the face of inherently unresponsive systems. (Paragraph 82)
11. We recommend that the Government, other public bodies and voluntary organisations should publicly champion an understanding of how the recognition of human rights principles can underpin a transformation of health and social care services. This should lead to a greater understanding of human rights in civil society and more effective implementation of the Human Rights Act within public authorities. (Paragraph 94)
12. We recommend that the Commission for Equality and Human Rights in fulfilment of its duty to "promote understanding of the importance of human rights" should ensure that such an understanding is widely disseminated. (Paragraph 95)

Department of Health's leadership

13. In our view, the political leadership from Department of Health Ministers that has been shown in the last few months (at least since we announced our inquiry) is commendable. But the fact remains that it has come seven years after the Human Rights Act came into force. The failure by the Department of Health to give a lead has meant that the Government's job has, of necessity, had to be done by voluntary organisations, often with few staff, no power and scarce resources. Inevitably it has been an uphill struggle to make an impact. (Paragraph 106)
14. We urge the Department of Health to maintain the clear political leadership that it has recently shown on the importance of human rights in health and social care. We recommend that in any constitution or statement of purpose which the Department of Health might draw up next year to celebrate sixty years of the NHS, a statement

about the importance of human rights to the provision of health services should be included. (Paragraph 107)

15. We urge the Government as a whole to maintain consistent and constructive support for the Human Rights Act and its importance in contributing to the improvement of our public services and the empowerment of people using them. (Paragraph 109)
16. We are impressed by the fact that there are ministers and senior officials within the Department of Health who have recently come to understand the importance of human rights in healthcare. The references to human rights in the published policy documents which we have seen are good but we are concerned about whether human rights principles are actually having an impact on policy-making in practice. (Paragraph 110)
17. None of the evidence that the Department of Health has provided to us during this inquiry gives us confidence that the Human Rights Act is in fact “an integral part of policy-making” within the Department. (Paragraph 114)
18. Our concern is that, although the policy developments on human rights referred to above, of which the British Institute of Human Rights initiative is the most significant, are all laudable, they are piecemeal and in danger of lacking impact because what is still missing is a department-wide strategy which can incorporate these actions within it. Without such a strategy endorsed at the highest departmental level, it is all too easy for good pieces of work to end up having little or no impact in practice. We cannot fathom what the Department means when it says it needs to “investigate options for dissemination of the outputs” – why can it not confirm, in plain English, as the Minister did, admirably in oral evidence, that it will make sure the framework document reaches the largest number of people providing healthcare services? (Paragraph 120)
19. We recommend that the Department of Health draw up and publish a strategy setting out how it intends to make the Human Rights Act integral to policy-making in health and social care across the whole department. (Paragraph 122)
20. We also recommend that the Department of Health publish an evaluation of the pilot project undertaken by the British Institute of Human Rights and five NHS trusts on using a human rights approach in healthcare. Using its normal channels of communication, it should distribute copies of *Human Rights in Healthcare – A Framework for Local Action* to all NHS trusts. (Paragraph 123)
21. The Department should then survey trusts within, say, a year to find out the extent to which trusts are incorporating a human rights approach in healthcare services. The Department of Health should also commit to providing sufficient funding to implement the emerging good practice more widely. This is likely to include capacity building for providers of health services as well as training of staff and provision of information to patients. (Paragraph 124)

