Rights at Risk

Older people and human rights

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The Human Rights Act (HRA) applies to the whole of the UK, and all legislation by the UK government must be compatible with it unless there is a specific declaration to the contrary. In England, the public services discussed in this report are also the responsibility of the UK government and will be covered by the proposed Commission for Equality and Human Rights (CEHR).

In Northern Ireland, Scotland and Wales these services are the responsibility of the devolved administrations, which are also required to act compatibly with the HRA. Institutional arrangements in the devolved administrations differ and are still evolving: there is a Human Rights Commission in Northern Ireland and one is planned for Scotland; in Wales there is likely to be a Commissioner for Older People. Relations between the proposed Commission for Equality and Human Rights and institutional arrangements in the devolved administrations will be clarified in forthcoming legislation to establish the CEHR.
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Summary of key points

The Human Rights Act is of fundamental importance for older people, but is not working effectively to protect them at present.

The Act lays down in UK law essential rights and freedoms that are sometimes taken for granted. The right to life, to be free from inhuman or degrading treatment and to respect for one’s private and family life are of particular significance for older people’s services. These rights are an entitlement, not a gift of the state, and they apply as much to older people as to anyone else. While there is as yet no law against age discrimination in the provision of goods and services, the Act requires that everybody’s human rights are accorded equal respect.

Older people’s human rights are most clearly at risk when they experience abuse or neglect at the hands of those charged with their care. Such abuse can be perpetrated by individual workers, whether by ignorance or design, and by the culture of some institutions – some hospital wards, care homes or agencies providing care in people’s own homes – which condone or foster abusive or neglectful behaviour.

Moreover, the very system by which care for older people is organised and provided also puts human rights at risk.

- Services for older people are so tightly rationed that many people fail to qualify for help and are left in deteriorating circumstances. Those in the most extreme circumstances who do qualify for help may not get it, or may have to wait long periods before they get it. They may suffer degrading treatment and their lives may be put at risk.

- Few services for older people go beyond practical help or aim to meet the social, psychological or emotional needs of older people, as required to sustain the dignity and integrity of the individual under the Human Rights Act.

- The situation is exacerbated by lack of access to the financial help that many younger disabled people get to help them sustain a dignified and decent quality of life and exercise choice over how they spend their time.

- The right of older people to respect for their private and family life is overridden when they are required to leave their home, and perhaps their spouse, against their will, because it is cheaper for the local authority to place them in residential care than to supply enough help at home.

- The closure of care homes deprives older people of their right to private and family life, and, unless it is handled with great care and respect for each person, can lead to premature death.

The Human Rights Act places an obligation on public authorities to respect and promote human rights. However, the great majority of care services for older people are provided not directly by public authorities but by private or voluntary organisations. The courts have found, contrary to the intentions of Parliament when the Act was passed, that private organisations are not subject to the Act. Consequently, many thousands of older people whose human rights are at greatest risk of being breached are not protected at present. This problem needs to be urgently addressed, through case law, regulation or legislation.

There are two routes through which the human rights of older people could be better safeguarded.
Summary of key points

• The first is to ensure that public authorities make human rights central to the way they conduct their business and to the standards of the services they provide or contract with. The forthcoming Commission for Equality and Human Rights, along with those bodies which set and regulate standards, will have a key role in ensuring that all public authorities understand and implement their obligations under the Human Rights Act.

• The second option is through the courts. Older people, like everyone else, have the right to seek redress if their human rights are breached. In practice, however, it is extremely difficult for those most at risk to take such a demanding and potentially expensive step.

The new Commission for Equality and Human Rights, which will have a duty and powers to promote human rights and undertake investigations and inquiries where there is cause for concern, offers a real chance of progress. But human rights also suffer when a breach is compounded by discrimination. There is a pressing need for age discrimination legislation to ensure that public services at all levels cease to treat people less favourably because of their age and do away with discriminatory policies and practices.
1 Introduction

The Human Rights Act is a crucial piece of legislation for older people. It lays down in UK law essential rights and freedoms that are often taken for granted – such as the right to have one’s life protected by law, the right to be free from inhuman and degrading treatment and the right to privacy and family life. All organisations which provide public services must by law act in ways which are compatible with and respect these rights; they also have a positive obligation to protect the human rights of those they serve.1

At present, the Human Rights Act is not working effectively to protect older people. While the ideal is admirable, it is not matched by reality as far as older people are concerned. The aim of this paper is to consider how and where the human rights of older people are currently at risk; to suggest what should be happening to safeguard those rights; to examine current barriers to proper protection; and to discuss what needs to happen to ensure that older people can feel confident that their human rights will be respected.

Older people’s human rights are at risk in a variety of circumstances, and particularly when they are dependent on the care of others for their well-being and quality of life. At that point, the state’s duty to respect their dignity and ensure that their human rights are protected is paramount. But when older people are neglected or mistreated on a hospital ward or in a care home, when they are assaulted or subjected to harassment in their own home, when there is a serious failure of respect for their dignity and humanity, it is rarely identified as a human rights issue.

It may even not be treated as a crime. It is more likely to be treated as a matter of poor standards, to be addressed by those responsible for the quality of health and social care services.

Of course, such standards have an important role to play, but when things go so badly wrong it is not just a case of poor standards. It is a breach of human rights as well. To fail to meet certain expected standards is unfortunate and may merit a rap across the knuckles; to violate someone’s human rights is a failure of a different order and is wholly unacceptable.

The Human Rights Act is widely used as a benchmark against which to judge the treatment by the state of those who are dependent on or in the power of the state. But the convulsions of public soul-searching that occur when a child dies in the care of the state, and the setting-up of inquiries such as the Laming Inquiry into the death of Victoria Climbié, fail to happen when an older person dies in equally devastating circumstances.

With a very few exceptions, such as the inquiry into the premature deaths over many years of Dr Harold Shipman’s elderly patients, we fail to ask the searching questions: how could this happen in this day and age? Who was responsible for ensuring the safety of this person and what went wrong? How can we make sure it does not happen again?

Older people, their families and friends are entitled to have confidence that their human rights will be respected and protected in all circumstances. And it is essential that our systems and institutions are effective in safeguarding the human rights of all those they serve.
The Human Rights Act (HRA) became law in 1998 and came into force in October 2000. It is based on the 1951 European Convention on Human Rights, which itself followed the Universal Declaration of Human Rights drawn up in 1948, in the aftermath of the Second World War. Britain played a big part in creating the European Convention on Human Rights and was the first country to sign up to it.

