A Review of the Impact of the Human Rights in Healthcare Programme in England and Wales

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Abstract

This article provides the background to an analysis of the Human Rights in Healthcare Programme in England and Wales. Using evidence from source materials, summary publications, and official reports, it charts a small but important change in the relationship between health and human rights and shows how a small number of National Health Service organizations used a human rights-based approach (HRBA) to develop resources aimed at improving the quality of health services and health outcomes. Through a case study of one participating organization, it examines the development of approaches to measuring the outcomes and impacts of HRBAs. The article argues that because of the way the Programme was set up, it is not likely to provide the level of evidence of impact required to bring about a profound change in the relationship between human rights and health care. There is a need for a different approach that considers the big human rights questions that need to be asked.

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Competing interests: None declared.

Introduction

The Human Rights in Healthcare Programme was established in England in 2005 as part of a government-led initiative to embed human rights into public services and develop a culture of respect for human rights. The purpose of the Programme—a collaboration between the Department of Health, the British Institute of Human Rights, and, by 2012, eight participating National Health Service (NHS) trusts—was "[t]o assist NHS Trusts to use a human rights based approach (HRBA) to place human rights at the heart of healthcare."[1]

Five broad principles, known as the PANEL principles, were recognized as core elements of an HRBA:

- People's right to participate in decisions that affect their lives;

- Accountability of duty-bearers to rights-holders;

- Non-discrimination and prioritization of vulnerable groups;

- Empowerment of rights-holders; and

- Legality: the express application of the 1998 Human Rights Act.

The aim was to use human rights as both an end and a means—in other words, as a source of legal standards and obligations as well as one of principles and practical methods that determine how those standards and obligations are to be achieved. At the time of its launch, the Programme enjoyed high-level support; for example, in the words of the minister of state for health services, "Quite simply we cannot hope to improve peoples' health and well-being if we are not ensuring their human rights are respected."[2]

In this article, I will consider the outcomes (likely or achieved effects, whether positive or negative) and impact (short- or long-term changes, whether intended or unintended, positive or negative) of the Programme. But first I will set out the context and explain how the Programme was originally shaped and delivered.

Context

There are three important background considerations: the extent of the Human Rights Act's implementation in public services, particularly health services; the fundamental reforms in health services that were taking place at the time the Programme was being implemented; and the growing public concern about standards of care in some hospitals and care homes in England and Wales.

The 1998 Human Rights Act

The Human Rights Act incorporates the European Convention on Human Rights into domestic law and provides a firm platform for the creation of a new culture of respect for human rights.[3] It outlines the civil and political rights that must be taken into account in the delivery of public services, including health services. These services are required not only to refrain from breaching human rights (negative obligations) but also to take proactive steps (positive obligations) to protect people from human rights abuses. Public service decision-makers, including those in health services, are expected to have a clear understanding of their obligations under the Human Rights Act, work within a human rights framework, and make decisions that protect human rights, such as the right to respect for private and family life and the right to be free from degrading treatment.

Soon after the law's passage, however, it became clear that its vision of bringing about cultural change in public services was not happening in practice. In 2003, in an official report analyzing progress across 175 public bodies in England, including health services, the Audit Commission found that the initial flurry of activity that had occurred immediately after the law's passage had waned and the impact of the Human Rights Act was in danger of stalling.[4] This was due in part to the fact that public bodies, including health services, were being subject to a continual host of new legislation that was seen as more important than the Human Rights Act.

