



AGE
Concern

On the right track?

A progress review of the human rights
of older people in health and social care

Policy Unit – Age Concern England

About Age Concern

Age Concern England (ACE) is a national voluntary organisation aiming to improve the opportunities and quality of life of people over 50. We work through campaigning, public policy development, research, information provision, publishing, training, grant-making and international and European work. ACE is part of Age Concern, the UK's largest federation of organisations working with and for older people. There are over 350 local Age Concerns in England and independent national Age Concerns in Scotland, Wales and Northern Ireland. Age Concern provides vital services and information locally throughout the country. Every day we are in touch with thousands of older people, enabling them to make more of life.

The Policy Unit develops the charity's public policy on ageing and older people, and influences Government and other policy makers through research, responding to consultations, working in partnership, and holding policy events.

Five key steps to a human rights based approach for service providers

1. **Get on board** – ensure the organisation's board understands and acknowledges the role of human rights in transforming standards of service and commits to a human rights-based approach.
2. **Change policy** – incorporate human rights into the strategic objectives of the organisation and develop a Single Equality and Human Rights Scheme so that human rights are mainstreamed within the organisation. Review current policies and procedures to ensure that they conform to the Human Rights Act and reflect human rights principles to help promote a human rights culture.
3. **Change practice** – after identifying the need for change to protect human rights, write action plans, with responsibility clearly designated, and monitor progress on a regular basis.
4. **Engage and empower staff** – develop training programmes and guidance for all staff (including all levels of management) which are tailored to their specific roles in the organisation, helping them to act and make decisions on the basis of human rights principles. Empower staff to propose changes in their own work and suggestions for the organisation to protect human rights.
5. **Engage and empower service users** – engage service users in service improvement by giving them opportunities to voice their views and experiences and suggest solutions. Give them information about their human rights and how they can expect to be treated. Ensure there is a clear and effective process to make a complaint and that everyone is informed of this process.

Foreword

One year ago, the Joint Committee on Human Rights published its hard-hitting report on older people's human rights in healthcare, bringing together evidence from academia, charities, public bodies and older people themselves. The committee made a number of recommendations about steps needed to ensure older people's human rights are protected when they use health and care services. I am pleased to introduce Age Concern's follow-up report, which assesses progress made on these recommendations over the past twelve months. It is clear that much work remains to be done.

It is important to remember that many older people experience care which protects and promotes their human rights from dedicated staff who joined their profession with an instinctive commitment to human rights values. But without a systematic approach to the positive use of the Human Rights Act in health and care at national and local level, infringements of human rights will persist alongside excellence, even within the same institution.

Age Concern welcomes the steps taken by government in the past year. It has extended human rights protection to many people living in care homes; committed to outlaw age discrimination in the health and care sectors; and continues to work with the British Institute of Human Rights on a series of Human Rights in Healthcare pilots. Now is a key time to build on this progress. We must seize the opportunities presented by the NHS Next Stage Review, the NHS Constitution, and the launch of the Care Quality Commission working alongside the Equality and Human Rights Commission. Human rights must become a core part of the work of all public services. Service providers must step up to the mark and learn from the models of good practice that are emerging from both the voluntary and statutory sectors, and commit to making human rights real within their own organisations.

Our report contains some shocking personal accounts of older people's experiences in health and social care services. It is our hope that those with the power to bring change will read them and be spurred on to take the steps we recommend, so that others are not subjected to such disgraceful indignities in future. Human rights provide the key to the cultural change that is so urgently needed.

Gordon Lishman
Director General

Contents

Summary	5
Age Concern's recommendations	7
Introduction	11
1. Steadfast support for human rights?	12
2. Embedding human rights in policy and strategy?	14
3. Sufficient protection through legislation?	16
4. Regulation underpinned by human rights?	20
5. EHRC – fulfilling its human rights role?	22
6. NICE – taking account of human rights?	23
7. Empowering older people?	24
8. Supporting the role of service providers?	27
9. Changing practice at the front line of care?	29
Annex 1 – Background to the Convention Rights	32
Annex 2 – Progress against Joint Committee on Human Rights Recommendations	36

Summary

In August 2007 the Joint Committee on Human Rights (JCHR) published the report of its Inquiry into the human rights of older people in healthcare. The report was frank in its assessment of the failures of leadership on this issue and called for an entire change in culture. One year on, *On the right track?* assesses progress against the recommendations made by the JCHR and sets out a further set of proposals which aim to ensure that the Department of Health's stated ambition can be achieved:

'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.'¹

Since the Human Rights Act 1998 (HRA) was implemented in 2000, weakness in government leadership has meant that the potential of the Act has not been realised. Poor leadership remains a significant problem in the overall approach to human rights across government departments. But more recently there has been positive action from the Department of Health, for example in extending human rights protection to many people in care homes, and in the introduction of a draft NHS Constitution which makes some implicit reference to human rights principles. The government has also announced its intention to introduce legislation to outlaw age discrimination in goods, facilities and services as part of its planned Equality Bill.

Despite these positive steps, much more can be done. The Department of Health is still inclined to rely on terms like 'dignity' and 'respect' in policy documents, without linking them to their legal underpinning, the Human Rights Act. Even when human rights are reflected in policy, there is often a lack of strategic planning as to how protection of rights will be achieved in practice. There is overwhelming evidence that abuses against older people's human rights continue and that the majority of service providers have not adopted a strategy for human rights. Despite this, ministers have taken no action in response to the committee's recommendation that the government should promote better understanding of public bodies' proactive human rights obligations – and consider options for clarifying these responsibilities within legislation.

New opportunities

The JCHR found that the regulation of services with respect to human rights has often fallen short, although there have been instances of good practice. The establishment of a new health and social care regulator, the **Care Quality Commission**, provides an opportunity to create an exemplar approach to the use of human rights in regulation. The Commission will need to develop a human rights framework to underpin all its work.

As the first statutory commission with responsibility for human rights, the **Equality and Human Rights Commission (EHRC)** will play a crucial role in protecting and promoting human rights in health and social care. The EHRC has now launched a human rights inquiry, which aims to set out findings on the state of human rights in Britain and develop recommendations to move the human rights agenda forward.

The proposed **NHS Constitution** provides an exciting opportunity to give both patients and NHS staff information about their human rights and to signal the importance of human rights to the future direction of the service.

Further action

The JCHR report argued that, to achieve a human rights culture in the UK, older people would need to be helped to understand and invoke their human rights. Information is key to this empowerment. Public understanding of the Act is very low and all levels of government, together with service providers, have a key role to play in making service users more aware of their rights and how to secure them. A further aspect of empowering older people is to ensure that there is a **clear and effective structure for voicing complaints**. We remain to be convinced that this will be achieved through the revised complaints structures which are being introduced for health and social care. Close and careful monitoring will be required.

Guidance and training are both essential in encouraging human rights-based approaches by organisations and individuals at the front line of service delivery. This support is essential to help organisations understand their responsibilities and share practical ideas for how to develop human rights-based solutions to any problems which arise. Good quality practical guidance needs to be disseminated widely throughout health and social care.

Professional regulators also have a key role to play in promoting human rights in **professional standards** and in the requirements for undergraduate training and continuing development.

Strong leadership from the centre and exemplary guidance, training and support are vital. But it is local organisations that need to make **the changes on the front line** for older people's human rights to be secured in health and social care. As the JCHR found, there is still much to be done to achieve this – but there are opportunities to build on good practice being developed by organisations such as the British Institute of Human Rights (BIHR).

This report sets out 24 recommendations for action which we believe are essential to achieve the culture change recommended by the JCHR and realise the Department of Health's commitments on older people's human rights. Progress against these will need to be closely monitored.

The government has now set out its ambitious transformation programmes for both the NHS and social care. It supports a vision of services which meet individual needs, are delivered with care and compassion, and attain the highest standards of quality. To achieve these aspirations, a human rights approach needs to be central to the development of both policy and practice in every health and social care organisation.

Age Concern's recommendations

Steadfast support for human rights?

1. The **Ministry of Justice** should demonstrate strong and proactive support for the Human Rights Act at all times. It should scrutinise the work of other departments to ensure that their work promotes human rights values.
2. A future Bill of Rights should not undermine or compromise the effectiveness of the Human Rights Act. Regardless of the Bill of Rights debate, the **Ministry of Justice** should renew its efforts to strengthen the Human Rights Act through educating the public, correcting inaccurate perceptions and urging other key government departments to step up their work on human rights.
3. The **Department of Health** should consolidate and improve its leadership on human rights, through championing the importance of human rights values in health and care services and by supporting capacity building within the NHS and social care providers.

Embedding human rights in policy and strategy?

4. The **Department of Health** should make it clear that notions such as dignity and respect are human rights values and expressly link them with the Human Rights Act in all policy-making.
5. The **Department of Health** should ensure that all human rights values – fairness, equity, and autonomy, as well as dignity and respect – are reflected in the NHS constitution. It should also make it clear that these values are underpinned by the Human Rights Act.
6. The **Department of Health** should report on its review of policy-making processes. It should publicise the human rights considerations which have been taken into account in all policy-making.
7. The **Department of Health** should support and promote human rights-based approaches in all health and social care organisations – including primary care trusts, acute trusts, mental health trusts and care providers – and consider this a core part of the long-term strategy of the Department.
8. The **Department of Health** should extend the Human Rights in Healthcare pilot programme to address embedding a human rights-based approach in acute hospitals and adult social care departments.