The Act creates a framework of fundamental rights and freedoms based on the principles of respect, equality and fairness. All public bodies have a positive duty to promote and protect the human rights of those they serve and must act at all times in ways that are compatible with its principles.

The Human Rights Act specifies certain fundamental rights and freedoms which every person possesses:

- Article 2: the right to have one's life protected by law
- Article 3: the right to be free from torture or inhuman or degrading treatment
- Article 4: the right to be free from slavery and forced labour
- Article 5: the right not to be deprived of one's liberty except in certain specific circumstances and where there are clear legal procedures
- Article 6: the right to a fair and public hearing by an impartial tribunal
- Article 7: the right not to be found guilty of an act which was not a crime at the time it was committed
- Article 8: the right to respect for one's privacy and family life, one's home and correspondence
- Article 9: the right to freedom of thought, conscience and religion
- Article 10: the right to hold opinions and express them
- Article 11: the right to peaceful assembly
- Article 12: the right to marry and start a family
- Article 14: the right not to be discriminated against in access to these rights because of one's sex, race, colour, language, religion, political views, national or social origin, property, birth or other status [age is not specifically mentioned but is included].

Article 14 emphasises that everybody is equally entitled to have these human rights respected, simply by virtue of being human, and irrespective of their citizenship or any other characteristics. However, article 14 applies only in respect of the human rights listed in earlier articles: it is not freestanding. Protocol 12 of the European Convention on Human Rights does give a freestanding right to equality, but has not to date been ratified by the UK Government, so does not form part of the British Human Rights Act.

Other articles have been added more recently: for example, the right to peaceful enjoyment of one's possessions (article 1, protocol 1); the right not to be denied access to education (article 2, protocol 1); and the right to free and fair elections (article 3, protocol 1).

Many of these rights are not absolute – there is scope for interpretation, and the rights of one person have to be balanced against those of others. For example, the right to free speech does not mean people are free to harass others; the right to privacy can be restricted in order to prevent crime (for example, by the use of CCTV cameras); and the right to family life may be restricted in order to prevent domestic violence or the abuse of children. The courts have to decide in each case whether restricting a right is proportionate and necessary.

What the Act does is to provide a framework, within UK law, against which such judgments must be made.
3 Why is the Act important?

Spelling out individual rights is significant for two reasons.

Firstly, it changes the balance of power between the individual and the state. As the Joint Committee on Human Rights has pointed out, human rights are not something to be conferred by the state and taken away by the state. They are an inherent entitlement, ‘an affirmation of the equal dignity and worth’ of each person, of which each person should be aware. The individual has a clear entitlement in law to be treated in a particular way, and the Act gives individuals a right of redress should their human rights be breached.

Secondly, the Human Rights Act asserts the equal dignity and worth of each person, regardless of their individual characteristics, status or circumstances, and thereby challenges the ageism and age discrimination that are so deeply entrenched in public attitudes to and services for older people.

Unlike discrimination on some other grounds, discrimination on grounds of age is not currently unlawful in the UK. While the European Directive on Equal Treatment will ban age discrimination in employment and training from October 2006, there is as yet no legislation to cover age discrimination with regard to goods, facilities and services or, in much of the UK, to require public bodies to promote age equality.

This contrasts sharply with anti-discrimination legislation for race, gender and disability, where it is already unlawful – and has been for many years in some cases – to discriminate in the supply of goods, facilities and services as well as in employment and training, and a positive duty to promote equality on these grounds is either already in place or is imminent.

(In Northern Ireland, Wales, Scotland and London, the devolved administrations do have a responsibility to promote equality generally, including for age, and have taken varying steps towards implementing these duties; however, this is not the case for most of England and hence for the majority of the older population of the UK.)

The Government announced in February 2005 that there would be a review of all anti-discrimination legislation, with a view to harmonising and updating it and creating a ‘simpler, fairer legal framework’ on equalities. This review will take place alongside the establishment of a new Commission for Equality and Human Rights (CEHR), which is due to be up and running in early 2007, and which will promote equality on grounds of age, sexual orientation and religion or belief, alongside those of race, gender and disability, for which wider anti-discrimination legislation already exists.

Organisations representing the interests of these groups have been involved in consultations on the role, powers and duties of the new body and all are now in favour, though there are still perhaps some misgivings amongst those with the most to lose.

However, virtually all the respondents to the Government’s consultation on the Commission for Equality and Human Rights said that setting up the Commission was not enough and that it was unjust that there was a ‘hierarchy of equalities’, whereby some groups are given much greater protection from discrimination than others. They also felt that the Commission’s work would be made more difficult by the bewildering patchwork of existing legislation and there needed to be a single Equality Act to create a consistent legislative framework which is easier for everybody – citizens, employers, private and voluntary organisations and public authorities – to understand.
Why is the Act important?

There is reason to be optimistic, therefore, that both broad legislation against age discrimination and the means to ensure it is effective will improve over the next years.

At present, however, in the absence of anti-discrimination legislation, there is little or no protection for older people with regard to their access to goods, facilities and services or the quality of those: older people can still legally be treated less favourably than others, and they have no right of redress.

While there is a growing awareness of the prevalence and the impact of age discrimination, not least amongst older people themselves, this lack of legislation means that there are no mechanisms to require those who provide goods, facilities and services to change their ways, and no legal basis for individuals to challenge discriminatory treatment.

While there is no legislation, however, it is the case that there are some policies that spell out the need for the equal treatment of older people. The National Service Framework for Older People (NSF), which in 2001 set out a range of standards for the NHS and for social care in England, had as its first standard the ‘rooting-out’ of age discrimination from these services: ‘NHS and social services should be provided regardless of age and on the basis of need alone.’ This standard, originally proposed by a group of older people advising on the development of the NSF, acknowledged that such discrimination exists, and that it is as unacceptable as any other form of unjust discrimination.

Experience of tackling other forms of unjust discrimination, such as discrimination on grounds of race, gender and disability, has shown clearly over thirty years that policies and exhortation alone will not change entrenched attitudes and ways of working. There needs to be a body charged with promoting equality and able to enforce anti-discrimination law.