The Audit Commission noted some progress regarding the adoption of human rights-based

policies, practice, and legislation in the field of health—such as the reform of mental health legislation; the NHS Plan 2000, "which was written with human rights in mind"; and the Health and Social Care Bill of 2001, "which was improved because of the scrutiny process against human rights principles."[5] But overall, the commission found that 73% of NHS organizations were "particularly poor" on human rights issues compared to other public services. Only 50% of NHS organizations were providing staff with human rights training and awareness-raising. Less than 58% of public bodies had developed a human rights strategy, with health organizations being "even worse." Sixty-one percent of public bodies were not ensuring that their subcontractors were complying with the Human Rights Act; and of these, the health sector "continu[ed] to lag behind." Sixty percent of health bodies (compared to 44% of public bodies) had not identified high-risk areas or performed audits to verify their compliance with the law; and 67% of health organizations (compared to 56% of public bodies) were failing to regularly monitor relevant human rights case law.[6]

By reviewing existing research and providing practical examples, the Audit Commission showed how the Human Rights Act could be used as a framework to improve service delivery. It argued that applying a human rights framework across public services, including health services, was not only a legal requirement but also a force for good:

> [Our] [r]esearch has shown that the application of human rights principles, for example, dignity and respect, can help improve a patient's experience and quality of care and will inevitably lead to improved outcomes.[7]

Health service reforms

The Audit Commission's report described the state of human rights in health care in England in 2003 and illustrated why the creation of the Human Rights in Healthcare Programme, whether or not it was a direct consequence, was essential. If health organizations had largely failed to observe the Human Rights Act during a period of relative stability, it was even less likely that human rights would be significantly advanced during the organization upheaval that was scheduled to occur.

The implementation of the Programme coincided with the implementation of the NHS Plan 2000 and the Health and Social Care Act of 2001, which set into motion the biggest change in health care since the NHS's establishment in 1948. Hospitals in England were required to apply to become foundation trusts—bodies with more independence and freedoms than other NHS hospitals and also more accountable, via membership arrangements, to their local communities. The organizations that had been responsible for commissioning and monitoring most NHS services were abolished and replaced with 200 new clinical commissioning groups, clinically led NHS bodies responsible for planning and commissioning health care services within a particular geographic area. Public health responsibilities passed to democratically elected local councils, and, in 2012, the responsibility for running the NHS was transferred from the Department of Health to an independent body, NHS England.[8]

A similar and equally fundamental restructuring of health organizations took place in Wales in 2009, with the creation of seven health boards and three NHS trusts responsible to NHS Wales.

In both countries, these changes involved a plethora of health reforms—including new financial and management arrangements, performance and productivity targets, and approaches to regulation and inspection—which inevitably took time and attention away from the important issue of human rights.

Concerns about standards of care

At the same time, health services were increasingly coming under the spotlight because of growing public concerns over standards of care in some hospitals and care homes across England and Wales. The most well known of a number of independent inquiries was the Mid Staffordshire NHS Foundation Trust Public Inquiry. This inquiry, which examined the conditions of care at Stafford Hospital between 2005 and 2009, found a culture of "appalling and unnecessary suffering" affecting hundreds

of people, concluding that between 400 and 1,200 patients may have died as a result. In a damning indictment, the inquiry revealed the pain, distress, neglect, hunger, thirst, and filth regularly suffered by patients, noting that some patients, for example, were forced to satisfy their thirst by drinking from flower vases. The inquiry argued that systemic failures in the hospital had resulted in a "lack of care, compassion, humanity and leadership."[9]

While the scale of the problems at the hospital were greater than those identified elsewhere, this was not an isolated case—indeed, many other scandals involving hospitals and care homes were hitting the headlines. These incidents suggested systemic problems in the health care system, a conclusion supported both by official statistics and by the Care Quality Commission, the independent regulator of health and social care in England.