Sufficient protection through legislation?

Human rights and independent care

9. As a matter of urgency, the **Department of Health** and **Ministry of Justice** should consider legislative options to secure human rights protection for all users of health and social care services, regardless of funding status.

Appropriate hospital discharges

10. The **Department of Health** should revise the Delayed Discharge Regulations so that both NHS and social care services fully understand their responsibilities and always put the needs of individual patients first. The **Department of Health** should ensure that payment systems in the NHS incentivise safe, supported discharge and the opportunity for rehabilitation for all who can benefit.

Age discrimination law

11. The **government** should promote better understanding of positive human rights obligations, and consider options for codifying these within legislation – for example through an integrated public sector duty or a purpose clause in the Equality Bill.

Regulation underpinned by human rights?

12. The **Care Quality Commission** should put the Human Rights Act at the centre of its work, recognising that human rights values should define the relationship between service providers and service users. In particular, its 'risk based' approach to regulation should take account of risk to human rights infringements.
13. The **Department of Health** should ensure that registration requirements in health and social care explicitly link with human rights requirements.

EHRC – fulfilling its human rights role?

14. The **Equality and Human Rights Commission (EHRC)** should demonstrate strong leadership on human rights, through:
 - promoting the value of human rights-based approaches
 - providing information and guidance to public authorities
 - assuring the quality of information provision to the general public
 - supporting the Care Quality Commission to monitor and drive forward legal compliance and good practice in health and social care.

NICE – taking account of human rights?

15. The **National Institute for Health and Clinical Excellence (NICE)** should adopt a human rights framework for all its work. All its decision-making on clinical practice should take into account the human rights of all patients who are affected.

Empowering older people?

Complaints about care

16. The **Department of Health** should commit to a new mechanism for the independent review of complaints. It should also put in place clear monitoring systems to review the quality of local complaints handling, involving patients and their relatives.
17. The **government** should urgently amend the remit of the Local Government Ombudsman through primary legislation so that it is wide enough to cover self-funding residents, and to ensure that it has adequate resources to fulfil its wider role. The proposed National Health Service Reform Bill could be used to do this.

Advocacy

18. The **government** should develop a national plan for advocacy. It should develop specific guidance for local areas on the commissioning and development of advocacy services that meet the diverse needs of older people.

Information on human rights

19. The **Department of Health** should oversee a local and national public communications campaign to inform people about the duties conferred on NHS organisations by the Human Rights Act and the NHS Constitution.
20. **NHS Trusts and local authorities** should ensure that their communication plans refer to the actions they are taking to protect human rights and what steps people can take if they have concerns.

Supporting the role of service providers?

Guidance

21. The **Department of Health** should ensure that guidance on human rights is widely disseminated throughout the NHS and social care sector.

Training

22. **Professional regulators** (General Medical Council, Nursing and Midwifery Council, etc) should take a strong lead in promoting human rights by reflecting the obligations of the Human Rights Act in professional standards and in their requirements for undergraduate training.
23. **Health and social care employers** should make sure that all staff are trained in human rights.

Changing practice at the front line of care?

24. **Service providers and commissioners** should follow the five steps set out in section 9 and adopt a human rights based approach to their work.

During a stay in hospital, the family of Mr B, aged 76, witnessed many instances of neglect. On one occasion Mr B was left to sit in his own excrement for 30 minutes and this was only dealt with after his family had twice asked for this to be done.

Mr B's son describes his father's care as 'an appalling mixture of incompetence, indifference and inappropriate care complemented by a seemingly dismissive approach to the elderly'.

Introduction

One year ago, spurred on by work in the voluntary sector including Age Concern's report *Rights for Real*², the Joint Committee on Human Rights (JCHR) published its report on older people's human rights in healthcare³. The committee investigated the issue in depth. It took evidence from a wide range of sources and scrutinised the work of government and service providers. The committee concluded that older people continue to suffer unacceptable levels of neglect and abuse when using health services and that a wholesale cultural change is required in the NHS before this will be rectified.

One year on, Age Concern has examined evidence of progress against the JCHR's recommendations. This is set out in detail in Annex 2. Over the past twelve months, there have been a number of positive steps, with particular opportunities at this time to achieve real change. But despite the momentum, there is evidence of continuing problems in the approach to older people's human rights in health and care services. Age Concern has a number of concerns about the current policies and practices of the key players: our report sets out new recommendations based on where we stand in 2008.

The Human Rights Act 1998 (HRA) incorporates the European Convention on Human Rights ('the Convention') into UK law. Human rights can help to counteract the neglect and abuse that continues to be inflicted on some older people in health and care services because it provides a legal framework defining how public bodies, such as NHS Trusts, must treat those who use them. The Act provides enforceable rights, allowing people to go to court if infringements occur. A summary of the Convention rights most relevant to older people appears in Annex 1.

More than this, human rights law also imposes positive obligations on public authorities. This means that public service providers have a duty to promote human rights and take proactive steps to ensure that human rights are protected when they provide people with services. This should mean that potential threats to older people's rights in health and social care are recognised and dealt with before infringements occur.

A human rights approach needs to be embedded in our health and social care systems. Inevitably, this will demand strong leadership.

1. Steadfast support for human rights?

Ministry of Justice

As the lead department on the Human Rights Act 1998 (HRA), the Ministry of Justice has an important role to play in creating a positive human rights culture across government. However its performance to date has been disappointing. The Act is a powerful piece of legislation that brings the European Convention on Human Rights (ECHR) into UK law, allowing UK citizens recourse to courts in this country if their rights are infringed. The legislation was intended to ensure that public authorities such as NHS Trusts change the way they provide services from the outset, before infringements occur. Services should be designed and delivered within a human rights framework so that that older people's human rights are respected.

The Joint Committee on Human Rights (JCHR) report identified a distinct lack of leadership and guidance from the Ministry of Justice in relation to human rights. This had contributed to the fact that service providers and the general public rarely understand the significance and implications of the Act. The JCHR report called for 'steadfast support for the Human Rights Act'.⁴

The Ministry of Justice should be leading across government and demonstrating unwavering commitment to the Act at all times. It should also scrutinise the work of other government departments and question why opportunities have been missed to centralise the HRA in policy-making, for example in healthcare. Yet only this year a report published by the Ministry of Justice questioned 'whether human rights can be used as a tool to improve the public's experiences of public services, or of life in this country more generally'⁵.

Recommendation 1

The Ministry of Justice should demonstrate strong and proactive support for the Human Rights Act at all times. It should scrutinise the work of other departments to ensure that their work promotes human rights values.

The Ministry of Justice is also leading a debate about whether the UK should adopt a Bill of Rights and, if so, what form such legislation should take. In its response to the JCHR's inquiry on this issue, the British Institute of Human Rights (BIHR) noted that the context for this debate is one of misunderstandings and misconceptions about the Human Rights Act. Because of weak leadership from government, a lack of positive information or active promotion, and a lack of capacity building within service providing organisations, the Act has not been embedded in the UK. This has allowed ignorance of the Act to fester and spread as it continues to be criticised by media and politicians alike. There is therefore a real concern that a Bill of Rights would be used as an opportunity to replace or water-down the HRA. It is particularly frustrating that this is happening just as we are beginning to see what the BIHR calls the first 'greenshoots' of good practice emerging⁶.

Recommendation 2

A future Bill of Rights should not undermine or compromise the effectiveness of the Human Rights Act. Regardless of the Bill of Rights debate, the Ministry of Justice should renew its efforts to strengthen the Human Rights Act through educating the public, correcting inaccurate perceptions and urging other key government departments to step up their work on human rights.

Department of Health

The JCHR's report found that in general the Department of Health's leadership on human rights had been disappointing. However there had been a marked improvement since the committee launched its inquiry in 2006. Prior to 2006 the department did not champion the importance of human rights; it failed to make the HRA an integral part of policy-making and it did not commit resources to capacity building within NHS organisations. These three failures contributed significantly to the fact that a human rights culture had not developed within the NHS and hence why human rights abuses continued.

The momentum generated in the months before publication of the JCHR's report has continued. The Department of Health has taken a number of positive steps in the past year. Work has continued on the Human Rights in Healthcare pilots which are being run by the Department of Health in conjunction with BIHR. The Department has allocated £2 million for a Comic Relief study of abuse, neglect and loss of dignity in the institutional care of older people. A draft NHS Constitution has been published which emphasises the right to be treated with dignity and respect. Finally, and very importantly, the department has announced that it will extend human rights protection to the majority of people living in independent care homes.

Recommendation 3

The Department of Health should consolidate and improve its leadership on human rights, through championing the importance of human rights values in health and care services and by supporting capacity building within the NHS and social care providers.

2. Embedding human rights in policy and strategy?

Mrs S, aged 102, felt isolated, disrespected and neglected while she was in hospital. Despite being blind, her meals and drinks were left on a trolley – in most cases without her being alerted. For the most part staff also did not offer any assistance with eating or drinking. As a result many of the meals were removed untouched. Mrs S also suffered a great indignity when she asked for a commode but was told by a nurse that she could use her incontinence pad. Staff frequently talked over her and about her rather than to her in the mistaken belief that she was unable to talk for herself.