While these were very welcome developments, and some progress has been made towards putting them into practice, they do not have the force of law, nor is it easy for individuals to challenge the way they are treated or to call health trusts, local authorities and other public bodies to account. In the face of the many other pressures on public services, and without the force of law behind them, it is all too easy for such policies to slip down the list of priorities.

Age discrimination is not necessarily deliberate or intentional. Indeed, it is often rather a matter of thoughtlessness and long-standing custom and practice: ‘We have always done it this way, and nobody has challenged us before.’ For example, it is customary for local authority Social Services to distinguish between services for ‘adults’ and those for ‘older people’ and to have different views about the quality of life those in each category are entitled to expect, even though the need for social care may be triggered by the same or very similar circumstances. These differences are reflected in the average unit costs for services for each group; expenditure on each older person is customarily markedly lower than for people in younger age groups.

Whether deliberate or inadvertent, however, the outcome for older people is the same. Age discrimination is damaging and unjust when it results in older people getting a lower standard of service and a poorer quality of life than younger people, and increases the likelihood of breaches of their human rights.

Experience of tackling other forms of unjust discrimination, such as discrimination on grounds of race, gender and disability, has shown clearly over thirty years that policies and exhortation alone will not change entrenched attitudes and ways of working. There needs to be a body charged with promoting equality and able to enforce anti-discrimination law.
Guidance needs to be produced, training undertaken and monitoring mechanisms put in place. Unjust practice needs to be challenged and service providers helped to improve. Individuals need to have the right in law to challenge discriminatory practice, with the backing of informed advocacy and legal advice. In other words, sticks as well as carrots are needed if public and private bodies responsible for the provision of goods and services are to have the incentive to change.

In the absence of legislation against age discrimination, Article 14 of the European Convention on Human Rights, enshrined in the Human Rights Act, which requires that everyone should have equal access to the rights outlined in the Convention irrespective of any other status, is extremely important. It at least ensures that the fundamental rights and freedoms outlined in the Act should be assured for older people as for others.

4 In what circumstances are the human rights of older people at risk?

Older people’s human rights can be breached in a wide range of different circumstances. The clearest examples occur when older people experience abuse or neglect at the hands of those charged with their care.

The Department of Health defines abuse as ‘a violation of an individual’s human and civil rights by any other person’. Action on Elder Abuse, a voluntary organisation specialising in this field, uses a different definition: ‘a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person.’

Abuse is usually classified under six headings: physical, psychological, financial, or sexual abuse, neglect or acts of omission (such as ignoring medical needs or failing to provide proper nutrition) and discriminatory abuse (such as racist, sexist or homophobic slurs or harassment). While most abuse happens within the family, a significant proportion — about one-third of the cases reported to the Action on Elder Abuse helpline — is perpetrated by paid workers.

Nobody really knows how common such abuse is: research is currently under way to try to ascertain prevalence more clearly. However, Action on Elder Abuse quotes one estimate that as many as half a million older people may be suffering abuse at any one time, and professionals working in this area suspect that only a tiny proportion of such abuse is reported. The Community and District Nursing Association recently informed the Health Select Committee that 88 per cent of district nurses report having seen cases of elder abuse.
Whatever the actual figure, cases of the abuse and neglect of older people, and hence breach of their human rights, come to the attention of Action on Elder Abuse, Help the Aged, Age Concern and similar organisations on a frequent and regular basis.

How does it happen that public bodies, legally bound to uphold the Human Rights Act and charged with the care of older people, themselves become the source of abuse and breach of those rights? We suggest that there are two principal categories of such behaviour: actions by individuals; and the existence of abusive institutional cultures. A third category calls into question the very systems and policies established to manage and supply public services.

5 Abuse by individual workers

Sometimes, abuse may be perpetrated by an individual paid worker whose job it is to provide day-to-day care in people’s own homes, or by individual members of staff in residential homes, hospitals and other settings.

The care worker who mistreats an older client behind closed doors in their own sitting-room, the nurse who handles someone roughly or fails to answer a call for help, the doctor who neglects to treat a treatable condition or strikes off a troublesome or expensive patient from their list, the night staff that residents of a care home are afraid of – all these may be examples of individuals who are at risk of violating the dignity and human rights of the older people they come into contact with. Dr Harold Shipman is an extreme example of this category, acting alone and undetected for two decades and deliberately causing the deaths of well over 200 of his patients.

There are always likely to be individuals who are unsuited to the often demanding job of providing care for older or disabled people. Moreover, many care workers and assistants in all settings are untrained and may have little or no understanding of the needs of sick and disabled older people or of their own responsibilities as care workers. Aiming for a fully trained workforce with an understanding both of the needs of older people and of their human rights is a first requirement, but we are a long way from that ideal at present.

A few people, put in a position of power over others, will inflict deliberate harm. They clearly need to be identified as quickly as possible and prevented from undertaking such work in the future, for the sake of those who need care but also in the interests of the many responsible and dedicated staff working with older people. This requires vigilance from those who manage such services and a readily accessible complaints procedure which older people and their relatives feel confident to use.

Complaints of bad treatment should clearly never be brushed aside. In July 2004 the Protection of Vulnerable Adults scheme (POVA) was introduced to ensure that those with a track record of harm to older and disabled people – whether deliberate or otherwise – are prevented from working in a similar role in future. A new system is scheduled to be introduced in 2007 and will be extended to include NHS employees. The intention is that POVA, and, in its place, the new scheme, will ‘significantly enhance the level of protection for vulnerable adults’.17 But there is also a need to recognise that harming others is a crime whatever the setting and should be prosecuted.
6 Institutional cultures which breach human rights

Abuse of human rights may result not only from the action of rogue individuals but may be tolerated, sustained or even encouraged by the culture of a particular institution. The usual moral safeguards against harmful behaviour break down and behaviour which violates people’s human rights becomes the norm. In 11 per cent of the cases that come to the attention of the Action on Elder Abuse helpline, more than one older person is being abused, and more than half of these cases concern institutional care. However, potentially abusive cultures can also exist within agencies charged with providing services in people’s own homes and in other settings.