Implementation of the Human Rights Act by providers of services

22. We regret the failure of both the Department of Health and the Ministry of Justice to provide proper leadership and guidance to providers of health and residential care services on the implications of the Human Rights Act since it came into force. (Paragraph 131)
23. We recommend that the Department of Health and representatives of health and social care bodies provide guidance to hospitals and care homes on implementing a human rights approach in the planning and delivery of public services. Such guidance should emphasise that implementation should not be exclusively legalistic and should avoid being merely a tick-box exercise. (Paragraph 137)
24. We recommend that the Commission for Equality and Human Rights ensures that public authorities, particularly in health and social care services, are receiving the right kind of guidance to enable them to implement the Human Rights Act effectively. (Paragraph 138)
25. We are concerned, however, by the implication from the case studies provided by the NHS Confederation that embedding human rights is merely an exercise in best practice rather than a requirement underpinned by statute. (Paragraph 139)
26. We remain unconvinced that public authorities are alert to the significance of ministerial language. The Government needs to do much more to explain in a clearer way what the positive obligation doctrine means. (Paragraph 142)
27. In our opinion, measures reinforcing the positive obligations doctrine under the ECHR would kick-start the institutional changes that are needed within public authorities. Unless an obligation encapsulating these positive requirements is provided for, we are not confident that public authorities will implement them. (Paragraph 151)
28. While recognising that there are problems of legal certainty, we recommend that the Government take the opportunity presented by its commitment to pass single equality legislation in this Parliament to make explicit that public authorities are under a positive duty to take active steps to protect and respect human rights where the Convention imposes a positive obligation to do so. (Paragraph 152)
29. We recommend that the Commission for Equality and Human Rights makes sure that public authorities are fully aware of their positive obligations under human rights law and we anticipate that it will actively participate in debates about including “respect for human rights” in the proposed single equality duty. (Paragraph 153)
30. We urge the Government to fulfil the welcome commitments it has recently made in Parliament to take action to bring private and voluntary care homes within the scope of the Human Rights Act as soon as possible by regulation in the short-term and by amendment to primary legislation in the longer term. However, we note that, this will not resolve the broader problem of the provision of public services by private providers (as referred to in our recent Report). (Paragraph 161)

Health and social care inspectorates and NICE

31. Although the requirements in the healthcare standards to “respect human rights” and treat patients with “dignity and respect” are welcome, they lack specificity and we recommend that the Healthcare Commission provides guidance to NHS trusts on what is required of them to meet these standards in practice. (Paragraph 173)
32. In order to avoid the unfortunate impression that the human rights of people in care homes are less important and less enforceable than the human rights of patients in hospitals, we recommend that, following the current review, the human rights of residents be more explicitly spelt out in the care home standards. (Paragraph 178)
33. Because of the recent court decision that private care homes are not public authorities under the Human Rights Act, we recommend, as an interim measure before legislation is passed, that the care standards regulations be amended to require, as the health standards do, that care homes respect residents’ human rights in accordance with the Human Rights Act. (Paragraph 179)
34. We also recommend that when the health and social care inspectorates are merged, that the standards applicable to quality of care and other issues engaging the human rights of users of services should be the same for both NHS trusts and care homes. The unified standards should expressly require compliance with human rights standards by hospitals and care homes and state that patients and care home residents have the legal right to respect for and protection of their human rights. The newly established inspectorate should provide guidance to providers of services on the implications of such requirements. (Paragraph 180)
35. In our opinion, the Healthcare Commission should not view the Human Rights Act as “one of a large number of sets of regulations” to which it is subject. Instead it should regard the framework created by the Act as over-arching and fundamental to all its work. We recommend that the Healthcare Commission ensures that the Human Rights Act is explicitly used in its regulatory work. We also recommend that the forthcoming merged inspectorate for health, social care and mental health adopt a human rights framework for all its work. (Paragraph 184)
36. We recommend that the forthcoming merged inspectorate for health, social care and mental health adopts a human rights framework with the intention that the framework informs all of the inspectorate’s work and so makes it more effective in fulfilling its statutory duties. (Paragraph 189)
37. We recommend that the newly established health and social care inspectorate surveys providers of health and social care services and reports on their levels of understanding of and compliance with the Human Rights Act within three years of the new commission starting operations. (Paragraph 190)
38. We are not convinced that the National Institute for Health and Clinical Excellence are fully taking human rights into account in their decision-making. (Paragraph 193)
39. We recommend that the National Institute for Health and Clinical Excellence demonstrates in all relevant publications that, in its decisions on clinical practice, it

has expressly taken into account the Convention rights of any patients who may be affected, as required by the Human Rights Act. (Paragraph 198)