Her friend reported that staff generally appeared ‘to see the elderly as non persons to be tolerated rather than individuals to be respected’.

Despite recent positive steps, there are still problems with the Department of Health’s approach to older people’s human rights. A year ago the JCHR voiced concerns that the Department of Health had still not made human rights and the Human Rights Act an integral part of its policy-making. The report observed that instead it tends to rely on notions like ‘dignity’ and ‘respect’ without making the link to the HRA. The result is that the general public, and even service providers, are unaware that dignity and respect are not simply vague ideals or gifts of the state, but basic human rights principles protected by the HRA. Using terms like ‘dignity’ and ‘respect’ in place of references to the HRA has continued over the past year with the launch of further dignity initiatives and the draft NHS Constitution. These all miss opportunities to root the values of the NHS and social care within existing human rights.

Recommendation 4

The Department of Health should make it clear that notions such as dignity and respect are human rights values and expressly link them with the Human Rights Act in all policy-making.

NHS Constitution

The JCHR called for the NHS Constitution to reflect explicitly the importance of human rights in the provision of health services. In July 2008 the Department of Health published a draft NHS Constitution setting out rights, responsibilities and pledges for people using and working in the NHS. Although the draft constitution refers to “the right to be treated with dignity and respect”⁷, it does not link this with the HRA. This is inexplicable since the Constitution is meant to articulate existing rights. The document provides a unique opportunity to ensure that all key human rights principles and the Human Rights Act are ingrained in the fabric of the NHS and that people are clear about their rights.

Recommendation 5

The Department of Health should ensure that all human rights values – fairness, equity, and autonomy, as well as dignity and respect – are reflected in the NHS constitution. It should also make it clear that these values are under-pinned by the Human Rights Act.

The JCHR made it clear that human rights need to become central to the work of government and that work on human rights needs to be more strategic. The Department of Health cited the Human Rights in Healthcare pilots a number of times in its response to the JCHR report as an example of the proactive work it is undertaking. This valuable project is building on learning and best practice from the voluntary sector to introduce a human rights based approach in five NHS trusts. Jointly with BIHR the Department published a report⁸ in March 2007 to explain human rights in a clear and practical way for NHS organisations. The report gives examples of how the HRA can and should be applied to their work. Despite the value of this project, the inescapable truth is that it involves only five pilot sites and work on human rights is very patchy across the rest of the Department's policy-making. Historically, many key Department of Health initiatives have failed to mention the HRA at all and when references appear this is mainly to hold services to account, rather than when developing policy. However, in its response to the JCHR report, the government agreed that 'human rights considerations should be reflected in all policy making' and committed to 'review our policy making processes to ensure that this is the case'⁹.

Recommendation 6

The Department of Health should report on its review of policy-making processes. It should publicise the human rights considerations which have been taken into account in all policy-making.

Even when human rights are reflected in policy, there is often a lack of strategic planning as to how protection of human rights will be achieved in practice. A prime example is *A New Ambition for Old Age*, the next steps document for the National Service Framework for Older People. The document acknowledged that older people's human rights were not being secured within the health and care system and set a clear timetable and aspiration for the future: 'Within five years, our ambition is 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'¹⁰. But this document has not been followed up with a strategy on how to achieve this ambition.

Recommendation 7

The Department of Health should support and promote human rights based approaches in all health and social care organisations – including primary care trusts, acute trusts, mental health trusts and care providers – and consider this a core part of the long-term strategy of the Department.

The Department of Health's strategy to develop human rights based approaches must include further stages to the Human Rights in Healthcare pilots. At present, none of the five pilot sites is in an acute trust setting. Yet the vast majority of concerns raised by older people and their families about breaches of human rights in the NHS relate to their experiences in general hospitals (as reflected in many of the case studies in this report). Most of the evidence submitted to the JCHR Inquiry also related to older people's human rights in hospital or in care homes. There will be a limit to the extent that findings from the current project can be generalised to other parts of the NHS and social care providing a very different range of services and facing different challenges.

The Department of Health wants to encourage further integration between health and social care. It has taken steps towards this, for example with the new integrated regulatory system for health and care. It has also extended human rights protection to cover residents in independent care homes (as discussed further below). Older people who use health and social care services would benefit from an integrated approach to human rights.

Recommendation 8

The Department of Health should extend the Human Rights in Healthcare pilot programme to address embedding a human rights-based approach in acute hospitals and adult social care departments.

3. Sufficient protection through legislation?

Human rights and independent care

The Joint Committee's report highlighted concerns about the legal status of independent care homes. In August 2007, the House of Lords confirmed in the YL case¹¹ that independent care home providers did not perform 'public functions' and were therefore outside the scope of the HRA. This ruling applies even to residents who are solely funded by the state. In May 2008 the government moved to close this 'human rights loophole' following calls for reform in the JCHR's report and by organisations like Age Concern. By amending the Health and Social Care Bill, the government effectively broadened the definition of 'public function', which will mean thousands of vulnerable older people living in independent care homes will be protected by the HRA. This could now be the catalyst to encourage care home providers to design and deliver their services within a human rights framework. If necessary, it will also allow residents to use the HRA in legal enforcement action if they experience ill treatment and abuse or are threatened with eviction.

The government's amendment to the Health and Social Care Bill goes a long way towards addressing the JCHR's concerns about the narrow scope of the HRA. However, this amendment will only benefit care home residents whose care is arranged by their local authority. The government has put on record its view that people whose place is arranged and paid for by the NHS are also covered by the HRA – but it is unclear whether residents who receive the NHS nursing care contribution in part payment of their care home fees would also be protected. Without doubt, people who arrange and wholly fund their own care will still be

outside the scope of the HRA. The government has publicly recognised the need to find a means to protect these self-funding residents¹². Age Concern looks forward to hearing the government's proposals once it has considered the issue further, in the context of a wider debate about the scope of the HRA for organisations performing 'public functions'.

Recommendation 9

As a matter of urgency, the Department of Health and Ministry of Justice should consider legislative options to secure human rights protection for all users of health and social care services, regardless of funding status.

Appropriate hospital discharges

The JCHR report raised specific concerns about the Delayed Discharge Regulations, particularly the short timescale permitted to arrange services to enable discharge to take place. The Delayed Discharge Regulations were originally developed with good intent, as older people do not want to stay in hospital longer than they need to. The regulations have certainly had an effect on practice: in November 2007 the Department of Health reported that the number of bed days lost due to delayed discharges from hospital had continued to fall, decreasing by another 5% in 2006/07¹³.

But there is evidence that, in focusing on swift discharge, too little attention has been given to safe, supported discharge. The JCHR received evidence of a series of problems, which suggest that Article 8 of the Convention (giving a right to respect for one's private and family life and home) is often contravened, particularly where the discharge is to a care home. These infringements included older people having no choice on discharge; being put into placements that did not meet their needs; having no chance to come to terms with the implications of discharge arrangements; being discharged to care miles away from families and friends; being discharged to care homes instead of receiving rehabilitation or returning to their homes with community support; and being discharged without adequate care in place or when they were still unwell. The consequence of this is that there has been a 31% increase in emergency readmissions to hospital between 1998 and 2006. In 2006 the NHS reported that more than 1 in 10 patients aged over 75 were subsequently readmitted to hospital in an emergency¹⁴.

Pressure to discharge patients has been increased by the application of the Payment by Results tariff which results in hospitals being paid at average costs: patients with longer than average lengths of stay are not profitable to NHS Trusts. The Department of Health has made a commitment to develop the Payment by Results system to support a greater focus on the quality of care. This will need to address how to ensure that organisations are encouraged to work together to achieve both safe discharges from hospital and the best possible level of independence for individual patients.

The Department of Health has maintained that there is sufficient flexibility in the regulations to ensure that older people are not discharged prematurely. But the fact that older people are still moved directly from acute beds to care homes (contrary to Department of Health guidance), the shortage of community support and the statistics on readmission rates all

point to a continuing problem. Furthermore, the final report from the NHS Next Stage Review acknowledges that partnership working between organisations must be improved and stresses the need to organise services around people, rather than people around services. One of the direct benefits it envisages from this approach is a reduction in unnecessary readmissions to hospital.

Recommendation 10

The Department of Health should revise the Delayed Discharge Regulations so that both NHS and social care services fully understand their responsibilities and always put the needs of individual patients first. The Department of Health should ensure that payment systems in the NHS incentivise safe, supported discharge and the opportunity for rehabilitation for all who can benefit.

Age discrimination law

An older person describes an incident witnessed while in hospital:

‘I was very distressed, and frightened for myself, at the treatment meted out to an elderly confused lady in the adjacent bed. She was bewildered but very quiet and no trouble. No one called her by name. She was rolled onto her injured leg with a brusque warning. Then the nurses exchanged jokes above her head. She was left without a word of explanation or kindness or feeling’.

As the JCHR report observed, ageist attitudes and discriminatory practices underlie many human rights abuses of older people within health and social care services. The committee’s report called for age discrimination in goods, facilities and services to be outlawed and for a public sector duty to promote equality for older people. Age Concern has welcomed the government’s announcement that it will include legislation to tackle age discrimination in goods and services within the Equality Bill. We also welcome the commitment that the Bill will include an integrated public sector duty across six equality grounds, including age.