There are numerous examples of poor treatment of older people in hospital wards which can be severe enough to constitute inhuman or degrading treatment, and which can put lives at risk. ‘Do Not Resuscitate’ notices placed on the records of older patients without their consent, which caused an outcry in the press in 2001, clearly reflect assumptions by medical staff about the quality of life of older people and violates their autonomy and right to life.

The recent Help the Aged Dignity on the Ward campaign uncovered over 1,300 cases of varying degrees of abuse and neglect in hospital care over a two-year period, some of which were undoubtedly life-threatening, and most of which concerned inhuman and degrading treatment, including neglect. More recently, the Commission for Health Improvement published a damning report of an investigation followed allegations of physical and emotional abuse of patients by care staff at a mental health unit for older people run by Manchester Mental Health and Social Care Trust.

It noted that this was ‘the third investigation by the health watchdog into the care of vulnerable older people, leading to concerns about standards of care for these people nationally . . . The care of older people nationally is very concerning’.

Inhuman and degrading treatment can become an everyday experience:

Every day without fail and regardless of my time of arrival I had to change my father as all his clothes were permanently soaked in urine.

Her meal would be on the tray cold and hardly touched. More often than not her teeth would be on the locker at the other side of the bed, well away from the chair on which she was sitting. At no time was she encouraged to eat, the food was not cut into bite-size pieces and no person seemed to be responsible to see that the patients received nourishment.

A nurse unceremoniously lifted the shift garment they had put on her and exposed her completely in front of my son and me. It seemed terrible to me for her to be treated in such an undignified and humiliating manner.

These quotations are from letters received by the Dignity on the Ward campaign. Such complaints remain all too familiar to voluntary organisations working with older people and demonstrate that in some institutions a profound lack of respect for the human rights and dignity of older people can become the norm.
Care homes are another form of institution in which a culture of denial of human rights can arise and the unthinkable can become normal. Older people may be routinely ignored when they call for help, or fed their breakfast while seated on the commode to save staff time.21 ‘The rules’ may impinge on residents’ autonomy and freedom of action, and older people may be bullied or ignored.

Inappropriate restraints, either physical or chemical, may be used, denying older people freedom of movement. Cleaning may be inadequate, leading to unpleasant and smelly surroundings, and food may be restricted or of poor quality. One inquiry found that the medical needs of residents in an expensive private care home were being ignored, and that they were required to share commodes.22

SeniorLine, the Help the Aged helpline for older people and their relatives and friends, reports on one call:

The caller found out yesterday that her mother is being abused in the care home where she lives. Her mother is malnourished and was taken to hospital yesterday because one of her toenails is missing.

As she is not mobile she could not have knocked herself. A care worker accompanied them to hospital and told the caller about all the abuse in the home, residents not being fed, not being taken to the toilet etc. One man has died and his wife is complaining, so the home is now under investigation. (SeniorLine, February 2003)

In a 2005 case, a daughter complained strongly to the Commission for Social Care Inspection about the lack of care given to her father in a care home, including lack of attention to personal hygiene, which resulted in his emergency admission to hospital with extensive bedsores which contributed to his death shortly afterwards.23

Lack of medical care and suitably qualified staff in care homes can put the lives of older people at serious risk.

An inquest in Eastbourne in October 2002 found that an elderly woman with Alzheimer’s disease died of dehydration after a week in a care home, because no one understood that she needed help with drinking and eating. In another case, in North London, a man with dementia was taken off medication for his heart condition when he went into a care home, in spite of detailed instructions left by his wife. Instead, Temazepam (a short-acting sedative) was administered. His health deteriorated rapidly and he died a few weeks later.24

Cases such as these clearly constitute inhuman and degrading treatment and are in breach of Article 3, while some have resulted in the deaths of older people, violating Article 2.

Inspection systems are intended to ensure that standards for the NHS and social care are upheld, but it is clear that such serious abuse and violations of older people’s rights and dignity cannot be left to twice-yearly inspections. It is largely in institutions with a ‘closed culture’, where discussion, dialogue and visitors are not welcomed, that such abuses take place. A culture of openness needs to be fostered, so that patients and residents and their relatives and friends feel free to come and go, raise issues and make suggestions, and managers value their contribution.

Abusive cultures may be even harder to detect in agencies which deliver care to people in their own homes, where one-to-one relationships are the norm and the service is given behind closed doors. Management systems must be proactive and robust and imbued with an understanding of human rights in order to prevent such abusive cultures developing, and where crimes have been committed these must be prosecuted with as much vigour as crimes against children or younger adults.
7 Systemic human rights breaches

The human rights of older people are also breached by some of the rules or expectations built into the system by which public bodies operate. Rather than the single individual who commits a crime against an older person, or the one bad ward, care home or domiciliary care agency, older people’s human rights can be put at risk by the very system charged with upholding them.

Systemic violations of human rights, while less intimate and personal, are in some ways even more disturbing than abuse perpetrated by individuals or condoned by institutional culture, because they are so widespread and so generally accepted. The principal human rights at risk are the right to life, the right to be free from inhuman and degrading treatment, and the right to privacy and family life.

Social services for older people are for the most part very tightly rationed. That rationing, where it results in difficulty in accessing services and poor-quality help, impacts heavily on the human rights and dignity of older people.

Some older people may be living in deteriorating circumstances, in dirty homes they cannot clean or heat properly, unable to manage their washing or cooking and unable to move freely around their own homes. In other cases, an older couple may be struggling to maintain the equilibrium of their everyday lives, as one or both need progressively more help. It is not unusual for someone in their eighties to be providing round-the-clock care to a sick spouse for month after month.

Increasingly tight eligibility criteria for accessing care from social services, due to restricted budgets, can result in help being denied or being delayed for weeks or months. As a consequence, many people who are finding it difficult to manage aspects of their daily lives get little or no help.

Everyone who may be in need of community care services is entitled to an assessment of their needs; so, independently, are family members or friends who provide care and support. When people have had an assessment of their needs, meet the eligibility criteria and qualify for help, the Social Services department has a legal duty to supply the relevant services.

Nevertheless the person may not necessarily receive them. Funding panels are established which review individual cases and allocate the available resources. Such panels are unlawful but unfortunately commonplace; they also call into question article 6 of the Human Rights Act, the right to a fair and impartial hearing. However, individual cases are settled to avoid threatened litigation and the practice continues. Individuals then find themselves unable to access the services they have been assessed as needing.

