

LAW AND “THE GOOD LIFE”: LEARNING DISABILITY, EQUALITY AND HEALTHCARE IN THE UK

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Introduction: the “Penalty of Disability”

Disabled people throughout the world fare badly against almost any measure of social deprivation. According to the United Nations (UN), they make up the world’s largest and most disadvantaged minority: an estimated 20% of the world’s poorest people are disabled; 98% of disabled children in developing countries do not attend school; an estimated 30% of the world’s street children are disabled; and the literacy rates for disabled people is as low as 3%, or in some countries 1% for disabled women.²

As the UN puts it:

“In every region in the world, in every country in the world, persons with disabilities often live on the margins of society, deprived of some of life’s fundamental experiences. They have little hope of going to school, getting a job, having their own home, creating a family and raising their children, enjoying a social life or voting. For the vast majority of the world’s persons with disabilities, shops, public facilities and transport, and even information are largely out of reach.”³

In some cases the degree of marginalisation can quite simply be a matter of life and death. In October 2010, the Council of Europe’s Human Rights Commissioner, Thomas Ham-

marberg, drew attention to the recent action of the Prosecutor-General in Bulgaria initiating criminal investigations into 166 deaths and 30 more cases of abuse of children living in state-run homes for young people with “mental disabilities”. As the Commissioner observed:

“In Europe today, thousands of people with disabilities are still kept in large, segregated and often remote institutions. In a number of cases they live in substandard conditions, suffering abject neglect and severe human rights abuses. In too many cases, premature deaths are not investigated or even reported.”⁴

In such circumstances, the objective of the State is quite blatantly one of isolation and control, with caged beds and other restraints regarded as entirely normal. Independent living and participation, for so long the goal of the worldwide disability movement, are in such circumstances an idle dream.

Yet, there are grounds for cautious optimism. In Albania, for example, results have been achieved by moving disabled people to community and family-based housing. In the Former Yugoslav Republic of Macedonia and in Serbia ambitious plans for similar reforms have been adopted⁵. As the UN points

out, in a few developed and developing countries more comprehensive law reform aimed at promoting and protecting the rights of disabled people has created the prospect of disabled people leading fulfilling and independent lives as students, workers, family members and citizens: “they are able to do so because society has removed the physical and cultural barriers that had previously hindered their full participation”.⁶

That society in some developed nations has taken these steps is in large measure due to the shift in perception of disability that at least in some quarters has occurred since the Second World War and more particularly in the last two decades. Whereas just a generation or two ago the disadvantage experienced by disabled people would have been greeted by a mixture of acquiescence and pity, the adoption of disability as a civil rights issue in the USA, albeit not as an explicit element of the Civil Rights Act 1964, created an environment in which such disadvantage is now more likely, and not just in the USA, to be greeted by a sense of indignation. At the same time, social theory has generated a way of thinking about disability that identifies “the problem” as residing in the arbitrary barriers to inclusion erected by society rather than in physical or mental impairment itself; and the law in turn has responded with anti-discrimination measures, such as the Americans with Disabilities Act 1990 (ADA) or, in Britain, the Disability Discrimination Act 1995, that have brought disability within the fold of equality legislation, alongside the more established “strands” of race and gender.⁷

Despite its relatively late emergence as a rights issue, disability can more recently claim a place in the vanguard of legislative reform designed to promote not just formal equality but substantive equality too. Critical

to these initiatives has been the concept of “reasonable accommodation” or “reasonable adjustment”, which has been described as inaugurating a “new paradigm” of equality law concerned not so much with equal treatment but with different treatment as a means of achieving equal participation in social, political and cultural life rather than simply equality of opportunity, diversity or non-discrimination.⁸ From being the Cinderella at the equality ball, disability has quickly emerged to stake a claim to the glass slipper of progressive legislation. The first UN human rights convention of the 21st century, in turn incorporating the concept of reasonable accommodation, as well as a firm commitment to the principle of “participation”, is after all the Convention on the Rights of Persons with Disabilities (the UN Convention), described by the Council of Europe Human Rights Commissioner as both “landmark” and a “roadmap towards better treatment of people with disabilities”.⁹

The picture, even in those few developed countries that have embraced disability rights legislation, is not, however, one of unremitting progress. In the USA, for example, it has been noted that there has been something of a “backlash” since the ADA was passed in 1990.¹⁰ In the UK, where the Disability Discrimination Act (DDA) was enacted in 1995, the most recent survey conducted by the Equality and Human Rights Commission suggests that disabled people remain seriously marginalised in employment, educational attainment, and income.¹¹ What Amartya Sen describes as “the penalty of disability” remains severe.¹²

This article considers one aspect of that “penalty”, namely disabled people’s experience of healthcare in the UK. It considers, in particular, how the legal framework, although not

a significant source of individual litigation in this area, has nevertheless played an important part as a catalyst for action by regulatory agencies and voluntary sector bodies. In doing so, it offers reflection on the, sometimes surprising, ways in which law can be mobilised to bring about systemic and cultural change.

1. Access to Healthcare in the UK: the Limits of Anti-discrimination Law

In the last decade the experience of disabled people in the UK healthcare system has attracted particular and sustained attention. Despite its vicissitudes under governments of different political complexion, the National Health Service (NHS) remains for many a gold standard of the post-1945 welfare state. As an index of performance against equality measures, therefore, it carries special and symbolic significance.