The entrenched and continuing problem of age discrimination within health and social care must be addressed through comprehensive legislation that is implemented without any further delay. There is clearly an urgent need. Age discrimination in the NHS and social care takes a number of forms. Some discriminatory rules persist and control access to treatment and care. For example at the age of 65 people may be transferred from ‘adult’ mental health services to services for ‘older people’ – often focused primarily on the needs of people with dementia. As a result, people can lose access to the care they need and are familiar with, such as day care services, even if their needs have not changed.

Mrs M suffers from depression following bereavement. For five years she has attended a drop-in centre where her condition improved but now she is 65 she has been asked to leave because the service is only for people of 'working age'. She has discovered that mental health services for the over 65s are mainly targeted at people with dementia.

Discrimination can also affect decisions about treatment in a less obvious way, as healthcare staff may not offer or refer older people for treatment because of their age. Peer reviewed research evidence suggests that treatment for minor strokes is covertly rationed for people over 80 and that doctors are less likely to refer angina sufferers to see a specialist or to have tests if they are over 65¹⁵.

Ageist attitudes can also compromise the standards of care that older people receive, although some hospitals have developed innovative strategies for counteracting this. In a 2008 Westminster Hall debate¹⁶, MPs discussed the practice in one hospital of putting photos of older people when they were younger next to their hospital beds to remind staff that they were people who have led valuable and important lives. Such images of the patients, as soldiers, parents and pillars of the local community 'brought home to the staff working there that they were dealing with real human beings who deserved the respect that they were giving them'. Welcome as it is, the fact that this kind of practice is needed underlines the real and significant the problems of age discrimination in health and care services.

Positive human rights obligations

The JCHR also recommended that the government use the opportunity offered by the Equality Bill to make explicit that public authorities have positive obligations under human rights law to promote and protect human rights. In 2003 the Audit Commission found that 58% of public bodies had not adopted a strategy for human rights, whilst in the NHS only a quarter of trusts were taking action¹⁷. The JCHR found little evidence to suggest that this had changed in the four years since the Audit Commission's report was published and concluded that the majority of public authorities still had limited understanding of their positive human rights obligations¹⁸.

Positive human rights obligations have been developed through the decisions of the European Court of Human Rights. The government maintains that, because the HRA makes it explicit that a public authority must not act incompatibly with a Convention right, these obligations do not need to be expressed in UK law¹⁹. But experiences on the ground tell us that this is simply not the case. Age Concern continues to receive stories of older people's neglect, ill treatment and even abuse at the hands of public service providers. Crucially, this occurs at a level at which it cannot be attributed to the actions of a few wayward individuals but reflects endemic failures or problems in the culture of organisations. As recently as May 2008 the British Medical Association found that 85% of its members were concerned or very concerned about healthcare services for older people²⁰. A Royal College of Nursing survey released in April 2008 found that eight out of 10 nurses had left work feeling upset or distressed because they were not able to ensure patients had been treated with dignity²¹.

The JCHR's idea of using the Equality Bill to codify positive human rights obligations within UK law, perhaps as part of an integrated public sector duty, is one that should be given serious consideration. To a lesser effect this could be achieved by prefacing the Equality Bill with a purpose clause, expressly recognising the close relationship between equality duties and human rights obligations. The EHRC could also assist the understanding of positive human rights obligations by developing and promoting a human rights code of practice. If placed on a statutory footing, such a code would be a powerful tool.

Recommendation 11

The government should promote better understanding of positive human rights obligations, and consider options for codifying these within legislation – for example, through an integrated public sector duty or a purpose clause in the Equality Bill.

4. Regulation underpinned by human rights?

Mr A, aged 92, was treated with a lack of care and dignity in hospital before he died. Basic elements of care were not provided and he was left in a state of extreme discomfort until his children requested care or even administered it themselves. Mr A's family felt that some of the staff showed a lack of respect for their father by talking about him in his presence without trying to explain to him what was happening.

When Mr A's daughters arrived at hospital the day he died he had been left semi-naked in a public ward in full view of other patients and their visitors.

The health and social care regulators play an important role in the human rights picture. Yet, as the JCHR observed, overall the work of the regulators has frequently fallen short. They have not made explicit the relevance of the HRA and they have not communicated its importance to service providers.

However there have also been some examples of good practice by regulators, including the Audit Commission's 2003 report on human rights, the Healthcare Commission's 2007 *Caring for Dignity* report and the joint report by the Healthcare Commission, Commission for Social Care Inspection and the Audit Commission, *Living Well in Later Life*, published in 2006. The Mental Health Act Commission has taken a particularly systematic approach to putting the Human Rights Act into the mainstream of its work.

The organisation of the regulation of health and social care is in the process of being changed dramatically. From April 2009 the Healthcare Commission, Commission for Social Care Inspection and Mental Health Act Commission will be merged into a new single regulatory body, the Care Quality Commission (CQC).

The development of the CQC presents a key opportunity to take the best practice from the existing commissions, but also to develop a consistent and exemplar approach to human rights across all health and social care services. For example, the new commission could work from the start jointly with the Equality and Human Rights Commission to develop inspection and monitoring procedures that routinely assess human rights compliance.

Recommendation 12

The Care Quality Commission should put the Human Rights Act at the centre of its work, recognising that human rights values should define the relationship between service providers and service users. In particular, its 'risk based' approach to regulation should take account of risk to human rights infringements.

Standards

The Department of Health has consulted on the registration requirements that the CQC will require from service providers. The CQC will consult separately on the standards it will require to demonstrate compliance with these registration requirements. The Department of Health's consultation document was positive; it made express reference to the HRA and human rights ideas underlie many of the registration requirements. However, the human rights language of the draft requirements could be made stronger, by stating explicitly that patients and care home residents have a legal right to respect for and protection of their human rights. For example, the proposed Standard 10, on responding to people's comments and complaints, notes that service users, relatives and carers need to be aware of and able to use simple and clear arrangements for handling complaints; but it does not at present make reference to specific human rights requirements.

Recommendation 13

The Department of Health should ensure that registration requirements in health and social care explicitly link with human rights requirements.

5. EHRC – fulfilling its human rights role?

As the JCHR recognised, the establishment of the Equality and Human Rights Commission (EHRC), a statutory non-departmental public body with responsibility for promoting and protecting human rights, presents another significant opportunity to address older people's human rights in health and care.

Part of the EHRC's remit is to investigate public authorities it believes are falling foul of the HRA and take targeted legal cases to test the legislation. Beyond this, it also has a role in raising awareness of the Act to the general public and providing an alternative narrative to the negative image of human rights that tends to be presented in the media.

The relevance of the HRA to people in health and social care settings provides the Commission with an ideal opportunity to promote human rights for everyone. Almost everybody will need treatment or care at some point in their life and when they do, they invariably wish to be treated with dignity, respect, fairness, and equality and to exercise autonomy. There is widespread public sympathy for groups like older people and people with disabilities who have a higher dependence on health and care services. Public perception of the Act is likely to improve if it is shown to be an instrument for guarding against neglect and abuse of these groups.

While it is fair to say that the Commission made a slow start in developing its work on human rights and the 'new' equality strands, its first business plan, published in April 2008, suggests that these areas have now been prioritised. The EHRC has now launched its human rights work with an inquiry, which aims to develop a reliable set of findings about the state of human rights in Britain and make recommendations to move the human rights agenda forward. It will investigate public attitudes to the HRA and consider how the Act is working, as well as how it is used by public authorities and other organisations. This scoping exercise, involving a broad-based gathering of evidence, is a positive start to the EHRC's work on human rights.

The EHRC should also pay close attention to the recommendations set out in the JCHR report. As well as calling on the Commission to demonstrate active leadership and promote the value of human rights, the JCHR called specifically for it to give information and guidance to public authorities, monitor information provision to the general public and keep under review the extent to which human rights are incorporated into health and social care.

Recommendation 14

The EHRC should demonstrate strong leadership on human rights, through:

- promoting the value of human rights based approaches
- providing information and guidance to public authorities
- assuring the quality of information provision to the general public
- supporting the Care Quality Commission to monitor and drive forward legal compliance and good practice in health and social care.

6. NICE – taking account of human rights?

The JCHR was not convinced that the National Institute for Health and Clinical Excellence (NICE) was fully taking human rights into account in its decision-making processes, despite its obligations as a public authority. In the past year, the government's NHS Next Stage Review has signalled an expanded role for NICE through increasing both the number and scope of national quality standards. The draft NHS Constitution proposes to establish the right to drugs and treatment that have been recommended by NICE, if they are judged to be clinically appropriate for an individual. These planned changes will make NICE and its decisions even more central to the health care that people receive. For these reasons it is essential that NICE's approach to its task be underpinned by human rights.

Since the publication of the JCHR report, NICE has consulted on an updated version of its Social Value Judgements, which guide NICE committees in their decision making. The revised version has now been published and in it, NICE explicitly recognises its responsibilities under the HRA. It also makes a commitment to actively consider the implications of its guidance for human rights.