The following examples are just a few from SeniorLine, the Help the Aged helpline:

The caller has asked Social Services for help with providing household adaptations and equipment for his mother, who is nearly 100. They have asked for information about what she needs but say it will be at least eight months until she can be assessed, and the equipment will not be provided before then. (April 2003)

The caller’s father has been in hospital for ten months and will be discharged soon. He has been advised that he can’t get on a waiting list for a wheelchair until he has left hospital and the waiting list is currently at 18 months. (February 2005)

The caller’s relatives receive social services care twice a day. The aunt is physically very frail and the uncle has dementia. The aunt was taken into hospital and the nurse was appalled at her condition – she died a couple of days later. When the caller visited their council property, he discovered rubbish everywhere, bare electrical wires and there was no light in the kitchen. (February 2005)
The caller’s parents are both suffering from dementia. Her father is 90 and mother 89. Her mother spends most of her time in bed. The caller and her sister have requested a social services assessment but were at first told there was a shortage of staff and her parents’ case was not a priority. The caller has severe heart problems and her sister has arthritis. They are paying for a carer to go in but both are aged over 60 and are finding caring a great strain. The caller has been trying to get her mother incontinence supplies, but every time she contacts them she is told that they are too busy to do anything. (January 2005)

The caller was discharged from hospital without a proper assessment. When she got home, she found that she could not use the toilet as she needed rails to push herself up. She contacted the occupational therapist, who said she would have to wait at least two months and could use incontinence pads in the meantime. She is not incontinent. She is upset by the indignity and feels suicidal. (January 2004)

These are examples of cases where lack of assessment or lack of services following an assessment not only cause extreme distress but clearly assault dignity and impinge on human rights.

When the Government issued guidance on eligibility criteria for accessing adult social care, it identified four levels of need that should govern eligibility: ‘critical’, ‘substantial’, ‘moderate’ and ‘low’. Few local authorities are able to devote resources to anything but the top two categories.

It is not known how many people die in their homes or following emergency admission to hospital because they have been denied an assessment or a service they were assessed as needing, but it is highly likely that people die as a result of lack of care. Inquests appear to be the exception rather than the rule when older people die as a result of their treatment by those responsible for their welfare, but the facts are hard to establish because there is no monitoring system.

The quality of services is also a major issue, of concern both to older people and to care workers themselves. It is usual for home care staff looking after sometimes very frail old people in their own homes to have a tightly defined set of tasks to perform when they visit – getting someone up, washed and dressed, ensuring they have a meal, possibly changing dressings or catheters and so on. They may have as little as 15 minutes or half an hour to complete these tasks. The opportunity to chat, to listen, to vary the programme according to the wishes of the older person or to address anything but the tasks in hand is remote. There can be a number of different staff visiting and little continuity; strangers can appear on the doorstep to help with intimate personal tasks. In these circumstances, it is difficult to build up the meaningful relationships that might enhance both the quality of life of someone living alone, or indeed the job satisfaction of the care worker.

With such pressure on essential practical help, it is perhaps not surprising that maintenance of the psychological and emotional well-being of older people takes second place. The capacity of some older people to pursue interests or to maintain a social or recreational life beyond the four walls of their home is frustrated by the lack of services to support such life-enhancing activities, even though these are recognised as part of the ‘physical and psychological integrity’ of a disabled person, protected under Article 8 of the Human Rights Act. Munby J’s judgment in the East Sussex case, noted above, says that physical and psychological integrity embraces two important concepts: firstly, human dignity and, secondly, the right to participate in community life; it develops an earlier judgment which confirms positive obligations towards disabled people that appropriate measures be taken to ensure access to essential economic and social activities and to an appropriate range of recreational and cultural activities.
Rights at risk

Older people, especially those in advanced old age, face a constant need to adapt to change, and changes are often unpredictable. Your spouse dies, friends die, an operation is due, you trip over a paving stone, fall and break a hip, a neighbour is burgled, it may become more difficult to read your letters, hear conversations or recognise your children, the post office stops paying out pensions, the corner shop closes . . .

Few other times in people’s lives bring so much change and uncertainty. Making decisions and staying in control of decisions when the world itself feels increasingly out of control is a major challenge. Older people make daily decisions about ‘managing risk’. Some cling to their way of life in spite of risks; others opt for greater security.

These are aspects of the experience of older people that current services rarely address. Responses to the needs of older people have become focused on medical requirements, in the drive to make hospitals more efficient, with the result that ‘intermediate care’ – helping people to regain their physical functioning and capacity – has become the prime focus of older people’s services.

Assessment is largely triggered by interaction with the healthcare system or a breakdown in people’s ability to care for themselves, and everything else is called ‘low-level needs’. However, these are not low-level needs – they are, or can be, enormous personal challenges and transitions at a time in life when it may be most difficult to face them because of loss of confidence and day-to-day control over one’s circumstances. There is little advice around about managing those risks or achieving a balance (sometimes in the face of pressure from relatives or others, such as a pressure to opt for safety at the expense of autonomy).

Older people are just expected to get on with it. Such constraints on the help and advice available, and the lack of attention paid to social, psychological and emotional needs, call into question the realisation of the dignity and emotional well-being of older people.

The circumstances of older people can be exacerbated by financial hardship and lack of opportunity to get out and about. People who become disabled below the age of 65 are eligible to apply for Disability Living Allowance, which can include a mobility component of up to £41 a week, and may also apply for support from the Independent Living Fund.

Those who become disabled after the age of 65, however, are eligible only for Attendance Allowance, which is harder to access, less generous and does not include money to enable mobility; equally, they are not eligible to apply to the Independent Living Fund.

A similar issue arises for people in care homes, who are permitted to retain only a personal expenses allowance of £18.80 (in England, Scotland and Northern Ireland, or £19.10 in Wales) from their income. This sum has to cover all expenses except the actual fees, including hairdressing, chiropody, toiletries, newspapers, extras such as sweets, clothing, the cost of phone calls and so on. It is not sufficient to enable people to pursue their interests, buy gifts for relatives, take part in social activities outside the home or make the kind of choices in their lives that are a normal part of the expectations of any other adult.