The role of staff in protecting human rights

40. In our view, human rights training should have been provided throughout hospitals and care homes and other public service organisations from 2000. We recommend that all staff working in healthcare (both clinical and non-clinical) receive targeted and regular training in human rights principles and positive duties and how they apply to their work. (Paragraph 222)
41. We recommend that the Department of Health review, within three years, the extent to which training has taken place within healthcare and the effects of that training. We also recommend that the Department of Health produce guidance, building on its pilot with the British Institute of Human Rights, including case studies and examples as appropriate, of best practice in training different groups of healthcare staff on human rights principles as they apply to their day to day work. (Paragraph 223)
42. We also recommend that the reports on individual healthcare providers by the newly merged health and social care inspectorate should include details of the human rights training that has been provided to staff. Further, we recommend that the Commission on Equality and Human Rights monitors the extent to which hospitals and care homes include human rights principles in their staff training. (Paragraph 224)
43. We recommend that a basic understanding of how the Human Rights Act requires the protection of basic principles such as dignity, fairness, respect and equality be included in qualifications, accreditation and re-licensing for health professionals. (Paragraph 226)
44. Whilst we do not want to increase the burdens on healthcare staff, we are conscious that they have a vital role to play in ensuring that all patients and residents with whom they come into contact are treated with dignity and respect and are not subjected to abuse. A duty to report suspected abuse is more than merely a moral duty and we consider that such a duty should be a requirement for all staff working in the NHS and in care homes. We therefore recommend that the Government include a requirement in both the Care Standards for Better Health and the National Minimum Standards for Care Homes for Older People (or, as we have already recommended, preferably in one set of integrated care standards) that hospitals and care homes should have a policy requiring all healthcare workers to report abuse or suspected abuse, with protection for whistle-blowing and confidentiality. (Paragraph 232)

Empowering older people

45. We were alarmed and concerned by how little protection care home residents appear to have against eviction, as compared to ordinary tenants in rented accommodation

who have the protection of housing legislation, and suggest that rectifying this anomaly be considered as a matter of urgency. (Paragraph 241)

46. In our view, in order to ensure greater protection of an individual's human rights, an individual (or his or her relative or carer) must have a real and effective means of raising concerns with service providers and, if they are not able to deal satisfactorily with the issue, a third party to which he or she can address complaints. Such mechanisms go to the very heart of ensuring that the human rights of patients and residents are respected in practice. (Paragraph 243)
47. We conclude that older people, especially those who are the most vulnerable, would greatly benefit from the assistance of independent advocates in order to secure their human rights on the same basis as the rest of society. We welcome the Minister's support for independent advocates and recommend that he ensures that the Department provides sufficient independent advocacy services to older people, with particular priority being given to older people with mental health problems or who are unable to communicate in English. These advocates should have an understanding of human rights principles and the positive duties of service providers towards older people. (Paragraph 249)
48. We welcome the Government's consultation on the merger of the inspectorates, although we are concerned that the consultation suggests that the new inspectorate will not handle individual complaints. We were alarmed that the Minister was unable to guarantee that the new inspectorate would be able to investigate individual complaints at the appropriate point in the process. We are convinced that complaints, including those raising human rights concerns, need to be investigated by an independent third party, rather than by the organisation against which the complaint is made and where the older person may continue to live. We therefore recommend that the newly merged inspectorate be empowered to investigate individual complaints, as the Healthcare Commission is currently able to do. (Paragraph 258)
49. There is clearly some important promotional work which needs to be carried out to improve the image of human rights within the population generally, including older people. We commend the former Minister for Human Rights and the former Lord Chancellor for the steps that they have taken, as part of the Government's *Common Values, Common Sense* campaign. We urge the new members of the Government, in particular the new incumbents in the Ministry of Justice, to be steadfast in their support for the Human Rights Act and its real importance for many ordinary people, including older people receiving health and care services. (Paragraph 269)
50. It is important that older people and their advocates or carers have sufficient information about their rights, to ensure that they can claim them from service providers if they wish to do so. However, this should be a matter of last resort. Given the power imbalance between older people and service providers, and their resulting reluctance to complain, we do not consider that it is either realistic or appropriate to expect older people to shoulder the burden for ensuring that service providers treat them with respect for their human rights. The primary responsibility for the

protection of human rights, as we have repeatedly said in this Report, falls on providers of public services. (Paragraph 272)