NICE's Equality Scheme and Action Plan for 2007-2010 claims to contain a detailed explanation of how NICE will comply with legislation on human rights, discrimination and equality. However the document contains little that is specific to human rights. It is not clear how the commitment to actively consider human rights implications will be delivered in the absence of a human rights framework for all of NICE's work.

Recommendation 15

NICE should adopt a human rights framework for all its work. All its decision-making on clinical practice should take into account the human rights of all patients who are affected.

7. Empowering older people?

The JCHR report concluded that empowering older people was a very important part of ensuring their human rights were protected. It noted that older people need access to information about rights, support through advocacy services, and easily negotiable complaints procedures.

Complaints about care

The son of a man who received very poor care while in hospital commented:

‘What is as disturbing as the poor care standards offered to an elderly person, is the way the Trust are dealing with our complaint and the inquest. They consistently ignore deadlines given to them and as a family we are disturbed that any lessons which may be learnt from our father’s untimely death are being lost as the hospital defend the indefensible.’

Strong, independent and easily negotiable complaints procedures are key to ensuring accountability and redress in the care system. Yet the government has just undone some of the strengths of the current system, by announcing that the Care Quality Commission (CQC) will not inherit the Healthcare Commission’s role in the independent review of complaints. Complaints will instead be dealt with at a local level and can be passed to the Ombudsman if they remain unresolved.

We have significant concerns with this approach. Whilst the government argues that dealing with complaints locally will mean that service providers must take heed and learn from their mistakes, there is no indication that this has happened in the existing system. As the JCHR noted, complaints handling is often poor. The CQC will have far less information on complaints about individual NHS Trusts than its predecessor and will not be in a position to assess improvements and failures in the system.

The national system of independent review of NHS complaints, managed by the Healthcare Commission, was introduced because of significant dissatisfaction with the previous regime, under which complaints were handled locally. The year-on-year increase in the number of complaints that have been referred for independent review to the Healthcare Commission does not inspire confidence that the time is right to abolish this option. There remains a strong possibility that people who are dissatisfied with responses to complaints from NHS Trusts will feel powerless in the new system to secure the changes and improvements they seek.

Mrs B encountered major difficulties trying to follow up a complaint about her father's treatment prior to his death in hospital. Having waited six months for a reply from the Trust involved, she complained to the Healthcare Commission, who deemed it serious enough to carry out an investigation of the Trust's conduct. At the end of the investigation the Healthcare Commission developed an action plan and informed the complainant that it was the Strategic Health Authority's responsibility to monitor the performance of the Trust. Yet the Strategic Health Authority denied responsibility for monitoring action plans and failed to respond to correspondence. The Trust took almost a year to implement the changes suggested by the Healthcare Commission.

The establishment of the CQC will not have the same impact on social care complaints, as the Commission for Social Care Inspection has never had a national complaints function. However, there are specific issues to be resolved in this area. Care home residents can face particular difficulties in making complaints because they lack security of tenure. There have been cases of eviction from care homes in response to a complaint about standards of service or abuse and neglect. The government has taken a step towards resolving the issue of complaints by self-funding residents who historically have had no recourse to an independent mechanism or statutory complaints procedure. It proposes to allow them to take complaints to the Local Government Ombudsman (LGO). There is now an urgent need to amend the remit of the LGO through primary legislation so that it is wide enough to cover self-funders, and to ensure that it has adequate resources to fulfil its wider role.

Recommendation 16

The Department of Health should commit to a new mechanism for the independent review of complaints. It should also put in place clear monitoring systems to review the quality of local complaints handling, involving patients and their relatives.

Recommendation 17

The government should urgently amend the remit of the Local Government Ombudsman through primary legislation so that it is wide enough to cover self-funding residents, and to ensure that it has adequate resources to fulfil its wider role. The proposed National Health Service Reform Bill could be used to do this.

Advocacy

The JCHR report noted the importance of advocacy to vulnerable older people, so that they are more able to secure their human rights on the same basis as the rest of society. There has been increasing reference to the importance of advocacy in recent health and care policy development, such as *Putting People First*, which describes plans for the transformation of social care. There has also been the important step of the introduction of Independent Mental Capacity Advocates through the Mental Capacity Act. But a stark divide remains between policy and practice in terms of the funding of, and access to, advocacy services – a particular issue for older people and those with mental health problems. There is significant geographical variation in the commissioning of advocacy services.

Recommendation 18

The government should develop a national plan for advocacy. It should develop specific guidance for local areas on the commissioning and development of advocacy services that meet the diverse needs of older people.

Mental Capacity Advocacy Project

The Department of Health has funded Age Concern England's Mental Capacity Advocacy Project (MCAP), which is testing a new volunteer advocacy service for older people who lack mental capacity in four areas of the country. This project is exploring the opportunities for a new model in advocacy services, which puts the older person at the centre and also aims to involve other older people as advocates.

MCAP received a referral for an older man with worsening physical health problems, who was also labeled as 'aggressive' and with 'mental health problems'. A volunteer MCAP advocate helped to ensure the man received long-overdue treatment for his physical conditions, which has also helped his mental health. The volunteer advocate is representing the man's wishes and ensuring local health and social care staff make every effort to involve this older person and allow him to have a voice.

Information on human rights

It is vital that the general public receives information about human rights in health and care. For health services, one of the ways for the Department of Health to address this is through the NHS Constitution. NHS Trusts and local authorities could also ensure that their communication plans with their local population inform them of the actions they are taking to protect human rights and what people can do if they have concerns.

Recommendation 19

The Department of Health should oversee a local and national public communications campaign to inform people about the duties conferred on NHS organisations by the Human Rights Act and the NHS Constitution.

Recommendation 20

NHS Trusts and local authorities should ensure that their communication plans refer to the actions they are taking to protect human rights and what steps people can take if they have concerns.

8. Supporting the role of service providers?

Guidance and training on human rights

Guidance and training are important to helping service providers understand their responsibilities in relation to the HRA, to understand the value of a human rights approach and to help them make decisions in their work in line with the Act. This is particularly well illustrated by an example of good practice by the British Geriatrics Society set out in the box at the end of this section. BIHR has also produced very useful guidance and training programmes on human rights-based approaches.

The Department of Health has commissioned two guidance documents which it mentioned in its response to the JCHR report: *Promoting Dignity in the Law*, published by the Social Care Institute for Excellence (SCIE), and *Human Rights in Healthcare*, which drew on evidence from the pilots being run in five healthcare trusts. SCIE has also published a practice guide on Dignity in Care on its website, which explains the relevance of the articles of the Convention to practitioners and provides practice points and examples. In order to ensure that such guidance has an impact, the Department of Health must ensure that it is widely disseminated to service providers.

Recommendation 21

The Department of Health should ensure that guidance on human rights is widely disseminated throughout the NHS and social care sector.

Training in human rights is an essential aspect of adopting a human rights approach within organisational culture. In many cases this is about helping people to do the job they want to do. It helps people to take human rights out of the 'defensive' and 'legal' box in their minds. This can be achieved by illustrating how a positive human rights-based approach will strengthen the quality of services and promote better relationships between service providers and service users.

Support for human rights training by chief executives, NHS boards and local authority members sends out a strong message that human rights are important to the organisation and that staff are expected to uphold them and highlight concerns. Training staff about human rights can give them a new language with which to speak about their work. It also helps them to have confidence about highlighting concerns, because in many cases behaviours they often sense are 'just wrong' are also in fact unlawful.

Despite the clear benefits, there has been little training on human rights in local authorities and NHS trusts, or in the pre- and post-registration education and training of professional staff. Professional regulators, such as the General Medical Council (GMC) and Nursing and Midwifery Council (NMC) could take a much stronger lead in promoting human rights training in undergraduate training.

In its response to the JCHR, the Department of Health also recognised the need for improved training, so that health and care service professionals understand their responsibilities. As part of the implementation of the *White Paper Trust, Assurance and Safety*, the Department of Health has set up a number of working groups, two of which it expects will look at training. It has also written to the Council for Healthcare Regulatory Excellence, the health regulatory bodies, strategic health authority education commissioners, Universities UK, the Council of Deans of UK University Faculties for Nursing and Health Professions and the Medical Schools Council to seek their advice on how to best take forward the training agenda.

Recommendation 22

Professional regulators (General Medical Council, Nursing and Midwifery Council, etc) should take a strong lead in promoting human rights by reflecting the obligations of the Human Rights Act in professional standards and in their requirements for undergraduate training.

Recommendation 23

Health and social care employers should make sure that all staff are trained in human rights.

***Behind Closed Doors* campaign by British Geriatrics Society**

The British Geriatrics Society's *Behind Closed Doors* campaign has produced a number of tools and solutions to help staff ensure as much privacy and dignity as possible for older people when using the toilet: for example, a list of standards for hospitals and other care settings and a decision aid to help the carer to decide how the person should use the toilet. This is based on the level of ability and level of safety that is needed for the person to use the toilet alone, allowing them to retain as much dignity and privacy as possible. The carer can also use this aid to discuss with the patient and the patient's family what is appropriate to their needs and circumstances so that they are better able to understand why certain options may not be available to the patient. The guidance and resources from this campaign have been widely disseminated and have been incorporated into 20 training courses in hospital wards, continence services and other settings to help ensure that older people's dignity and privacy are better respected.