Treating adults with a lifetime of responsibility and experience behind them like children allowed pocket money is to deprive them of dignity. Unsurprisingly, the incidence of depression amongst older people who need help to live a normal life is high (though it is poorly diagnosed and treated), and older people in care homes report the lowest quality of life, regardless of their level of health or disability.
There can be little doubt that many older people in these circumstances are experiencing inhuman and degrading treatment and a loss of human dignity. The Human Rights Act is being contravened by the omission of those services and resources which would enable older people to retain their dignity and self-respect in the face of increasing physical or mental ill health.

In both the examples below (again from SeniorLine), respect for private and family life, Article 8 of the Human Rights Act, would seem to be being overlooked.

The caller rang some months ago for advice about paying for residential care as her husband was in hospital and had been assessed as requiring residential care. He is still in hospital, which is not a suitable environment for him. His case keeps coming before the funding panel but keeps being refused. The latest letter from Social Services said the delay was due to severe funding difficulties caused by the number of people requiring residential care. (May 2003)

A 92-year-old woman was in a residential home until she had an unsuccessful operation just over a year ago. She was then assessed by the hospital social worker as needing nursing home care. For a year Social Services paid £500 of the full weekly cost of the nursing home, with the woman’s daughter paying the additional £25. However, Social Services have now told the daughter that they will only pay £385, their usual rate, so the woman will have to move. She is partially sighted and deaf. The present home takes time to understand her, unlike the previous residential home where she was abused when she could not understand. There has been no reassessment of the woman’s needs and her daughter is concerned that another move would be detrimental to her mother’s health. (April 2003)

The right to respect for private and family life (Article 8) is also infringed by the widespread practice of requiring older people to leave their homes when the cost to the local authority of maintaining them at home would be greater than the cost of a residential place. In contrast to younger people who need support, older people may be allowed a more limited amount of care at home before it is decided that ‘the time for residential care has come’.

Particularly emotive stories crop up from time to time concerning older couples who are forced to separate against their will, because one of them needs more care than can be provided at home. In one case in Oxfordshire (November 2002) an older couple was placed in two different homes, though this was soon rectified when exposed in the press. In Portsmouth in August 2003 a couple who had been married for 61 years were placed in homes five miles apart because they had different needs: she had advancing dementia and he was physically disabled and in a wheelchair, and a home suitable for them both could not be found.

They agreed to this, on condition that an adapted taxi would be supplied five days a week to enable the man to spend the day with his wife. However, that arrangement broke down when resources became tight.

Both the cases above resulted in an outcry in the press which stimulated action. But the fact remains that financial considerations can and often do override the right to family life of older couples.
The closure of care homes is one field where the Human Rights Act has been used to try to protect human rights. Care homes close for a number of reasons – they may not meet the physical standards required and may not be amenable to alteration; they may not be financially viable; or the home owner may decide to sell the home for business reasons.

Residents, by definition sufficiently ill or disabled to need round-the-clock care, have no tenancy or residency rights and can be asked to leave at any time. The impact of closure on the residents is of course profound: not only do they lose the home they have become accustomed to and expected to be in for the rest of their lives, but they lose friends and familiar staff as well. Their right to private and family life is certainly at issue.

Research into the effect of home closures shows that older people's well-being, their health and indeed their lives are at risk unless the greatest care is taken in making the move. In two 2003 cases, those of Violet Townsend in Gloucestershire and Winifred Humphrey in Hastings, both of whom were moved from their care home at short notice and without their consent, each resident died within two or three weeks of being moved.

One inquiry into the proposed closure of a local authority care home in Plymouth went to the lengths of interviewing each of the affected residents and subsequently issued a set of guidelines for good practice in closing homes, involving careful consideration of the needs and desires of each resident. In those cases where the court has upheld a decision to close the home, it has largely been because the local authority has taken all reasonable measures to inform and involve the residents and has therefore minimised the risk to their lives. However, the right of the residents to stay in the home of their choice has still been overridden.

So it is clear that sheer financial pressure on local authority budgets can result in situations where the human rights of older people are at risk. So can rules, procedures and custom and practice which fail to take account of human rights. Individual human rights suffer in a system which is both under-funded and under pressure, and older people are at particular risk because the services intended for their use are already likely to start from a lower baseline. Older people thus habitually suffer discrimination (contrary to Article 14) in the enjoyment of their human rights.

8 The problem of private organisations

The Human Rights Act applies to bodies which are public authorities. However, the great majority of care services for older people – about 90 per cent of care homes and over 60 per cent of domiciliary care agencies – are no longer run by the state but by private (or sometimes voluntary) organisations, although about two-thirds of those using these services are paid for by local authorities. Since a decision in 2002 (the Leonard Cheshire case), the courts have been interpreting the definition of a ‘public authority’ in a very narrow way.

That case found that people receiving services from a private body did not benefit from the protection of the Human Rights Act. This decision still stands, though it seems clear that it was perverse and contrary to the intentions of Parliament when the Act was passed. This situation has been a matter of sufficient concern for the Joint Committee on Human Rights to hold an Inquiry into ‘the meaning of public authority’ in 2003, which reviewed the possible options for change but concluded that the courts had simply got it wrong and should interpret the meaning more widely.
There appear to be four possible courses of action to improve the protection of the human rights of people who receive services from private organisations, but each has drawbacks.

- The courts could make a different decision in a similar case and so reverse the case law. There are a number of bodies, possibly including the Government itself, which would be prepared to give expert evidence in support of such a case. However, this course of action is potentially slow and uncertain, as it depends on a suitable case arising and the courts taking a different line.

- Local authorities could build compliance with the Human Rights Act into contracts with private bodies when they commission services, just as they already do for Health and Safety and race equality issues. This would ensure that two-thirds of older people who currently receive private sector services were covered, but it would leave out the one-third of older people who have savings or who own their own homes and are therefore required to make their own arrangements for care. It would also make seeking redress for breach of human rights more difficult since the older person would have to sue the local authority for failing to protect their human rights, rather than the direct service provider for the actual breach.

- Human rights could be built into care standards and monitored and inspected accordingly. All agencies providing care and nursing services have to be registered and inspected by the Commission for Social Care Inspection and/or the Healthcare Commission and their Scottish/Welsh/Northern Irish counterparts, which are themselves public bodies and therefore have a positive duty to secure human rights. Compliance with the Act and its principles could become a condition of registration for all providers of services. This would have the advantage of benefiting all users of that service, whether they are paid for by the local authority or not, but it would still be difficult for individuals to go to court directly to claim breach of their human rights, if those rights are through a third party.