One area of concern, for example, was hydration and nutrition—essential components of care for the preservation of life and recovery from illness. The Office for National Statistics reported that 1,094 hospital deaths in England in 2010 were linked to or directly caused by dehydration and malnutrition.[10] In 2011, after a series of unannounced visits to 100 hospitals, the Care Quality Commission reported that half of these hospitals were not doing enough to ensure that elderly patients had enough to eat and drink. In one hospital, the Alexandra Hospital in Worcestershire, doctors had resorted to prescribing drinking water to their patients in order to ensure that nurses did not forget.[11]

Concerns about the quality of care in some English hospitals were mirrored in Wales, where the Older People's Commissioner described the treatment of some older people in Welsh hospitals as "shameful," and where the Wales Audit Office reported that many patients were not receiving the nutritional care they needed.[12]

The Human Rights in Healthcare Programme

The Human Rights in Healthcare Programme was initiated against this backdrop of a general lack of respect for human rights, massive organizational change, and a growing number of scandals surrounding hospitals and care homes. The Programme was designed to integrate human rights into NHS processes and use an HRBA to health.

The Programme adopted a collaborative approach. Funding and overall direction was provided by the Department of Health, while human rights training, advice, and support was provided by the British Institute of Human Rights. Project management was provided by independent consultants, and the market research company Ipsos MORI supported the NHS organizations in research and evaluation and in building the evidence base for an HRBA to health service design.

Eight NHS organizations participated in the Programme between 2005 and 2012. Their efforts focused on developing and testing a range of practical human rights-based resources (summarized below). It was a "stop and start" affair, with each active phase lasting around 12 months. Each succeeding active phase was dependent on both ministerial approval and continuation funding from the Department of Health. This inevitably resulted in gaps between active phases and some discontinuity.

Phase one, which took place during 2005–2006, involved five NHS organizations:

1. *Birmingham Teaching Primary Care Trust*: developed an action plan for creating an organizational human rights-based culture;

2. *Mersey Care NHS Trust (Mersey Care) in Liverpool*: developed a human rights-based decision-making process within its Learning Disability Service;

3. *Southwark Health and Social Care*: developed an HRBA to commissioning fertility services;

4. *Surrey and Borders Partnership NHS Trust*: embedded human rights into its equality and diversity strategy; and

5. *Tees, Esk and Wear NHS Trust*: developed an HRBA to the trust's service charter and care planning.

Phase two, which took place during 2007–2008, involved the same organizations (although the names of two trusts had changed):

1. *Heart of Birmingham Teaching Primary Care Trust*: developed an integrated human rights and equality strategy and staff training program;

2. *Mersey Care*: developed an HRBA to risk assessment and a human rights learning program for and with Learning Disability Service staff and users;

3. *Southwark Health and Social Care*: developed an HRBA commissioning framework;

4. *Surrey and Borders Partnership NHS Trust*: developed an integrated human rights and equality strategy and staff training; and

5. *Tees, Esk and Wear Valleys NHS Trust*: developed a business case for an HRBA.

Phase three took place during 2009. Three of the organizations moved from a development to an implementation phase:

1. *Heart of Birmingham Teaching Primary Care Trust*: piloted an HRBA to end-of-life care planning in three of its twelve district nursing teams;

2. *Southwark Health and Social Care*: introduced a human rights capacity-building program aimed at improving services for older people in two nursing homes run by a private sector provider; and

3. *Surrey and Borders Partnership NHS Trust:* introduced a human rights capacity-building program for staff in three care homes for people with complex learning disabilities.

Tees, Esk and Wear Valleys NHS Trust ceased to be involved, and Mersey Care focused on evaluating the human rights-based resources developed in phase two.

Phase four took place during 2011–2012. The Department of Health made two-year continuation funding available but, because it was handing commissioning responsibilities over to NHS England,

ceased to be actively involved. The department contracted Mersey Care to provide leadership and management. Given that two of the original participating organizations had disappeared through reorganization (Heart of Birmingham Teaching Primary Care Trust and Southwark Health and Social Care), other NHS organizations, including one in Wales, were invited to take part:

1. *Betsi Cadwaladr University Health Board in Wales*: developed a toolkit for ward staff that placed human rights at the heart of nutrition and hydration;

2. *City Hospitals Sunderland NHS Foundation Trust*: developed a human rights-based survey to measure inpatients' human rights experiences and identify potential violations;

3. *NHS Blackburn with Darwen Teaching Care Trust Plus*: developed a human rights guide with and for its local Health Watch Board, which, under the new arrangements, had the right to enter health care premises and report on findings; and

4. *Mersey Care's Learning Disability Service*: developed a human rights-based board game enabling people to learn about human rights in a fun way, as well as a DVD featuring people with learning disabilities sharing their experiences standing up for their rights. The Older People's Service also took part by developing a human rights-based tool to assess the quality of life of patients in dementia wards and to ensure the fulfillment of their rights.