9. Changing practice at the front line of care?

Mr C spent just under a month in hospital before he died. While in hospital he lost a lot of weight and became malnourished. He was given inappropriate food that he either wasn't supposed to eat because he had diabetes or couldn't eat because it was too difficult for him. He was not given any help to eat until his relatives complained.

One morning Mr C had a toilet accident and had to ask repeatedly for assistance with this. His daughter discovered that the nurses were refusing to get him up and help him to go to the toilet in the mornings, so as to prevent such accidents, because they said he was 'irritable and nasty'.

Mr C's family had the strong suspicion that he was sedated numerous times in the course of his stay in order to make him easier to care for. This resulted in him being drowsy and unaware of what was happening. Following his death, it was confirmed to his family that Mr C had been prescribed anti-psychotic drugs.

Service providers, such as NHS Trusts and local authority social services departments, play one of the most important roles in the human rights picture. Although leadership, guidance, support and compulsion must come from government and other national bodies, commissioners and service providers must turn policy into practice and theory into reality on the front line of health and social care. There is little evidence of action on this to date.

Human rights should be embedded into all stages of the commissioning cycle, including the needs assessment, service specification and monitoring stages. This will send a strong message to service providers about the importance of human rights and will help commissioners to ensure they provide a high quality of care.

Few service providers have appreciated the relevance of the HRA to their work and the transformative potential that the Act offers. In spite of their legal obligations to promote and protect human rights, the HRA has tended to be seen as an issue for lawyers alone. As the JCHR highlighted, there has been a distinct lack of clarity from central government and the regulators about the importance of the Act and the need to make it core to the work of NHS and social care organisations. To move forward and make the value of the HRA understood on the front line, a positive human rights culture must develop. Only then will we see older people's human rights protected at the interface with those delivering services.

BIHR continues to work on developing human rights based approaches within both the statutory and voluntary sectors in the UK and is at the forefront of thinking on how these can be implemented. It has developed a range of principles for achieving this, including putting human rights at the heart of policy and planning; ensuring responsibility and accountability is clear within the organisation; the empowerment of staff and patients; and especially taking account of vulnerable groups, such as people with visual or cognitive impairments, who may face particular challenges²².

Building on the principles developed by BIHR, Age Concern is recommending five steps that service providers need to take to develop a human rights culture in their organisation. This is not simply because it is their legal duty to take positive action to protect human rights, but because it is an important way to create caring and principled organisations where staff enjoy working and service users feel safe, comfortable and secure.

Recommendation 24

Service providers and commissioners should follow the five steps set out above and adopt a human rights-based approach to their work.

Five key steps to a human rights based approach

1. **Get on board** – ensure the organisation's board understands and acknowledges the role of human rights in transforming standards of service and commits to a human rights-based approach.
2. **Change policy** – incorporate human rights into the strategic objectives of the organisation and develop a Single Equality and Human Rights Scheme so that human rights are mainstreamed within the organisation. Review current policies and procedures to ensure that they conform to the Human Rights Act and reflect human rights principles to help promote a human rights culture.
3. **Change practice** – after identifying the need for change to protect human rights, write action plans, with responsibility clearly designated, and monitor progress on a regular basis.

4. **Engage and empower staff** – develop training programmes and guidance for all staff (including all levels of management) which are tailored to their specific roles in the organisation, helping them to act and make decisions on the basis of human rights principles. Empower staff to propose changes in their own work and suggestions for the organisation to protect human rights.
5. **Engage and empower service users** – engage service users in service improvement by giving them opportunities to voice their views and experiences and suggest solutions. Give them information about their human rights and how they can expect to be treated. Ensure there is a clear and effective process to make a complaint and that everyone is informed of this process.

***Hungry to be Heard* campaign by Age Concern**

In August 2006, following research which found that six out of 10 older people were at risk of becoming malnourished or their situation getting worse in hospital, Age Concern launched its '*Hungry to be Heard*' programme, promoting good mealtime practice in hospital. There are numerous examples of very positive changes in practice as a result of this initiative; two are set out below.

Bromley Hospitals NHS Trust

Bromley Hospitals NHS Trust has implemented seven steps to end malnutrition in the hospital: the setting up of a food and nutrition steering group; developing a nutritional policy; introducing protected mealtimes; introducing a red tray scheme (which identifies for staff which patients need assistance with their food); purchasing specialist cutlery and china; recruiting volunteers to assist at mealtimes; raising awareness among hospital staff; holding a public focus group and completing national screening tools and audit.

Mid Staffordshire NHS Hospitals

The Chief Executive of Mid Staffordshire hospitals contacted the local Age Concern to seek help in identifying a way of supporting older people, both at mealtimes and by adding to the quality of their stay while in hospital. The two organisations developed changes which involved volunteers working to encourage older people to eat at mealtimes, access drinks throughout the day and offer one-to-one support for those less able, such as helping fill in the menu cards; and to sit and chat or read the papers. A six month pilot proved a great success and Mid Staffordshire NHS Hospitals commissioned Age Concern to expand the programme to cover two hospitals, involving 100 volunteers.

Annex 1

Background to the Convention Rights

The European Convention on Human Rights was brought into being as a response to the horrors of the Second World War. British lawyers played a central role in writing the Convention, and the UK was the first country to sign the treaty in 1951. The Human Rights Act 1998 (HRA) brings the Convention into UK law, incorporating most of its Articles. Those which are most relevant for older people as users of health and social care are Articles 2, 3 and 8, explained below. Articles 2 and 3 are 'absolute' rights, which mean they cannot be restricted or limited in any way. In contrast Article 8 can be restricted by the state if there are competing interests and the interference in the right is proportionate and necessary.

Article 2 – the right to life

Article 2 enshrines the right to life, placing a positive obligation on the state to protect this right through legislation, together with a negative duty to refrain from intentionally or unlawfully interfering with someone's right to life. This Article also requires institutions such as prisons and care homes to take steps to protect life in the face of any real risk. If a person in an institution dies unexpectedly, public authorities will have a duty to carry out an effective and impartial investigation into the death.

The most serious instances of malpractice and abuse in health and social care settings can result in patients' deaths and therefore constitute breaches of Article 2.

Abuse of anti-psychotic drugs

There is a common practice of controlling the behaviour of patients with dementia through the inappropriate use of anti-psychotic drugs as a means of sedation. These drugs increase the risk of strokes for older people with dementia, so this practice may be a breach of Article 2. In 2008, the All Party Parliamentary Group on Dementia completed an inquiry into this practice in care homes and found it to be widespread in spite of guidance to the contrary. The government has now launched a review into this issue.

Malnutrition in hospitals and care homes

Older people do not always receive appropriate food and drink or get the help they need with eating – a problem that can lead to life-threatening levels of malnutrition. In 2006, Age Concern England published its campaign report *Hungry to be Heard*, which found that six out of ten older people in hospital are at risk of becoming malnourished, or their situation getting worse whilst in hospital. Sometimes, food and drink are not provided as often as they should be, while in other cases they are not provided in a suitable form or in suitable containers. Hospital and care home staff do not always monitor how much a

patient is eating and drinking and Age Concern has heard of many cases of trays with water and food being left out of reach of patients, only be cleared away untouched²³.

Unsafe hospital discharge

As a result of incentives in the system, such as the Delayed Discharge Regulations and Payment by Results, many older people are discharged from hospital without adequate community support. As a consequence high numbers have to be readmitted in an emergency, often with life-threatening conditions. There has been a 31% increase in emergency readmissions between 1998 and 2006²⁴.

Article 3 – the right to not be subjected to inhuman or degrading treatment

Article 3 places a duty on the state not to subject individuals to degrading treatment leading to humiliation or fear, or inhuman treatment that causes intense mental or physical suffering. Whether the right has been violated depends on a wide range of factors, including the victim's age and state of health and the circumstances in which the treatment occurred.

At the core of this right are the concepts of dignity and respect. Unfortunately Age Concern still hears of many cases of older people being treated in a way which does not uphold this right.

Use of toilet in hospital

Toilet practices are discussed at greater length below, under Article 8 – the right to respect for privacy. However the most serious cases involve degrading treatment and so represent a breach of Article 3. Age Concern has heard of patients being refused a commode and being told to use an incontinence pad instead. The Healthcare Commission's investigation into Maidstone and Tunbridge Wells NHS Trust found that patients were told to 'go in their beds' and left in their waste for long periods²⁵. We have also heard of families having to ask multiple times to deal with toilet accidents.

Abuse and neglect

Some older people are subjected to abuse in institutional settings which is serious enough to be a breach of Article 3. In 2004 Action on Elder Abuse reported that 23% of calls to their helpline concerned care homes, where less than 5% of the older population live²⁶. The report documented many cases of physical, sexual and psychological abuse that were clear breaches of Article 3, including hitting, dragging and pulling the hair of elderly care home residents. Grave neglect can also breach Article 3, including serious pressure sores and older people being left in distress by ignoring calls for help.

Article 8 – the right to respect for private and family life, one’s home and correspondence

Article 8 protects individuals from interference in their personal life as well as in their relations with others. The protection of family life extends to relationships with partners, siblings and other near relatives such as grandparents. The right to respect for one’s home includes enjoyment of an existing home, and respect for correspondence covers all forms of communication including e-mail and text messages.