51. We consider that a dual approach is required: firstly, older people need information about their human rights; and secondly, institutions need to mainstream human rights within their work. We recommend that the Department of Health, the inspectorates, healthcare policy-makers and every provider of healthcare services make a public commitment to: (a) embed a human rights approach in hospitals and care homes across the country and (b) make sure that accessible information on human rights and how to use them are provided to patients, care home residents, relatives, carers and advocates, and the public as a whole. (Paragraph 276)
52. In addition, we recommend that the Commission for Equality and Human Rights, in partnership with organisations representing older people, assesses the quality of the information available to older people, their families and carers on the application of human rights principles to their lives and makes sure that the best information is widely disseminated. Independent advocates and advisors have a crucial role to play in assisting people to understand and apply these concepts. (Paragraph 277)
53. We recommend that information on human rights be presented by the NHS in an appropriate way to older people. (Paragraph 282)
54. We recommend that information on the human rights of older people and the duties of service providers as “public authorities” under the Human Rights Act be provided to older people, in an accessible form, on entry to the care home or hospital. The applicable care standards for hospitals and care homes should be revised to require that service providers make specific reference to an individual’s human rights and the avenue for making a complaint. (Paragraph 288)

Formal Minutes

Monday 16 July 2007

Members present:

Mr Andrew Dismore MP, in the Chair

Lord Judd

Lord Lester of Herne Hill

Lord Plant of Highfield

Baroness Stern

Nia Griffith MP

Dr Evan Harris MP

Draft Report [Human Rights of Older People in Healthcare], proposed by the Chairman, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 288 read and agreed to.

Annex read and agreed to.

Summary read and agreed to.

Resolved, That the Report be the Eighteenth Report of the Committee to each House.

Several Papers were ordered to be appended to the Report.

Ordered, That the Chairman make the Report to the House of Commons and that Baroness Stern make the Report to the House of Lords.

[Adjourned till Monday 23 July at 3.30pm.]

List of Witnesses

Page

Monday 5 March 2007

Ms Jean Gould, Legal Officer, Help the Aged; **Mr Philip Hurst**, Policy Manager, Health and Social Care, and **Ms Nony Ardill**, Legal Policy Adviser, Age Concern England; and **Dr Gillian Dalley**, Chief Executive, Residents & Relatives Association Ev 1

Monday 26 March 2007

Ms Anna Walker, Chief Executive and **Ms Amanda Hutchinson**, Head of Long-Term Conditions, Healthcare Commission Ev 18

Dame Denise Platt, Chair and **Mr Mike Rourke**, Director of Inspection, Regulation and Review, Commission for Social Care Inspection Ev 23

Mr Andrew Dillon, Chief Executive, **Dr Carole Longson**, Health Technology Evaluation Centre Director, National Institution for Health and Clinical Excellence Ev 28

Monday 23 April 2007

Mr Gary FitzGerald, Chief Executive, Action on Elder Abuse and **Mr Andrew Chidgey**, Head of Policy and Campaigns, Alzheimer's Society Ev 34

Ms Katie Ghose, Director, British Institute of Human Rights, and **Dr Theo Gavrielides**, Head of Policy, Race on the Agenda Ev 42

Monday 14 May 2007

Professor Peter Crome, British Geriatrics Society, and **Ms Pauline Ford**, Royal College of Nursing Ev 49

Ms Jenny Owen and **Mr Dwayne Johnson**, Association of Directors of Adult Social Services, and **Dr Gill Morgan**, NHS Confederation Ev 57

Monday 4 June 2007

Mr Ivan Lewis MP, Minister of State, **Mr David Behan**, Director General, Social Care, and **Mr Surinder Sharma**, National Director for Equality and Human Rights, Department of Health Ev 67

