

Clinical practice and the UK Human Rights Act 1998: protecting individual rights in the interest of the wider community

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ABSTRACT – Health professionals have expressed concern that the UK Human Rights Act 1988, which came into force in 2000, may threaten their autonomy in clinical practice/decision-making and resource allocation by health authorities. Although healthcare-related cases have so far been slow to emerge under the Act, it seems clear that in clinical practice the transition from duty to legal obligation will involve a degree of change for health professionals, in attitude if not in behaviour. With regard to resource allocation, it appears that the UK courts are likely to consider challenges to health authorities' decisions in a way that takes into account the need to set priorities, so long as these decisions do not discriminate unfairly and can be shown to have been made in the best interest of the wider community.

It is now approaching a year since the European Convention on Human Rights, a treaty adopted by the Council of Europe in 1950 and ratified by the UK in 1951, was fully incorporated into English law in the form of the Human Rights Act 1998. (Officially, the Act came into force in England, Wales, Scotland and Northern Ireland on 2 October 2000, but in practice it had already had an effect in Scotland, Wales and Northern Ireland because, under the terms of devolution legislation, the devolved institutions in those parts of the UK can have no power to do anything incompatible with the Convention rights.) The UK Act includes most, but not all, of the Convention rights and was described by the Home Secretary as 'the most significant statement of human rights in domestic law since the 1689 Bill of Rights'¹. Outside government, initial reaction to the new legislation was mixed. While tabloid newspapers compared the act to a 'time bomb' that would affect every aspect of British life², human rights activists hailed it as a landmark in human rights protection³, an unprecedented safeguard for citizens against arbitrary state power⁴.

Healthcare has been very much a part of this debate, with many questions raised about the impli-

cations of the Act for the NHS, health professionals and patients in the UK⁵⁻¹². Health professionals have expressed particular concern that the Act will threaten their professional autonomy, at individual and organisational levels, in two key areas of responsibility: decision-making in clinical practice and resource allocation. For patients, on the other hand, the Act can be seen as an opportunity to ensure better access to information, more involvement in treatment decisions, greater privacy and access to care previously denied them on grounds of insufficient resources. The founding principle of the NHS (providing access to care to all on the basis of need, not ability to pay), together with the balance between individual and collective rights so crucial to the public's health, lie somewhere between this perceived threat to professional autonomy and the opportunity to enforce patient rights.

In this article we focus on the implications of the Act for professional autonomy in the provision and funding of healthcare in the UK. Does the Act challenge individual autonomy with regard to decision-making in clinical practice and related issues such as patient access to information, privacy and confidentiality? At an organisational level, does the Act allow health authorities to allocate scarce resources so as to obtain maximum benefit for the whole community or will it force them to satisfy the demands of some patients at the expense of others? More broadly, to what extent does the Act put the human rights of individuals above the interest of the wider community? And will it be possible to strike a fair balance between individual and collective rights?

The Act since its incorporation

The health-related literature published at the time of the Act's incorporation is understandably speculative in nature, as it was not yet clear exactly how the Act would affect the NHS, health professionals and patients. In the absence of English case law on which to base any discussion of the Act's implications, most of this literature refers to the case law of the European Court of Human Rights (ECtHR) in

Strasbourg. Almost a year on, domestic case law still fails to provide a sufficient basis from which to refute or substantiate initial concerns regarding healthcare.

Perhaps because UK citizens brought a disproportionately large number of the cases heard by the Court in Strasbourg, it was expected that the incorporation of the Convention into UK law would engender a new spirit of litigation, resulting in an avalanche of lawsuits overwhelming the judicial system¹³. To the surprise of many, this has not been the case. Between 2 October 2000 and 12 March 2001 in England and Wales only 109 cases were brought under the Act, which affected the outcome, reasoning or procedure of 56 of these cases¹⁴. The figures were similar in Scotland six months after devolution¹³, and at the time of writing no cases have been brought against the Northern Ireland Assembly and Executive¹⁵.