Article 8 is a ‘qualified’ right, meaning that the state can interfere with it providing certain conditions are met. The interference must be set out in the law and fall within one of the legitimate aims listed in the Convention, including national security, public safety or the prevention of crime, the protection of health or morals or the protection of the rights and freedoms of others. Any interference in Article 8 rights must also be proportionate, and necessary in a democratic society.

Use of the toilet in private

Many older people have their privacy violated when they use the toilet in hospital or care homes. The British Geriatrics Society started a campaign in 2006 in response to this problem because of the kind of practices witnessed by concerned doctors and nurses. This included older people being forced to use commodes and bed-pans in wards when they could have gone to the toilet with assistance, older people being left on commodes/bed-pans for unnecessarily long periods of time, patients being left in full view of others when using toilets, and staff entering closed curtains without ascertaining why they were closed.

Older couples being separated in different care homes

Recently, there have been several well-publicised cases where local authority social services departments have split up married couples by sending them to different care homes, in breach of their right to respect for private and family life. The government has made a commitment to open discussions with local authorities on the provision of joint residential care for older couples, with a view to making it clear that couples should not be separated, other than in exceptional circumstances.

Mixed sex accommodation

Mixed-sex accommodation in hospital can represent a breach of privacy. There has been little improvement on this issue in the past year, despite the government’s long standing commitments. The most recent survey of inpatients by the Healthcare Commission found that nearly a quarter had shared sleeping areas such as a room or bay with a member of the opposite sex when first admitted to hospital²⁷.

Care home evictions

Care home residents are licensees rather than tenants and have no protection from eviction. Typically, the contract with a care home permits a resident's occupancy to be terminated on 28 days' notice. There have been many cases of older people facing eviction from residential or nursing care homes in response to a complaint being made about standards of service or allegations of abuse and neglect, often made by concerned relatives. Older people have also experienced eviction from care homes that face closure. Care home evictions represent a breach of the right to respect for one's home.

Hospital discharge into residential care

The Delayed Discharge Regulations, designed to ensure speedy discharge from hospital, can lead to older people being put under pressure to accept an unwanted move into residential care, rather than return to their own home with appropriate support. This may be in breach of someone's right to have their home and private life respected.

Annex 2 – Progress against Joint Committee on Human Rights Recommendations

Location in JCHR report	JCHR Recommendation	Government response*	Age Concern comments
Central Government			
Leadership on human rights			
p93, point 11	Champion an understanding of how the recognition of human rights principles can underpin a transformation of health and social care services.	6	There have been some positive steps in the past year, including the continuing work on the Human Rights in Healthcare pilots, new dignity initiatives and the announcement of £2 million funding for the joint Department of Health/Comic Relief study on elder abuse. The government has used an amendment to the Health and Social Care Bill to close the human rights loop-hole for most people living in care homes. However the government should be clearer about how human rights can transform services.
p98, point 49	Be steadfast in their support of the HRA and its real importance for older people, including older people receiving health and social care services.	None made	The government continues to miss opportunities to demonstrate strong support for the Human Rights Act. Recent announcements on strengthening the dignity agenda did not make it explicit that dignity is a human rights principle underpinned by the HRA. There is a real concern that the proposed Bill of Rights would replace or water down the Human Rights Act. Documents published by government departments, such as the Ministry of Justice's Human Rights Insight Project, have also questioned whether the HRA can be used as a tool for improving public services.
p94, point 15	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.	No	As above.
Protection of older people and promotion of cultural change			
p95, point 28	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.	13	There is no indication that a positive duty to promote and protect human rights will be included in the Equality Bill, and the government has failed to appreciate the difference such a duty would make to achieving a positive human rights culture.
p92, point 6	Age discrimination legislation should be extended to cover the provision of goods, facilities and services, so as to encompass (amongst other activities) the provision of healthcare.	4	The government has announced that the Equality Bill will include measures to outlaw age discrimination in goods, facilities and services – although the detail of the legislation is likely to be set out in regulations, rather than on the face of the statute. The measures are expected to be implemented only after a lengthy transitional period. This is a welcome legislative step that should help to ensure that older people are treated fairly and equally in healthcare and other services.

■ Significant progress
 ■ Some progress
 ■ Little to no progress
 ■ Too early to evaluate

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Location in JCHR report	Recommendation	Government response*	Age Concern Comments
p92, point 6	Create a positive duty on providers of health and residential care to promote equality for older people.	3	The government has announced that the Equality Bill will include an integrated public sector duty to promote equality across six equality grounds, including age. The legislation will set out a general duty to promote equality, with more detailed, specific duties set out in regulations. A positive duty to promote age will be an important lever for change, ensuring that public authorities consult people of different age groups when designing services and 'age proof' all aspects of their business.
p95, point 26	Explain in a clearer way to public authorities what the positive obligation doctrine means.	No	In its response to the JCHR report, the government did not comment on this recommendation. Age Concern has found no evidence that the government has helped to explain to public authorities the meaning of 'positive obligations' to promote and protect human rights.
Delayed discharge regulations			
p92, point 3	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.	1	The government maintained that there is flexibility in the regulations in its response to the JCHR report. Evidence shows both a significant increase in emergency readmissions and the continued practice of transferring people directly to care homes from acute hospital beds. There is a clear gap between what the government believes the Regulations require and the reality for older people being discharged from hospital. The government needs to address this, either by introducing greater flexibility into the Regulations or by ensuring the intentions are clear through guidance to acute trusts and social services departments.
p92, point 3	Issue guidance for hospitals and local authorities on the application of the Regulations to ensure respect for the Article 8 rights of older people.	2	In a parliamentary debate in March 2008, the Minister for Care Services said that if clarification was necessary, the government was willing to clarify the Regulations. The evidence shows that such clarification is needed.
Human Rights loophole			
p95, point 30	Full commitments 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.	No	The government has moved to close this loophole through the Health and Social Care Bill. However self-funding residents who arrange their own residential care will still not be protected by the Human Rights Act. Further legislation is needed to bring this group within the scope of the Act and the government should look at this urgently as part of a wider consideration of the meaning of 'public authority' under the HRA.

 Significant progress	 Some progress	 Little to no progress	 Too early to evaluate
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* Government Response to the Committee's Eighteenth Report of Session 2006-07: The Human Rights of Older People in Healthcare

Location in JCHR report	Recommendation	Government response*	Age Concern comments
Department of Health			
Department of Health leadership on human rights and dissemination of best practice			
p99, point 51	Make a public commitment to embed a human rights approach in hospitals and care homes across the country.	33	Whilst the <i>Human Rights in Healthcare</i> report is clear about the value of a human rights approach, recent public statements by the Department of Health have focused on dignity, without explicitly linking this to a 'human rights approach' or the Human Rights Act. The draft NHS constitution, which is meant to bring together existing rights, only refers to human rights in respect of NHS staff. Patients' human rights are overlooked.
p94, point 19	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.	9	Age Concern is not aware of any progress having been made against this recommendation.
p94, point 20	Publish an evaluation of the pilot project undertaken by the BHR and 5 NHS trusts on using a human rights approach in healthcare. Distribute copies of Human Rights in Healthcare, using its normal channels of communication and then survey trusts within a year to find out the extent to which trusts are incorporating a human rights approach in healthcare services.	10	The government has committed to evaluating the pilots and producing guidance. It is vital that a clear strategy for disseminating this guidance is developed and for ensuring that it is given high priority by service providers.
p94, point 21	Commit to providing sufficient funding to implement emerging good practice more widely (which is likely to include capacity building for providers of health services as well as training of staff and provision of information to patients).	No	The government did not comment on this recommendation in its response to the JCHR inquiry. There needs to be a clear response on this issue.
p93-94, point 14	If the Department of Health draws up a constitution or statement of purpose to mark 60 years of the NHS, this should include a statement about the importance of human rights to the provision of health services.	8	The draft NHS Constitution includes some human rights principles but makes no direct reference to the role of human rights or in the provision of health services.

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Complaints			
p98, point 48	Ensure that the newly merged inspectorate is able to investigate individual complaints, as the Healthcare Commission is currently able to do.	32	The government has announced that the Care Quality Commission will not inherit the Healthcare Commission's powers to investigate individual complaints. Instead it plans to strengthen local complaints handling functions and pass unresolved cases to the Local Government Ombudsman. It is not clear that the Ombudsman will provide an appropriate means of redress for such complaints, nor that it will have the resources to undertake the additional work involved. Legislation is urgently needed to extend the LGO's remit.
Care home standards			
p96, point 32	Following the current review, more explicitly spell out the human rights of social care residents in care home standards.	16	The Human Rights Act was explicitly mentioned in the consultation on the proposed registration requirements for health and social care providers. The draft requirements are also structured around guarding against behaviours which have threatened older people's human rights in health and social care settings, for example making sure people get the nourishment they need and making sure people get care and treatment in safe, suitable places which support their independence, privacy and personal dignity. The requirements would be made stronger by being linked more explicitly with the specific Articles of the Convention to make it clear that they are not criteria, but fundamental rights of citizens in the UK.
p99, point 54	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.	36	Draft standard 10 deals with responding to people's comments and complaints and notes that service users, relatives and carers need to be aware of and able to use simple and clear arrangements for handling complaints. The draft standard does not make reference to specific human rights requirements.
p97, point 44	Include a requirement in both the Care Standards for Better Health and the National Minimum Standards for Care Homes for Older People (or 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.	30	The draft registration requirements for health and social care include a requirement to safeguard people when they are vulnerable, ensuring that people are protected and do not experience any form of abuse. One of the roles of the Care Quality Commission will be to determine how compliance with registration requirements will be assessed. The Department of Health is undertaking a review of No Secrets – guidance on the protection of vulnerable adults. This is expected to be completed in autumn 2008.