- The Human Rights Act could be amended to make it clear that private bodies carrying out functions which would otherwise fall to the state are covered by the Act. This would seem to be the simplest and most effective way of remedying the current anomaly but could open up political difficulties.

All four options are being explored at present. What is clear, however, is that until this glaring gap in protection is closed the Human Rights Act will be failing many thousands of the very people who most need its protection.
9 How can the Human Rights Act become more meaningful for older people?

Two outcomes were expected when the Human Rights Act was introduced: firstly, it was envisaged that public bodies would adopt the Act as the foundation for quality and standards in public services and would develop a ‘human rights culture’; and secondly, individuals who felt that their human rights had been breached would in future be able to seek redress through the courts in the UK, rather than going through the European courts.

Neither has yet been realised. Human rights have yet to be taken to heart as fundamental to the quality of public services, while those who are most likely to need the protection of the Act (children, older people and disabled people, for example) are often those least in a position to claim it. Much therefore depends on the forthcoming Commission for Equality and Human Rights.

10 The responsibilities of public services

Under section 6 of the Human Rights Act, public authorities are required to act compatibly with Convention rights and are breaking the law if they fail to do so. But they also have positive obligations to protect those rights and to be proactive in so doing.

The intention of the Human Rights Act was to make human rights central to the way that public authorities conduct their business. Service decisions would be made with reference to basic rights, such as the right to privacy and family life, the right to a fair hearing and the right not to suffer degrading treatment. It was to become part and parcel of efforts to improve public services and to raise standards.

But the Act alone was not enough to effect such a change, and no organisation was established charged with making sure that the Act was understood and taken to heart by public bodies. The British Institute for Human Rights in 2002 and Help the Aged in 2003 both highlighted examples of instances where vulnerable individuals and groups experienced treatment which certainly appeared to breach their human rights.

When the Audit Commission undertook a study of the impact of the Act in 2003, it found that it had indeed had little impact on public services and that frontline managers were largely unaware of the Act and its implications. Rather than seeing the Act as an opportunity to review and improve practice, public bodies had tended to take a defensive attitude: there had been no cultural shift of the kind envisaged.

By 2003, the Joint Committee on Human Rights and other human rights experts were sufficiently concerned to recommend the establishment of a human rights commission to underpin the Act and ensure that public bodies took a positive and proactive approach to human rights. Following the European Directive on Equal Treatment, when the Government decided to put in place a single commission to promote and enforce equality in 2004, human rights were included within its remit.

The role of the forthcoming Commission for Equality and Human Rights will undoubtedly be significant in promoting human rights to public bodies, and it will have real powers to undertake inquiries and investigations on human rights issues. Regrettably, it will not be able to support individuals wanting to claim breach of their human rights, or to take action on their behalf. None the less, it offers the
best hope of raising awareness of the human rights of older people, undertaking exemplary inquiries and investigations and highlighting necessary action by government and public authorities.

IPPR, the Institute for Public Policy Research, a left-of-centre think-tank, suggests that the voluntary sector too has a key role to play in bringing human rights to attention of public bodies. The Human Rights Act presents an opportunity for the voluntary sector to rethink its approach to tackling discrimination and disadvantage. There is firmer ground for using (campaigning and influencing) approaches based on rights rather than needs now that there is domestic legislation which can support them. Voluntary organisations at local and national level themselves need to develop a good understanding of the Act and its potential. Many are of course themselves service providers, and need to integrate human rights principles in their own services (whether or not the Act applies directly to them as ‘public authorities’).

But IPPR also suggests that they have an important proselytising role in informing their membership, keeping themselves and others up to speed on how case law develops and on successful attempts to influence practice; developing coalitions and alliances to promote equality and human rights principles; using human rights as a framework for work in other policy fields, including using human rights language and arguments in lobbying government and professional bodies at all levels. All such efforts serve to highlight human rights principles and make them part of the currency of public and professional debate and discussion. None the less, a duty on public bodies to promote human rights (comparable to the existing duty to promote race equality) would re-emphasise and highlight the human rights responsibilities of all public authorities.

11 Seeking redress for breaches of human rights

The other way that older people can in theory make use of the Human Rights Act is through litigation on individual cases. A case has to be brought by the individual concerned (though third parties, including voluntary organisations, can act in support).

Legal action has drawbacks: it is a slow, uncertain and expensive way of ensuring that people have access to fundamental rights and freedoms. It usually takes place only after the event, once a breach of human rights has taken place, so while it may benefit others in similar circumstances, it does not necessarily offer immediate practical help to the individual concerned.

None the less, the right to take such action and to seek redress is extremely important. Individual cases play a key role in clarifying the law and its application, and can undoubtedly have a significant impact on the behaviour of public authorities.

Unlike for anti-discrimination cases, however, the new Commission for Equality and Human Rights will not be able to support individuals who wish to take human rights cases through the courts, or to take cases on their behalf (though it will be able to address human rights issues inherent in anti-discrimination cases). Instead it will still be up to individuals to take action on their own behalf should they feel that their human rights have been breached. This is cause for considerable concern, for a number of reasons.

Firstly, older people may be unaware of their rights under the Human Rights Act or any other statute or policy. When the whole system operates as if older people had no rights, it is not surprising that older people themselves may not know they have them or feel able to exercise them.
The first stage of seeking redress for injustice is normally through the ordinary complaints procedures of the public authority concerned. At this stage of a complaint, older people would be reliant on the support of advice workers (e.g. a local Citizens Advice Bureau, older people’s advocacy scheme or disability advice line, for example).

Should the complaints process fail to offer satisfaction, the older complainant has a choice: he or she can either appeal to the Ombudsman (as happened on the issue of eligibility for continuing care funded by the NHS) or can apply to the High Court to take the public authority concerned to judicial review. At this stage of the process, the complainant will need advice from a solicitor and a barrister. Judicial review examines not the facts in a particular case, but whether the process by which the public authority reached a decision was lawful, rational and procedurally fair.