Documentation of cases relating to healthcare brought under the Act in England and Wales is not yet forthcoming. Although the government-sponsored Human Rights Research Unit at King's College, London, keeps track of all human rights litigation, their statistics are based on aggregate data and do not break down cases by subject matter. The NHS Litigation Authority (NHS LA) plans to compile a list of health-related cases, but has only just begun to collect the necessary information. What is certain is that the number of cases relating to healthcare heard to date is very low: one concerning patients in a permanent vegetative state and a handful regarding mental health. We make reference to the resource allocation implications of one mental health case, but issues relating to the detention and treatment of mentally ill patients merit a separate discussion and are therefore beyond the scope of this paper.

There are several explanations for this apparent lack of litigation. The Lord Chancellor initially advised lawyers to exercise caution in their use of the Act and urged judges to be robust in their dismissal of its unnecessary application. This led the human rights organisation Liberty to claim that the UK courts have been overly conservative and that many of their cases would have been decided in favour of the victim had they been brought before the Court in Strasbourg¹⁶. With regard to healthcare, the NHS LA point out that over 95% of claims brought against the NHS (not under the Act, but in general) are settled out of court¹⁷, although solicitors have suggested that human rights cases may have been filed, but are still waiting to be heard¹⁸. It is also possible that many people are not yet aware of their rights under the Act, or are uncertain how to proceed. We contend that some of these issues, essentially problems of uncertainty and access to information, could be resolved by establishing a human rights commission in the UK (see below).

How does the Act affect public authorities?

The Human Rights Act 1998 obliges UK courts to interpret legislation in a way that is 'compatible with the Convention rights' (Section 3). The Act also makes it unlawful for a 'public authority' to act in a way that is 'incompatible with a Convention right' (Section 6). Importantly, this prohibition applies to positive acts as well as omissions. A public authority

Key Points

Although many health professionals already apply appropriate ethical standards in clinical practice, the transition from duty to legal obligation involves a degree of change, in attitude if not in behaviour

The UK courts recognise health authorities' need to set priorities, given limited resources, and seem willing to give them some leeway in resource allocation decisions, as long as these decisions do not discriminate unfairly and can be shown to have been made in the best interest of the wider community

From the patient's perspective, equity in access to healthcare cannot be guaranteed by legislation alone, and much remains to be done in this area

is defined as a court or tribunal and 'any person certain of whose functions are functions of a public nature' (Section 6). Health-related public authorities include: the Department of Health, health authorities, health trusts, primary care groups and trusts in England, primary care trusts in Scotland, local health groups in Wales, the equivalent bodies (still to be established) in Northern Ireland, individual doctors working within the NHS and general practitioners. If the Act is interpreted widely, doctors working privately may also be considered as public authorities. The British Medical Association (BMA) has recommended that, as a matter of good practice, all doctors should ensure that their decisions are compliant with the Act⁷.

Individuals who believe their human rights have been breached by a public authority can use the Act to resolve matters informally, take the authority to court in the UK (instead of travelling to the ECtHR in Strasbourg as before) or rely on the Convention rights concerned in any legal proceedings (Section 7). Only a 'victim', defined as someone who has been or could be affected by a breach of the Act, can bring cases under the Act (Section 7). While UK judges are required to take ECtHR case law into account, they are not bound by it and may go even further.

If a breach of human rights has occurred because a public authority has been complying with an Act of Parliament (whether passed before or after the Human Rights Act), courts can declare the civil Act to be *incompatible* with the Convention (Section 4), but the 'declaration of incompatibility' does not achieve any other remedy for the victim. Courts are not permitted to declare an Act of Parliament to be *invalid*, even though this is possible in other countries such as the Republic of Ireland, Germany, the USA and South Africa. All those proposing new laws must state that a Bill is compatible with the Act, or that it is incompatible but should be passed anyway, thereby giving Parliament the opportunity to block it.