As well as developing additional ways to put an HRBA into practice in health settings, the fourth phase included the development of an online repository of information on human rights in health care, and a guide on how to evaluate the impact of an HRBA to health care.[13] The guide was seen as essential given that in the absence of funding for independent evaluation, previously supplied by Ipsos MORI, health care organizations could not be presumed to have the necessary knowledge and skills to undertake their own evaluations of human

rights-based interventions. The purpose of the guide was to build capacity around research and evaluation and to

- *ensure that evaluation of a human rights-based intervention is built in from the earliest possible stage*
- *encourage a realistic and proportionate approach to evaluation and*
- *embed evaluation of human rights developments into the culture of NHS organizations.*[14]

The guide does not suggest a single or "right" way to approach evaluation, instead examining a variety of possible methods through nine case studies on different human rights-based interventions, mostly drawn from the Programme. It does, however, promote some tried and tested techniques from social research and emphasizes the importance of establishing a baseline, having clear objectives, using both quantitative and qualitative methods, using multi-methods to ensure more reliable findings, and cross-checking and triangulating data—standard research methods that may not be obvious to clinical staff implementing an HRBA.

More detail on the Programme can be found in three publications that attempt to meet the glaring gap in practical human rights guidance for NHS organizations.[15] These publications introduce the Human Rights Act and use examples from the Programme to demonstrate how particular human rights are relevant to and can support better health services and health outcomes.

Evidence of impact

Ipsos MORI's research role in phase three of the Programme was to establish the following:

- *Any evidence of measurable outcomes/outputs*
- *Evidence of thinking of how to measure success in implementing a human rights based approach and*
- *Recommendations on future approaches to development of appropriate metrics.*[16]

It found, through a range of methods (including observations of local and national project steering meetings, the collection and collation of information from participating organizations, and interviews with key individuals involved in the third phase of the Programme, which took place during 2009 and is summarized above), that there were identifiable and specific short- and medium-term outcomes—changes that had occurred during that time period and changes that were anticipated to occur in the following three to twelve months. These included the following:

- *Providing an objective and comprehensive way of identifying and prioritizing what is important to patients and service users to improve services;*
- *Giving staff, patients and service users a common language to work through challenging issues; and*
- *Helping patients and service users to assert themselves and engage in how their services were delivered.*[17]

But Ipsos MORI also found that the Programme's overall design prevented the effective evaluation of impacts on the quality of health services and on health outcomes—which were the long-term reasons for the Programme's creation. These limitations included the stop-and-start nature and short time spans of each active phase, which allowed little time for scoping, implementation, and evaluation; the fact that some trusts were focused more on implementation than on evaluation; and the difficulties experienced by some trusts in getting buy-in for their planned human rights projects from key stakeholders, which left less time for evaluation.