List of Written Evidence

	<i>Page</i>
1 John Coggon	Ev 85
2 Medical Ethics Alliance	Ev 85
3 British Geriatrics Society	Ev 92
4 British Geriatrics Society	Ev 96
5 British Geriatrics Society	Ev 97
6 Herefordshire Older People's Champions Group	Ev 97
7 Faculty of Old Age Psychiatry of the Royal College of Psychiatrists	Ev 99
8 National Pensioners Convention	Ev 103
9 Christian Council on Ageing	Ev 104
10 Department of Health	Ev 105
11 Department of Health	Ev 106
12 Department of Health	Ev 116
13 Department of Health	Ev 121
14 Janet Pyle	Ev 122
15 Professor Peter H Millard of St. George's, University of London	Ev 123
16 Age Concern	Ev 124
17 Mind (National Association for Mental Health)	Ev 134
18 Alzheimer's Concern Ealing	Ev 140
19 The Healthcare Commission	Ev 143
20 The Royal College of Physicians of Edinburgh	Ev 153
21 The British Psychological Society	Ev 156
22 Help the Aged	Ev 159
23 The British Institute of Human Rights	Ev 170
24 The Commission for Social Care Inspection	Ev 176
25 Law Centre (NI)	Ev 180
26 The Royal College of Nursing	Ev 186
27 The Royal College of Nursing	Ev 189
28 The Royal College of Nursing	Ev 190
29 Professor Peter Kinderman	Ev 190
30 Residents and Relatives Association	Ev 191
31 Race On The Agenda	Ev 196
32 National Institute for Health and Clinical Excellence	Ev 204
33 Alzheimer's Society	Ev 211
34 Action on Elder Abuse	Ev 219
35 Association of Directors of Adult Social Services	Ev 223
36 Association of Directors of Adult Social Services	Ev 228
37 NHS Confederation	Ev 230
38 NHS Confederation	Ev 232
39 Ken Mack	Ev 239

Reports from the Joint Committee on Human Rights in this Parliament

The following reports have been produced

Session 2006–07

First Report	The Council of Europe Convention on the Prevention of Terrorism	HL Paper 26/HC 247
Second Report	Legislative Scrutiny: First Progress Report	HL Paper 34/HC 263
Third Report	Legislative Scrutiny: Second Progress Report	HL Paper 39/HC 287
Fourth Report	Legislative Scrutiny: Mental Health Bill	HL Paper 40/HC 288
Fifth Report	Legislative Scrutiny: Third Progress Report	HL Paper 46/HC 303
Sixth Report	Legislative Scrutiny: Sexual Orientation Regulations	HL Paper 58/HC 350
Seventh Report	Deaths in Custody: Further Developments	HL Paper 59/HC 364
Eighth Report	Counter-terrorism Policy and Human Rights: Draft Prevention of Terrorism Act 2005	HL Paper 60/HC 365
Ninth Report	The Meaning of Public Authority Under the Human Rights Act	HL Paper 77/HC 410
Tenth Report	The Treatment of Asylum Seekers: Volume I Report and Formal Minutes	HL Paper 81-I/HC 60-I
Tenth Report	The Treatment of Asylum Seekers: Volume II Oral and Written Evidence	HL Paper 81-II/HC 60-II
Eleventh Report	Legislative Scrutiny: Fourth Progress Report	HL Paper 83/HC 424
Twelfth Report	Legislative Scrutiny: Fifth Progress Report	HL Paper 91/HC 490
Thirteenth Report	Legislative Scrutiny: Sixth Progress Report	HL Paper 105/HC 538
Fourteenth Report	Government Response to the Committee's Eighth Report of this Session: Counter-Terrorism Policy and Human Rights: Draft Prevention of Terrorism Act 2005 (Continuance in force of sections 1 to 9 order 2007)	HL Paper 106/HC 539
Fifteenth Report	Legislative Scrutiny: Seventh Progress Report	HL Paper 112/HC 555
Sixteenth Report	Monitoring the Government's Response to Court Judgments Finding Breaches of Human Rights	HL Paper 128/HC 728
Seventeenth Report	Government Response to the Committee's Tenth Report of this Session: The Treatment of Asylum Seekers	HL Paper 134/HC 790
Eighteenth Report	The Human Rights of Older People in Healthcare: Volume I- Report and Formal Minutes	HL Paper 156-I/HC 378-I
Eighteenth Report	The Human Rights of Older People in Healthcare: Volume II- Oral and Written Evidence	HL Paper 156-II/HC 378-II
Nineteenth Report	Counter-Terrorism Policy and Human Rights: 28 days, intercept and post-charge questioning	HL Paper 157/HC 394