In 1999, the government set up a Human Rights Task Force to help government departments and public authorities prepare for implementation of the Act¹⁹. It has also set up a Parliamentary Committee on Human Rights to examine laws as they are made and ensure that the Act is properly taken into

account during the legislative process. Although the government established a human rights commission in Northern Ireland in March 1999, it has so far rejected proposals for a commission for the UK as a whole. This may be to its disadvantage.

Professional autonomy in clinical practice

The issue of professional autonomy in clinical practice directly concerns the behaviour of doctors and nurses at an individual level. Shortly after the Act came into force, the BMA published a comprehensive report on the Act's implications for clinical decision making⁷. Based on ECtHR case law and supported by useful case studies, the report presents a detailed analysis of the way in which doctors and nurses may be affected by the Act. It argues that because the requirements of the Act closely reflect existing good practice, the Act does not represent a major change in practice or pose a new challenge to professional autonomy in the area of clinical decision making. Solicitors for the Medical Defence Union expressed a similar view at the time of the Act's incorporation. It was their opinion that clinicians already applied appropriate ethical standards in difficult cases, and they did not therefore expect to see a flood of cases instigated by the introduction of the Act²⁰.

However, the Chairman of the BMA's Medical Ethics Committee has acknowledged that 'what was formerly advocated as a professional and ethical duty will now become a legal obligation'⁷, and it seems inevitable that the transition from duty to legal obligation will involve a degree of change, in attitude at least if not in behaviour. The volume of cases brought under the Act is likely to be determined, among other things, by the speed and extent of this change. Unfortunately, rights legislation and other non-legal frameworks do not guarantee change, and we have to acknowledge the shortcomings of using legal means to promote patient focused behaviour¹¹. As one commentator has observed:

in some {European} countries, where laws on the rights of patients have been introduced during the last decade, experience shows that legislation doesn't necessarily change the behaviour of health services personnel²¹.

According to the Lord Chancellor, the Act creates 'a more explicitly moral approach to decisions and decision-making' (our italics)²². In practice, this means that health professionals must be able to demonstrate that they are acting in a patient's best interests, particularly where the withdrawal of treatment is concerned, as this may infringe the right to life established in Article 2 of the Act (right to life). In some instances it will be necessary to obtain the Court's approval before treatment is withdrawn, but the cases of NHS Trust A v Mrs M and NHS Trust B v Mrs H suggest this will be forthcoming.

In October 2000, the NHS trusts treating Mrs M and Mrs H, two women in a permanent vegetative state, applied to the Court for permission to withdraw treatment²³. Both applications were supported by the patient's family and by the hospital staff. In 1993, the House of Lords ruled that doctors could withdraw tube feeding from patients who were in a permanent vegetative

state, because it conferred no benefit on them (Airedale NHS Trust v Bland), but the law needed to be reconsidered in the light of the Act. The official solicitor representing the patients had considered arguing that withdrawing treatment would breach their right to life under Article 2, while lawyers for the families were planning to argue that Article 3 (prohibition of torture) justified that course of action. However, the presiding judge, Dame Elizabeth Butler-Sloss, agreed that withdrawing treatment would not infringe the patients' right to life as it was not in their best interest to continue artificial nutrition and hydration. She concluded that medical staff could lawfully discontinue all life-sustaining treatment and supply treatment to ensure they died with dignity. The judge went on to clarify that Article 3 did not, in her judgement, apply to these two cases, as it:

requires the victim to be aware of the inhuman and degrading treatment which he or she is experiencing, or at least to be in a state of physical or mental suffering.

Health professionals will need to make extra effort to ensure that patients and their relatives are given adequate information and are properly involved in treatment decisions. Article 10 (freedom of expression) guarantees patients' right to receive all information that is considered to be appropriate and necessary, without interference by a public authority, giving patients unrestricted access to their medical files, including access to records for individuals born through artificial insemination³. It also provides additional protection to 'whistleblowers' in clinical and research settings¹¹, while Article 8 (right to respect for private and family life) imposes on health professionals a legal obligation to maintain confidentiality, so NHS records, information from diagnostic tests and genetic data should now be fully protected under the Act from disclosure to a third party without express consent¹¹.