The scope of this article does not permit a comprehensive discussion of the Programme as a whole, and the apparent lack of clarity of some participants on an HRBA makes any overall evaluation of outcomes and impact challenging. Therefore, I will focus on certain aspects of Mersey Care's contribution, as I am familiar with this work and because Ipsos MORI found that, of the trusts involved, Mersey Care had the strongest track record in implementing and embedding an HRBA at multiple levels within the organization, as well as the best set of evaluation metrics.[18]

Mersey Care's contribution to the Programme was built on a firm base. Since its formation in

2001, Mersey Care had been developing its strategy, policies, practices, and culture around an explicit HRBA, which was already producing some evidence of impact on both the quality of services and health outcomes. By 2010, Mersey Care had built a national reputation for its creation of a team of over 200 service users (patients) and carers (family members) who were trained, supported, and paid (£12 an hour) to participate as equals with managers and staff at all levels of decision making, including on the trust management board, in the recruitment of staff, and in all service change and development.[19]

In a 2009 study on the state of human rights in Britain, Alice Donald cites the level of users' and carers' participation in Mersey Care as illustrating a "paradigm shift towards one of power sharing."[20] This is evidenced through Mersey Care's work in promoting the right to family life, which was recognized in a national study on best practice.[21] The study observed that the trust had importantly acknowledged that a hospital stay can represent a significant crisis not just in terms of the individual patient's mental health but in terms of overall family life; that hospital stays can have long-term repercussions beyond the period of hospitalization itself; and that the intention to provide safety and support during a time of acute distress can fail to promote recovery if the specific effects of hospitalization on family life are not taken into account. The study explored a particular example in which this recognition had led to a significant change in practice. Parents who were hospitalized wanted to see their children but did not want them to visit a mental health ward. Children wanted to see their parents but were scared to enter the wards. So, supported by an independent organization, Barnardo's, in Liverpool, young carers were invited to improve the quality of Mersey Care services by designing the first "family rooms" in mental health services in England—cozy lounges with toys, games, television, and baby-changing facilities where children could see their parents in familiar surroundings. By 2011, there were 15 family rooms in Mersey Care, each one allowed to put the "Jelly baby" logo, designed by one of the young carers, above the door

if the trust had met the quality standards set by young carers.

While it is not possible to say that there is a direct causal link between the participation of service users and carers in decision-making at Mersey Care and good outcomes, there is evidence that Mersey Care was using human rights to improve both the quality of services and health outcomes.

Trust documents show that every three years (2005, 2008, and 2011), the SURE (Service User Research and Evaluation) group—made up of service users and carers with the skills to carry out research and evaluation—performed an evaluation of the participation of service users and carers at Mersey Care. In 2011, for example, postal surveys were sent to 236 actively participating service users and carers (with a 37% response rate) and 138 trust managers (with a 59% response rate). The results were consistent with previous findings.[22]

Of the trust managers who responded, 82% reported being personally responsible for enabling the participation of service users and carers, which indicates the spread of participation throughout the trust. In addition, 96% reported that the participation of service users and carers had positively affected them as a person, 68% reported that it had positively affected their attitudes, and 74% indicated that it had positively affected their practice.

Of the service user and carer respondents, 94% reported that their participation in decision-making made a positive difference for them as a person, and 61% reported that they were more involved in decisions about their care and treatment than they had been three years prior. Most interestingly for the purposes of this article, 78% of service user and 79% of carer respondents indicated that their participation in decision-making at Mersey Care had a positive impact on their mental health recovery or well-being, citing improved clinical recovery outcomes, greater confidence and self-esteem, engagement in purposeful activity, and use of their skills. None of the service users and carers reported that their participation in decision-making had a negative impact. As SURE concluded:

> *There was strong evidence to suggest that [partici- pation in decision-making] is having a positive im-*

pact on the mental well-being of service users and carers; and also that the Trust is benefitting from service user and carer input and is a better, more person-focused organization as a result.[23]

Donald suggests that these findings are supported by the literature, which shows that such participation has

- *challenged entrenched and often prejudicial attitudes to service users as passive recipients of care or services, rather than as active participants in shaping and evaluating those services*
- *made services more responsive to the people that use them*
- *improved relationships between service users and staff and made them partners in finding shared solutions to problems, and*
- *eroded stigma and mistrust between service users and professionals.*[24]

In this enabling environment, Mersey Care's Learning Disability Service sought to build a picture of the ways to measure the impacts of an HRBA to health services for people with learning disabilities. In phase three of the Programme in 2009, the Learning Disability Service focused on evaluating the innovative human rights-based resources that it had designed and developed in phase 2 to meet its specific needs. For illustrative purposes, I will briefly review two of these evaluations.