Because section 6 of the Human Rights Act requires public authorities not to act in a way which is incompatible with Convention rights, the violation of such a right could give rise to a case of judicial review for unlawful breach of statutory duty by the public authority concerned. Individual cases may turn narrowly on their own facts, but some may have more general application; a decision of the High Court, the Court of Appeal or the House of Lords can then have a direct impact on the policy and practice of public authorities.

Both complaints procedures and litigation are demanding and long-drawn-out processes, and there are numerous pitfalls along the way. Firstly, independent advice and advocacy in which older people can have confidence, and which might support them in asserting their rights, is in short supply; it has been called ‘the best-kept secret’. While report after report calls for local advocacy schemes specifically targeted at older people, its availability is patchy and funding uncertain.

Where an advocacy agency does exist, older people may have difficulty accessing it. Evidence from the Action on Elder Abuse helpline shows that ‘many relatives were phoning to discover what could be done to help a victim who could not contact the helpline themselves – for example, because they lived in a care home and had no access (or no private access) to a phone or they had dementia or another disorder which meant that they had communication difficulties.’

Secondly, even getting to the first stage of making a complaint can be difficult when people feel powerless and are dependent on those they wish to complain about. It takes a high degree of confidence to take on and challenge the might of a public authority and the weight of professional judgment. The Help the Aged Dignity on the Ward campaign received over 1,300 complaints from members of the public which ranged in severity from dirty wards and lack of respect to abusive treatment and downright neglect; the great majority of those complaints came from relatives of the abused person, and often only after that person had died. It was common for the older person not only to remain silent, but to plead with relatives ‘not to make a fuss’, while relatives themselves often felt that to complain would only put the person concerned at even greater risk.

To take a case further, to the High Court and beyond, requires even greater resources, energy and conviction. It also requires the support of a solicitor who is well versed in the law relating to health, social services or the specialist field in question – and these are in short supply, partly for financial reasons. Judicial review cases are prohibitively expensive unless the individual older person is eligible for public funding by the Legal Services Commission; those with modest capital would fail to qualify, particularly in the early stages of a case when a solicitor would need to undertake a great deal of the work.
Individuals taking such a case need to be eligible for legal aid, or so well off that money is no object, particularly since there is a risk that they could become liable for the costs incurred by the public authority if their application for judicial review is unsuccessful.

For the vast majority of those older people whose human rights may have been breached, litigation is simply not a realistic option. They and their relatives are rarely in a position to take on such a daunting commitment, however strongly they may feel about their treatment.

12 Conclusions and recommendations

Stronger action is needed if the Human Rights Act is to become meaningful for older people and they are to benefit from its protection. Action is needed not just by those whose main focus is on human rights and equality issues but by all public bodies charged with the support of older people at risk.

If human rights are to be safeguarded, those services that are intended to support older people must in practice be able to do so. One priority should therefore be to ensure a sufficient level and quality of services to support those ill or disabled older people whose human rights are most likely to be at risk. These services need to be capable of delivering a level and quality of support that meets contemporary standards, obligations and expectations, including human rights considerations.

The priorities and spending decisions of public authorities still discriminate against older people, leading to difficulties in accessing assessments, waiting lists for services even for those in severe need, and, too often, skimpy services and low standards.

Services are in short supply for all adults who need support to live decent, ordinary lives, but for older people the shortfall is compounded by ageist and discriminatory policies and practices which greatly exacerbate the situation. In some fields, notably health and social care, policies prohibiting such discrimination already exist. They need to be vigorously implemented. In others (e.g. disability benefits), government action is needed to do away with such injustice.

The new Commission for Equality and Human Rights, due to be operational by early 2007, offers a real chance of progress. The Commission will have responsibilities in relation to human rights but also in relation to equality matters. As this paper has demonstrated, the risk to human rights is compounded by discrimination against older people. While legislation banning age discrimination in access to goods, facilities and services may still be a few years off, the risk to human rights and the associated inequality cannot be allowed to persist unchallenged and unchecked.

Recommendations

- Public bodies, including Government, should recognise that human rights are put at risk when essential services, such as health and social care for older people in their own homes, in care homes or in health-care settings, are tightly rationed and limited in scope and quality, and when widespread and deep-rooted policies themselves breach human rights principles. Implementing human rights requires a willingness to address these fundamental problems in the system.
The Commission for Equality and Human Rights should give high priority to reminding public bodies about their positive obligation to promote and protect the human rights of those they serve. A positive duty on public bodies to promote human rights would strengthen this obligation. The CEHR should use the full range of its powers of education, promotion, inquiry and investigation to ensure that the Human Rights Act becomes meaningful and effective in those situations where older people’s rights are most at risk.

Public authorities need to receive a clear, firm and consistent message about how human rights apply to the services for which they are responsible, and how practice should change to reflect these fundamental rights and freedoms. In order to ensure that human rights become integral to the culture of public services, the Commission should work closely with those bodies which are charged with setting and promoting standards for public services and for inspecting such services, such as Government, the Healthcare Commission, the Commission for Social Care Inspection and the Audit Commission.

Urgent Government action is needed to ensure that the older people who receive care or similar services from private or voluntary organisations come under the protection of the Human Rights Act, irrespective of who pays the fees.

The Commission should identify those areas of service where there are the greatest grounds for concern about human rights (for example, the availability of medical care in care homes or the use of restraints) and undertake early investigations, in order to establish a baseline of respect for human rights and send a clear signal about compliance to all service providers.

The Commission should not shrink from undertaking specific inquiries where it suspects that a particular organisation is failing to meet human rights principles or is in breach of its human rights obligations.

Older people need to be able to access independent local advice and advocacy bodies geared to their needs if they are to be empowered to assert their rights or to seek redress under the law. The Government should review the availability, funding and training of the independent advice sector to ensure that all those whose human rights are at risk can access justice.

Since many of those whose rights are most at risk are least able to seek the protection of the law, the Commission should be able to offer legal assistance to, and take action on behalf of, individuals whose human rights have been breached, in the same way as it will be able to do for cases of discrimination.

If the Human Rights Act is to become meaningful to older people, the Commission for Equality and Human Rights is of paramount importance. Clearly, a great deal will depend on the resources that the Commission has at its disposal for human rights purposes, how proactively and effectively the new Commission uses its powers to promote equality and its powers on human rights, and where it chooses to focus its priorities. Older people and their organisations will be looking to the Commission to make their concerns an early priority for action.
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