Health authorities' autonomy in resource allocation

At an organisational level, the issue of health authorities' autonomy in allocating resources may be more problematic. Traditionally, UK law provided individuals with freedom to act as they chose, so long as their actions did not infringe the freedom of others. These 'negative' rights simply provided protection against interference by others. The Act brings with it the concept of 'positive' rights that entail active measures from others in order to be fulfilled. As the Home Secretary explained to Parliament in 1998:

those freedoms alone are not enough; they need to be complemented by positive rights that individuals can assert when they believe that they have been treated unfairly by the state, or that the state and its institutions have failed properly to protect them²⁴.

The concept of positive rights has serious implications for the provision of healthcare. Although the Convention does not expressly recognise a direct right to healthcare, the Act makes it clear that the right to life is not adequately protected by law if the

State merely refrains from taking life intentionally. Article 2 (right to life) imposes a positive obligation on the State to safeguard life, which may include providing all necessary healthcare²⁵. For this reason, insufficient resources may no longer be an acceptable line of defence and could give rise to claims brought under Article 14 (prohibition of discrimination) if resources have been denied as a result of postcode rationing or blanket bans¹². (Article 14 covers sex, race, colour, language, religion, political or other opinion, origin, property and birth. It relates to all other Convention rights, where a breach occurs on grounds of discrimination, but cannot be applied on its own.) Will the Act encourage patients in the UK to demand that health authorities uphold their right to certain types of (usually expensive) treatment? If the courts are prepared to intervene, to what extent will they be equipped to determine how best resources should be allocated? Will this jeopardise health authorities' ability to provide a sufficient standard of healthcare for the whole community?

Before the incorporation of the Act, health authorities were largely left to decide for themselves how best to allocate their limited resources. If allocation decisions were challenged in the courts, judges were likely to apply the *Wednesbury* principle of unreasonableness: that is, they would intervene only if the allocation itself was 'wholly unreasonable'. Applying this principle has prevented the courts from intervening in two cases, one in which treatment not yet vital to a baby's survival was postponed due to a shortage of nurses, and another involving an urgently needed heart operation²⁶. But in a widely publicised 1995 case concerning Cambridge Health Authority's decision not to fund life-saving treatment of a young child, as it would only prolong her life for a few months, the judge cited the Convention in deciding that the authority was under a positive duty to sustain life if there was a chance of survival, however small¹⁰.

This landmark decision, based on Convention rights, might have set the tone for future cases involving resource allocation brought under the Act. However, when Cambridge Health Authority appealed against the decision, the presiding judge in the Court of Appeal, Sir Thomas Bingham, took a different approach, allowing the appeal on the basis that the health authority was entitled, if not bound, to allocate resources within its limited budget to the best advantage of its many patients. It is worth quoting at some length from his concluding statement, in which he notes that:

it is common knowledge that health authorities of all kinds are constantly pressed to make ends meet ... Difficult and agonising judgements have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgement which the court can make ... The courts are not, contrary to what is sometimes believed, arbiters as to the merits of cases of this kind. Were we to express opinions as to the likelihood of the effectiveness of medical judgement, then we should be straying far from the sphere which under our constitution is accorded to us. We have one function only, which is to rule upon the lawfulness of decisions. That is a function to which we should strictly confine ourselves²⁷.

Sir Thomas Bingham's assertion that the courts should confine themselves to ruling 'upon the lawfulness of decisions' was subsequently echoed, albeit with important qualifications, in a case involving North-West Lancashire Health Authority's policy of refusing gender reassignment surgery to transsexuals, save in exceptional circumstances, and the ensuing appeal case in 1999. Although the judges in both cases agreed that 'the Court {would} not seek to allocate scarce resources in a tight budget', they saw it as their duty to:

ensure that the Health Authority has asked the right questions and has addressed the right issues before arriving at a policy that is lawful²⁷.