The "Keeping Me Safe and Well" Risk Screen

This is an HRBA to assessing and managing risk, which the Learning Disability Service describes as originating from the premise that positive risk management is preferable to traditional approaches that focus on assessing and managing "threats" to the service user, carer, or community members. It consists of four key elements:

- Using the principle of *proportionality* to make decisions that balance the rights involved in the person's risky behavior against the rights (or restriction of rights) involved in the strategy being proposed to manage that risk;

- Being *proactive* rather than reactive in assessing and managing risk, by analyzing the individual's

life history and the context in which any difficult behavior occurs;

- Maximizing the *participation* of the service user; and

- Using human rights as a unifying framework to integrate *equality and diversity* considerations into risk management.

During phase three of the Programme, the Learning Disability Service evaluated how effectively this risk screen had been integrated into its routine assessment work, as well as whether, from the perspective of staff using it, the screen better recognized and supported service users' human rights during the risk assessment and management process.[25]

This evaluation—which was done through a clinical audit of case files, a thematic analysis of a small sample of five case notes, and three focus groups with staff—focused on the extent to which an HRBA to risk assessment was implemented by the three community learning disability teams rather than on long-term impacts on the quality of services or health outcomes.

The clinical audit showed that between one-fifth (21%) and one-third (33%) of eligible files across the three sites contained a completed risk screen and suggested that when the new risk screen was used (particularly a picture-based version), service users were more involved in the risk assessment process than previously, although participation varied widely across the teams (80%, 61%, and 38%). The thematic analysis of case notes, which compared the language used before and after the HRBA risk screen had been implemented, showed a shift from implicit to explicit discussions of the FREDA principles (fairness, respect, equality, dignity, and autonomy), which underpin human rights principles. The thematic analysis also indicated a shift from crisis intervention to early intervention, as well as more empathy and respect among staff when meeting with patients. The focus groups showed that staff were positive about the integration of an HRBA into the risk assessment and management process and that they saw the new risk screen as facilitating an HRBA. Specifically, staff felt that the

new risk screen was useful in enabling them to influence other agencies by highlighting the specific needs of service users.[26]

Although the numbers are very small, this evaluation suggests that an HRBA to risk assessment and management may be useful for improving the quality of services for people with learning disabilities. The focus groups identified ways in which the risk screen could be improved, and the evidence base for the impact of the risk screen is a work in progress. Further evaluation is necessary to demonstrate whether an HRBA to risk assessment and management is any more or less effective than an alternative "positive" approach, and whether any related improvements to the quality of services also result in improved health outcomes.

The Human Rights Benchmarking Tool

This tool was developed to establish standards against which to measure and compare outcomes in relation to the support that people with learning disabilities receive from a variety of organizations and to assess the extent to which they are enabled to enjoy their human rights.

The Human Rights Benchmarking Tool identifies a number of important dimensions of individual support packages—risk assessment, physical intervention, staffing, health action plans, involvement in care planning, confidentiality, essential lifestyle plan, employment, and housing—and establishes color-coded standards with attached scores for each dimension: green (75% and above), amber (64–74%), and red (63% and below). The tool was piloted within the Learning Disability Service's community residential service and evaluated through a clinical audit of case files, a detailed study of eight randomly selected individual support packages, and interviews with service users. Overall, the community residential service achieved an "amber" standard, which was considered a positive outcome given that an HRBA had not yet been fully implemented within the service.