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p96, point 34	Apply the same standards to both NHS trusts and care homes regarding quality of care and other issues engaging human rights of users of services. 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.	18	As part of the integration of the regulation of health and social care there will be one set of registration requirements. The current draft introduction to proposed topics for registration requirements makes express links with the Human Rights Act and human rights ideas underlie many of the standards. The human rights language of the current draft standards could be made stronger, as they do not currently state explicitly that patients and care home residents have legal rights to respect for and protection of their human rights.
Guidance to NHS Trusts and social care			
p95, point 23	Provide guidance to hospitals and care homes on implementing a human rights approach in the planning and delivery of public services, emphasising that this implementation should not be exclusively legalistic, nor merely a tick-box exercise.	11	The Department of Health has commissioned two guidance documents which it mentioned in its response to the Joint Committee: <i>Promoting Dignity in the Law</i> , published by the Social Care Institute for Excellence (SCIE), and <i>Human Rights in Healthcare</i> , which drew on evidence from the pilots being run in five healthcare trusts. SCIE has also published a practice guide on Dignity in Care on its website, which explains the relevance of the articles of the Convention to practitioners and provides practice points and practice examples.
p97, point 41	Produce guidance, which builds on the BIHR pilot and includes care studies and examples of best practice in training different groups of healthcare staff on human rights principles as they apply to their work.	26	The first Human Rights in Healthcare report contains useful information for NHS Trusts on the relevance of the Human Rights Act to their work. However none of the pilot areas in the Human Rights in Healthcare project are acute trusts. There has been no specific guidance to care homes on a human rights approach.
Information			
p99, point 54	Information on the human rights of older people and the duties of service providers as 'public authorities' under the HRA is provided to older people in an accessible form on entry to care homes or hospital.	36	There has been no mention of any obligation on the Care Quality Commission to provide information on human rights and the duties of service providers in the consultation on registration requirements.

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p99, point 53	Ensure that information on human rights is presented by the NHS in an appropriate way to older people.	35	The Department of Health has committed to ensuring that 'in taking forward Human Rights in Healthcare, the Department will recommend that when NHS organisations present human rights information it is available in formats that take account of the needs of the audience'
p99, point 51	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.	33	There does not appear to be a strategic approach to the delivery of the accessible information recommended. Whilst the government's response to the JCHR commented on the Ministry of Justice toolkit distributed to public bodies, it did not make clear any plans to ensure comparable guidance reaches patients, service users and the public.
Advocacy			
p98, point 47	Provide sufficient independent advocacy services, 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.	31	A stark divide remains between policy and practice in terms of advocacy services, particularly to older people and those with mental health problems. Whilst the importance of advocacy is highlighted in policy documents such as <i>Putting People First</i> , in many parts of the country advocacy services are not being developed and some have been cut.
Qualifications and training			
	Provide regular and targeted training in human rights principles and positive duties and how they apply to their work.	24	The professional regulatory bodies have responsibility for setting the educational standards for pre-registration education and training. In its response to the JCHR, the government recognised the need for improved training so that healthcare professionals understand their responsibilities. As part of the implementation of the white paper <i>Trust, Assurance and Safety</i> , the government has set up a number of working groups, two of which they expect will look at training. It has also written to key stakeholders to seek their advice on how to take forward this agenda.
	Review within three years, the extent to which training has taken place within healthcare and the effects of that training.	25	Timescale for this recommendation beyond one year.

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NICE			
p97, point 39	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.	23	NICE's consultation on its revised social value judgments recognised its responsibilities under the Human Rights Act and made a commitment to the active consideration of the implications of NICE guidance for human rights. The application of the commitment will need to be monitored.
Voluntary Organisations (as lobbyists)			
p93, point 11	Champion an understanding of how the recognition of human rights principles can underpin a transformation of health and social care services.	6	There has been little evidence that the approach of voluntary sector organisations to the HRA has changed significantly in the past year.
p99, point 52	In partnership with the EHRC, assess the quality of information available to older people, their families and carers on the application of human rights principles to their lives and make sure that the best information is widely disseminated.	34	While it is too early to draw conclusions on this point, the EHRC's current Human Rights Inquiry is promising and could lead to productive partnerships between the EHRC and voluntary sector organisations in the future.
Service providers			
p99, point 51	Embed a human rights approach in hospitals and care homes across the country.	33	There is no evidence that this recommendation has been taken up consistently by service providers.
p93, point 11	Champion an understanding of how the recognition of human rights principles can underpin a transformation of health and social care services.	6	Whilst there has been some good work to publicise the benefits of a human rights approach, this is still very patchy. All NHS trusts and local authorities need to publicly acknowledge human rights as central to their work.

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p97, point 40	Provide regular and targeted training in human rights principles and positive duties and how they apply to their work.	40	There has not been a marked change in the availability of training in the past year. Government has acknowledged that more training in human rights needs to become available. As part of realising a human rights approach to their work, service providers need to develop or commission training programmes on human rights so that staff are able to make the connections between human rights and their work.
p99, point 51	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.	51	We have not been able to establish whether this is the case. Progress should be monitored by the Care Quality Commission.
Care Quality Commission			
Human rights approach			
p96, point 35 - 36	Adopt a human rights framework for all its work, with the intention that the framework informs all of the inspectorate's work and so makes it more effective in fulfilling its statutory duties.	20, 21	The Care Quality Commission has not yet been established. The Health and Social Care Bill which creates the organisation includes a requirement on the CQC to have regard to the need to protect and promote the rights of people using health and social care services. There is therefore a clear opportunity for the CQC to adopt a human rights framework for all its work.
p99, point 51	Make a public commitment to embed a human rights approach in hospitals and care homes across the country.	33	As above – this will require further assessment once the CQC has been established and has begun its work.
Guidance			
p95, point 23	Provide guidance to hospitals and care homes on implementing a human rights approach in the planning and delivery of public services, emphasising that this implementation should not be exclusively legalistic, nor merely a tick-box exercise.	11	As above – this will require further assessment once the CQC has been established and has begun its work.
p96, point 34	Provide guidance to providers of services on the implications of human rights requirements	18	As above – this will require further assessment once the CQC has been established and has begun its work.

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Location in JCHR report	Recommendation	Government response*	Age Concern Comments
Information			
p99, point 51	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.	33	As above – this will require further assessment once the CQC has been established and has begun its work.
Monitoring			
p96, point 37	Survey providers of health and social care services and report on their levels of understanding of and compliance with the HRA within three years of the new commission starting operations.	22	The timescale for this recommendation is beyond the period of this report.
Professional regulators			
p97, point 43	Qualifications, accreditation and re-licensing for health professionals should include a basic understanding of how the HRA requires the protection of basic principles such as dignity, fairness, respect and equality.	29	Although the codes of conduct developed by professional regulators such as the General Medical Council and Nursing & Midwifery Council include reference to basic principles such as dignity and respect, they are not described explicitly as human rights principles. The government's White Paper on the regulation of health professionals in the 21st century (Trust, Assurance and Safety) made no reference to human rights.
Equality and Human Rights Commission			
Promoting human rights			
p93, point 12	Ensure that an understanding of how human rights principles can transform health and social care services is disseminated widely.	7	Following its launch in October 2007, the Equality and Human Rights Commission took several months to develop a clear programme of work relating to its human rights remit. It has now launched its Human Rights Inquiry, which is a multi-faceted programme of work with the overall aims of promoting an understanding of the importance of human rights, encouraging good practice and promoting awareness of human rights, understanding and protecting human rights, and encouraging public authorities to comply with the Human Rights Act.
p95, point 29	Actively participate in debates about including 'respect for human rights' in the proposed single equality duty.	14	As the EHRC has only recently developed a programme of work on human rights, it is too early to audit this recommendation.

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Information and guidance			
p95, point 24	Ensure 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.	12	As the EHRC has only recently developed a programme of work on human rights, it is too early to audit this recommendation.
p95, point 29	Make sure that public authorities are fully aware of their positive obligations under human rights law.	14	As the EHRC has only recently developed a programme of work on human rights, it is too early to audit this recommendation.
Monitoring human rights approaches			
p93, point 7	Monitor the implementation of human rights and equality legislation in healthcare for older people and report on this in its State of the Nation report.	5	As the EHRC has only recently developed a programme of work on human rights, it is too early to audit this recommendation.
p97, point 42	Monitor the extent to which hospitals and care homes include human rights principles in their staff training.	28	As the EHRC has only recently developed a programme of work on human rights, it is too early to audit this recommendation.
Monitoring information provision			
p99, point 52	In partnership with voluntary organisations, assess the quality of information available to older people, their families and carers on the application of human rights principles to their lives and make sure that the best information is widely disseminated.	34	As the EHRC has only recently developed a programme of work on human rights, it is too early to audit this recommendation.

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