In both cases the health authority's policy was quashed on the grounds that it was 'Wednesbury unlawful and irrational'. The judge in the appeal case noted that the health authority should:

reformulate its policy to give proper weight to its acknowledgement that transsexualism is an illness, apply that weighting when setting its level of priority for treatment, and make effective provision for exceptions in individual cases from any general policy restricting the funding of treatment for it.

Interestingly, both judges disagreed with the lawyer acting for the transsexuals, who had argued that the health authority's refusal to fund surgery infringed their human rights under Article 3 (prohibition of torture). In the first case the judge stated that:

the Convention does not give the applicants rights to free healthcare in general or to gender reassignment surgery in particular. Even if the applicants had such a right it would be qualified by the respondent's right to determine healthcare priorities in the light of its limited resources.

The judge in the appeal case was also of the view that:

Article 3 was not designed for circumstances of this sort of case where the challenge is as to a health authority's allocation of finite funds between competing demands.

He added that Article 8 (right to respect for private and family life) 'imposes no positive obligations to provide treatment'.

In a case heard in February this year, involving the continuing detention of a mentally ill patient due to a health authority's inability to fund the care and treatment in the community considered necessary for that patient's discharge by a mental health review tribunal, the court found that the Mental Health Act 1983 imposed on health authorities a duty, but not an absolute obligation, to provide aftercare facilities for patients discharged from mental hospitals²⁸. The nature and extent of those facilities fell within the discretion of the health authority, which had to consider other demands on its budget. Therefore, where a health authority could not, despite its best endeavours, procure for a patient the requisite care and treatment in the community, the patient's continuing detention did not violate the right to liberty conferred by Article 5 (right to liberty and security). The judge noted, however, that different considerations would apply if the patient in question had been cured of

mental illness. In the latter instance, deferral of discharge would have to be proportionate and could not become indefinite.

Where claims are brought under Article 14 (prohibition of discrimination), health authorities will have to show that their policy not to provide a particular treatment does not violate positive obligations under other Articles in a manner that discriminates, for example, on the basis of a patient's age or place of residence. In principle, under the Act, the provision of life-saving treatment should not depend on how old you are or where you live. Blanket bans, which by definition do not consider patients in terms of their individual characteristics, will almost certainly be deemed illegal.

The issue of whether patients will demand that healthcare be provided as a right under Article 2 (right to life) has yet to be tested in the courts. There has been some suggestion of the courts using Article 2 to justify a new approach to dealing with resource allocation decisions, involving closer scrutiny of claims relating to the efficacy of a particular drug or the cost-effectiveness of certain treatments²⁹. In the light of such suggestion it is fair to question whether the courts are sufficiently equipped to intervene in this way.

It seems clear from the rulings described above that challenges to health authorities' decisions brought under other Articles will continue to be considered in a way that takes into account the need to set priorities, given limited resources, so long as health authorities can demonstrate that in coming to their decisions they have asked the right questions and addressed the right issues. Health authorities should treat their responsibility for decision making in resource allocation with due respect, taking care to identify substantial and objective justification for decisions that infringe Articles 2 and 3³⁰. Solicitors also advise that, where necessary, they should be ready to produce more detailed financial evidence than has previously been required to support these decisions.

We cannot say for certain whether the Act will jeopardise health authorities' ability to provide a sufficient standard of healthcare for the whole community, as this depends, to some extent, on the way in which they respond to the Act's requirements. But we do suggest that the search for a fair balance between individual and collective rights is central to human rights thinking in general, and the Convention in particular⁴, and that the Act may not therefore pose a threat to health authorities in so far as they are able to maintain such a balance. The case law developed by the ECtHR has established that the principle of 'proportionality' is pivotal in finding this balance. As an ECtHR judge pointed out in 1998:

*in determining whether or not a positive obligation exists, regard must be had to the fair balance that has to be struck between the general interest of the community and the interests of the individual, the search for which balance is inherent in the whole Convention*³¹.