As with the previous example, the impact of the benchmarking tool is a work in progress. Further evaluation is required to assess whether using an HRBA to develop standards in this way can result in improved residential support services or health outcomes for people with learning disabilities. Nonetheless, this initial evaluation indicates that this area is worthy of further exploration. The evaluation of the benchmarking tool could form the basis of a comparative study, since, albeit on the basis of a very small number of care packages, the evaluation found that the benchmarking tool's ability to assess packages of care was as consistent as another tool used in the service: the Life Events Checklist, produced by the British Institute of Learning Disabilities. As the evaluation indicated, the benchmarking tool appeared to be good at highlighting those areas within care packages where there is a great need for improvement.[27]

Conclusion

A 2009 inquiry to assess the progress being made toward a culture of respect for human rights in Great Britain found that much remained to be done to give effect to international agreements.[28] While there has been no UK-wide survey since the 2003 Audit Commission report, Donald and colleagues found no evidence to show that the lack of attention to human rights in health care has changed.[29] The pioneering work of the Human Rights in Healthcare Programme has, perhaps inevitably, been overshadowed by health service reorganization, but this should not detract from its achievements, which include the following:

- Marking an important shift from looking at human rights in health services as a matter of legal compliance to looking at the potential benefits of using an HRBA to improve policy and practice and thus improve the quality of health services and health outcomes;

- Development and testing of a range of practical human rights-based resources that are essential to the spread of good practice; and

- Independent evaluation by Ipsos MORI that shows the potential benefits of an HRBA: for example, increased knowledge and understanding about human rights; empowerment of service

users; changed attitudes and behavior of staff and their relationships with service users; improved policies, processes, and practice; and the tackling of difficult issues such as risk assessment and management.[30]

While these are important outcomes, the way the Programme was set up means that it is unlikely to achieve its long-term aim of providing evidence of impact of an HRBA on the quality of health services and health outcomes. We do not know, for example, whether the Betsi Cadwaladr University Health Board was successful in its long-term objective of using an HRBA to achieve a sustainable increase in hydration and nutrition within inpatient wards or whether this had a measurable impact on patients' recovery or on the prevention of deaths from malnutrition and dehydration. Vital questions like this remain unanswered.

The current phase of the Programme (2014–2016) is being led by the Equality and Human Rights Commission, an independent organization whose mandate is to combat discrimination and protect and promote human rights in England. The organization's website shows that it has now included both health and social care within the remit of the Programme and commissioned four entities, including the British Institute of Human Rights and Mersey Care (the only NHS organization now involved in the Programme) to produce 15 human rights-based resources to assist in the implementation of an HRBA in health and social care. These resources include *Human Rights and Maternity Services: A Resource for Midwives*; *Human Rights and Health and Social Care: A Learning Tool for Health Practitioners*; and *Human Rights in Healthcare: A Resource for Nurses*.[31]

It will be interesting to see the outcomes of this new approach to spreading human rights-based resources via professional groups with large memberships. It seems probable, however, that any evaluation of long-term impact will be as equally hampered as was that of Ipsos MORI by short time frames for development, implementation, and evaluation. If so, this new approach is unlikely to

provide the evidence base for the effectiveness of human rights-based interventions—an essential prerequisite for any profound changes in the relationship between human rights and health care.

What should happen next? Given that the impact studies of an HRBA in health care are at such an early stage of development in England and Wales, it would seem useful to learn from impact studies of human rights-based interventions in health elsewhere. Flavia Bustreo, Paul Hunt, et al. point to the need for three elements in evaluating the impact of HRBAs: (1) a better understanding of the big policy and research questions that need to be asked and answered, (2) a wide definition of evidence, and (3) a multidisciplinary approach.[32]

A better understanding of the big policy and research questions that need to be asked and answered

One area of interest to Ipsos MORI was the elaboration of human rights standards and whether, over and above the specific outcomes of each project, the Programme had the potential to develop more generic, higher level measures of human rights that could apply across all human rights-based interventions in health care.[33] Such a measurement tool, it concluded, would be difficult to devise but would go a long way in helping determine which human rights-based interventions are effective and which interventions would enable HRBAs to health services to be channeled in the most productive and cost-effective ways. A subsequent question might be whether interventions that adopt an explicit HRBA to health policy and practice—as in the case of the benchmarking tool developed at Mersey Care—can be pursued with comparable resources and produce similar or better outcomes than non-HRBA approaches. If so, how might an HRBA be preferable?