Session 2005–06

First Report	Legislative Scrutiny: First Progress Report	HL Paper 48/HC 560
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Second Report	Deaths in Custody: Further Government Response to the Third Report from the Committee, Session 2004–05	HL Paper 60/HC 651
Third Report	Counter-Terrorism Policy and Human Rights: Terrorism Bill and related matters Volume I Report and Formal Minutes	HL Paper 75-I/HC 561-I
Third Report	Counter-Terrorism Policy and Human Rights: Terrorism Bill and related matters Volume II Oral and Written Evidence	HL Paper 75-II/HC 561-II
Fourth Report	Legislative Scrutiny: Equality Bill	HL Paper 89/HC 766
Fifth Report	Legislative Scrutiny: Second Progress Report	HL Paper 90/HC 767
Sixth Report	Legislative Scrutiny: Third Progress Report	HL Paper 96/HC 787
Seventh Report	Legislative Scrutiny: Fourth Progress Report	HL Paper 98/HC 829
Eighth Report	Government Responses to Reports from the Committee in the last Parliament	HL Paper 104/HC 850
Ninth Report	Schools White Paper	HL Paper 113/HC 887
Tenth Report	Government Response to the Committee's Third Report of this Session: Counter-Terrorism Policy and Human Rights: Terrorism Bill and related matters	HL Paper 114/HC 888
Eleventh Report	Legislative Scrutiny: Fifth Progress Report	HL Paper 115/HC 899
Twelfth Report	Counter-Terrorism Policy and Human Rights: Draft Prevention of Terrorism Act 2005 (Continuance in force of sections 1 to 9) Order 2006	HL Paper 122/HC 915
Thirteenth Report	Implementation of Strasbourg Judgments: First Progress Report	HL Paper 133/HC 954
Fourteenth Report	Legislative Scrutiny: Sixth Progress Report	HL Paper 134/HC 955
Fifteenth Report	Legislative Scrutiny: Seventh Progress Report	HL Paper 144/HC 989
Sixteenth Report	Proposal for a Draft Marriage Act 1949 (Remedial) Order 2006	HL Paper 154/HC 1022
Seventeenth Report	Legislative Scrutiny: Eighth Progress Report	HL Paper 164/HC 1062
Eighteenth Report	Legislative Scrutiny: Ninth Progress Report	HL Paper 177/HC 1098
Nineteenth Report	The UN Convention Against Torture (UNCAT) Volume I Report and Formal Minutes	HL Paper 185-I/HC 701-I
Twentieth Report	Legislative Scrutiny: Tenth Progress Report	HL Paper 186/HC 1138
Twenty-first Report	Legislative Scrutiny: Eleventh Progress Report	HL Paper 201/HC 1216
Twenty-second Report	Legislative Scrutiny: Twelfth Progress Report	HL Paper 233/HC 1547
Twenty-third Report	The Committee's Future Working Practices	HL Paper 239/HC1575
Twenty-fourth Report	Counter-Terrorism Policy and Human Rights: Prosecution and Pre-Charge Detention	HL Paper 240/HC 1576
Twenty-fifth Report	Legislative Scrutiny: Thirteenth Progress Report	HL Paper 241/HC 1577
Twenty-sixth Report	Human trafficking	HL Paper 245-I/HC 1127-I
Twenty-seventh Report	Legislative Scrutiny: Corporate Manslaughter and Corporate Homicide Bill	HL Paper 246/HC 1625
Twenty-eighth Report	Legislative Scrutiny: Fourteenth Progress Report	HL Paper 247/HC 1626
Twenty-ninth Report	Draft Marriage Act 1949 (Remedial) Order 2006	HL Paper 248/HC 1627
Thirtieth Report	Government Response to the Committee's Nineteenth Report of this Session: The UN	HL Paper 276/HC 1714

	Convention Against Torture (UNCAT)	
Thirty-first Report	Legislative Scrutiny: Final Progress Report	HL Paper 277/HC 1715
Thirty-second Report	The Human Rights Act: the DCA and Home Office Reviews	HL Paper 278/HC 1716