What this means in practice is that any limitations on individual rights must not only be necessary to pursue a legitimate goal, like protecting the wider community from a public health threat, but must also not go beyond what is strictly necessary to achieve that purpose⁴.

Implications for equity in access to healthcare

In our introduction we noted that the Act was a welcome opportunity to enforce patients' rights in terms of better access to information, more involvement in treatment decisions, greater privacy and access to care previously denied them on grounds of insufficient resources. While the Act certainly provides support to patients in achieving the first three of these expectations, it may disappoint patients with respect to ensuring access to healthcare. Even if the Convention and the Act were to express a direct right to healthcare, the literature makes it clear that equity in access to healthcare (ie on the basis of need) cannot be guaranteed by legislation alone³². Patients' charters or bills of rights in themselves are not sufficient to remove the many barriers (such as levels of income, education, information) that stand in the way of achieving access to healthcare on an equitable basis. This means that those who accept the principle on which the NHS was founded (providing access to care to all on the basis of need, not ability to pay) must continue to work towards ensuring equity in access by other means, and not rely on the Act or the courts to do this for them.

A human rights commission for the UK?

That litigation citing the Act has been slow to emerge may disappoint both those who had predicted that the Act would generate a culture of self-serving individualism and those who welcomed it as a means of protecting citizens from state-sponsored abuse. Given time, we are likely to see much more litigation, including in the area of healthcare, some worthwhile and some of questionable value.

A human rights expert points out that bills of rights are not like other pieces of legislation:

*part symbolism, part aspiration and part law, they are fundamentally a set of broadly expressed entitlements and values. As a result they are open to wide and varied interpretation by their enforcers. Their impact, therefore, depends on many other factors outside the formal terms in which they are written*⁴.

If the Act were to fall from political favour or come to be seen as of little relevance to the population as a whole, then compliance with the Act would probably be viewed 'as a defence against legal action rather than as a shift in public service norms'⁴. This would be a missed opportunity, not only for patients, but also for health professionals.

We suggest that a human rights commission for the UK could be instrumental in ensuring that the Act continues to be interpreted in an appropriate manner: that is, in a way that benefits the whole community, not just a few individuals. A human rights commission would be able to advise Parliament on areas of law and practice that were likely to contravene the Act and other international standards, so preventing expensive legal action³³. It could become a resource for developing policy and practice to assist public authorities in complying with their duties under the Act, as well as providing advice in specific areas, such as healthcare. In this respect, it could also ensure

consistency in the way human rights are applied throughout the UK. And, where legal remedies cannot be found, it might open up alternative ways of ensuring that individuals and groups of people are able to access justice. In raising awareness and providing information and advice, a human rights commission would be helping to foster a culture of rights, as opposed to a culture of litigation, in the UK.

Human rights commissions have already been set up in countries such as Canada, New Zealand and Australia³³. Closer to home, the Republic of Ireland established a commission last year, the UK government set up a commission in Northern Ireland in March 1999, and the possibility of establishing a commission in Scotland is currently under consideration by the Scottish Parliament. The United Nations General Assembly has repeatedly passed resolutions calling for countries to establish national institutions and the Council of Europe passed a resolution in 1997 calling for greater attention to be paid to the creation of, and co-operation between, national commissions³³. We think the government should reconsider its decision not to set up a human rights commission for the whole of the UK.

Conclusion

Bodies representing health professionals claim that the Act will not threaten professional autonomy in clinical practice or necessitate major changes in behaviour as its requirements closely reflect existing good practice and health professionals already apply appropriate ethical standards. This remains to be seen, and much will depend on the extent to which health professionals are able to respond to patients' rights in terms of information, privacy and confidentiality. With regard to health authorities, the courts seem prepared to give them leeway in allocating resources, so long as their decisions do not discriminate unfairly and they can show them to have been made in the best interest of the wider community. From the patient's perspective, no amount of legislation can guarantee equity in access to health care, and further work needs to be done in this area.

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