Other big questions that need to be looked at through a human rights lens are not difficult to find: for example, the unacceptable number of deaths in hospitals in England and Wales as a result of patients not receiving sufficient nutrition and hydration, as discussed above. This is an important issue in relation to the right to life, as no one should die because of basic failures in hospi-

tal care, and unnecessary deaths are likely to be symptomatic of wider failings. It would be useful, in shaping future health policy and practice, to collate existing evidence and develop new evidence (disaggregated by, for example, age, sex, ethnicity, and location) to paint a complete picture of these avoidable deaths; of the policy and environmental determinants (including decision-making processes, financing, and practices) that influence such a catastrophic outcome for patients; and of whether explicitly human rights-based interventions, such as those introduced by the Betsi Cadwaladr University Health Board, can reduce the number of such deaths compared to other interventions introduced elsewhere and designed to have the same outcome.

It would also be beneficial to look through a human rights lens at the widespread health inequalities in England and Wales and use human rights to address the institutional discrimination experienced by people with learning disabilities who are less likely to get the health care they need, which sometimes results in avoidable deaths.[34]

A wide definition of evidence

Clinicians often rely on randomized controlled trials as an evidence base for a particular intervention or drug treatment. While this approach may have a place in impact evaluations of human rights in health care, an important lesson from the Programme is that a wider definition of evidence needs to be used. Mersey Care, for example, sought to establish an evidence base for an HRBA from a variety of sources, including a clinical audit, a case note analysis, and focus groups with service users and staff. The SURE group's evaluation of participation in Mersey Care underlines the importance of collecting evidence of impact from service users and carers, and the Learning Disability Service's experience illustrates the importance of developing innovative ways of acquiring this evidence and enabling people with learning disabilities—who are particularly vulnerable—to have their voices heard.

A multidisciplinary approach

Donald's guide to evaluating human rights-based interventions in health care emphasizes the need to encompass both quantitative and qualitative methods and use a broad array of methods and tools.[35] The level of understanding required to answer the big human rights and health care policy and research questions, as Bustreo and Hunt argue, cannot be provided by one discipline alone.[36] Clinicians, for example, are not likely to be the best people to answer questions relating to the cost-effectiveness of an HRBA. The SURE group's evaluation at Mersey Care suggests that service users are more likely to "tell it as it is" to researchers who also have experience as patients and are likely to be empathetic and understanding. Ipsos MORI suggests that processes may be just as important as impacts, and therefore ethnographic analyses can be particularly useful in capturing how human rights are understood, made meaningful, and applied in health settings.[37]

In summary, the Human Rights Act has not brought about the cultural change in health services that was originally envisaged. The most consistent evidence from the Programme suggests that the development of human rights-based resources can have a beneficial effect; but in the form that the Programme has taken thus far, it has not asked the big human rights questions about health care or sought answers through a multidisciplinary approach encompassing a sufficiently wide definition of evidence. This level of work would seem vital to establishing the "business case" for a step change in human rights in health care. There are over 460 NHS organizations in England and Wales, and despite the commitment to human rights in the NHS's constitution, there is little evidence to suggest that these organizations are persuaded by the moral and legal arguments for human rights or even by the power of human rights to address inadequate services.[38] NHS England, as well as other commissioners and providers of NHS services in England and Wales, may be persuaded to pay due regard to human rights only if it can be proven that investing in human rights-based services and interventions meets legal obligations while also delivering health impacts—better quality services and health improvements that are equally, if not more, cost-effective compared to other interventions.

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