Of particular interest has been the experience of those with learning difficulties or mental health problems, not least since estimates suggest that even among disabled people it is they who experience the highest levels of exclusion and are among the most vulnerable.¹³ As the report of an independent inquiry put it in July 2008:

“The health and strength of a society can be measured by how well it cares for its most vulnerable members. For a variety of reasons, including the way society behaves towards them, adults and children with learning disabilities, especially those with severe disability and the most complex needs are some of the most vulnerable members of our society today.”¹⁴

As the evidence of the last decade has accumulated it has become increasingly clear that

if this is indeed a reliable measure, then the UK “cares” not very well at all. What has perhaps been especially disturbing is the extent to which, despite 15 years of anti-discrimination law and a decade of domestic human rights provision, the findings suggest that discrimination and prejudice have played a significant part in the pattern of deprivation.¹⁵ The ability of the law to provide effective protection is to that extent called into doubt.

The DDA 1995, recently absorbed and amended by the Equality Act 2010, has since 1996 provided legislative protection against discrimination in the receipt of goods, facilities and services. In principle, it has since then been open to individual disabled people to bring discrimination claims against the providers of healthcare services, including since 1999 for breaches of the duty to make reasonable adjustments, for example, for failure to provide auxiliary aids and services where to do so would make an otherwise unreasonably difficult or impossible to use service accessible.¹⁶ In fact, there is very little sign of anyone having brought such cases to challenge, for example, the failure to conduct accessible health checks, to adapt screening programmes, to communicate effectively and to provide training aimed at the distinctive needs of disabled people.¹⁷

There are several possible reasons. In general, the goods, facilities and services provisions have attracted relatively little litigation of any sort by comparison with the employment provisions of the DDA. For example, during the years 1996-2001, there were just 53 goods, facilities and services claims, as opposed to approximately 8,900 employment claims.¹⁸ In part, this is no doubt due to the relative ease of bringing claims in the specialist employment tribunals; by compar-

ison, claims to the civil courts for breaches of the goods, facilities and services provisions are potentially expensive and technical. The employment tribunal also provides a more accessible appeals process, which leads to the regular reporting of appellate cases so that there has emerged a relatively sophisticated and well-known body of case law. In the civil courts, the likelihood and ease of appeal is much reduced, with the result that there have been scarcely a handful of reported higher court decisions on the goods, facilities and services provisions. Whatever the reasons, in a common law jurisdiction this lack of precedent is potentially fatal to the visibility and development of the law, at least as an instrument of individual litigation.

It should not be supposed, however, that potential causes of action did not exist. According to the Disability Rights Commission (DRC),¹⁹ the number of potential goods, facilities and services cases referred to it between 2004 and 2007 numbered 25,117, compared to 35,534 employment cases. There are no figures to indicate how many such enquiries related to the provision of healthcare.²⁰ What is clear, however, is that the majority of the goods, facilities and services cases highlighted by the DRC as noteworthy at the end of its seven-year lifespan were almost exclusively about commercial consumer disputes in relation to shops, restaurants, bars and transport facilities. None related to learning disability and health services, notwithstanding the DRC's strategic commitment to treat people with learning disability as a priority for litigation support and the consistently damning reports on the overall provision of healthcare for people with learning disabilities that have emerged during the course of the decade.²¹

The closest the DRC came to touching upon health and social care issues in its conduct

of litigation was through the device of intervening as an interested third party in cases being brought under the Human Rights Act 1998. One such case involved a challenge to a local authority's manual handling policy in domestic social care settings, on the basis that it amounted to a 'no lifting' ban and was unlawful;²² another case, more directly concerned with healthcare services, related to the circumstances in which artificial nutrition and hydration may be withdrawn from disabled patients.²³ Whilst it is significant that the ability to get close to health and social care issues entailed recourse to human rights legislation rather than anti-discrimination law, the cases themselves served rather to accentuate the general invisibility of healthcare services as the subject matter of anti-discrimination litigation. Despite the existence of relatively comprehensive laws in the UK, healthcare services have so far remained largely beyond the reach of individual disabled litigants.

2. A Different Approach: The DRC and "Equal Treatment: Closing the Gap"

In 2006-2007, the final year of the DRC's existence, a new approach to implementing the law was inaugurated by the introduction of the Disability Equality Duty,²⁴ developing the approach to race equality that had been in place since 2001 following the Stephen Lawrence Inquiry and its popularisation of the concept of "institutional discrimination". The new duty placed the onus on public authorities to take positive steps to promote equality for disabled people in the delivery of their services and functions. In so doing it effectively turned disability rights law on its head, shifting attention from retrospective, individual litigation to prospective, collective action aimed at remedying systemic and structural defects in the provision of services to disabled people. This was an example of

what has been described as the fifth, “transformational” phase of equality legislation in the UK, which has recently been extended to all protected characteristics in the Equality Act 2010.²⁵

It was partly in anticipation of the implementation of the Disability Equality Duty in December 2006 that the DRC commenced a formal inquiry into the health inequality experienced by people with learning disabilities or mental health problems. As the DRC’s chairman, Bert Massie, commented in the foreword to the inquiry report’s identification of serious deficiencies in the level of service provided by the NHS: “The implementation of the Disability Equality Duty provides the impetus to remedy this neglect through a strategic and proactive approach.”²⁶

The implication was that the new duty would have the potential to penetrate into those areas of healthcare service that had in effect remained immune from individual litigation, despite the best intentions of the framers of the DDA, and indeed of the DRC, during its lifespan. In the meantime, the DRC had chosen to use its own investigative powers in a prospective and systemic way that anticipated to some extent the approach that would be made possible by the new duty.

The DRC’s investigation in fact proved to be an important piece in an emerging pattern of public audit and non-governmental organisation campaigns in the first decade of the 21st century. As the report explained, the inquiry had produced new evidence that “people with learning disabilities and people with mental health problems are more likely to experience major illnesses, to develop them younger and die of them sooner than other citizens”;²⁷ they are less likely to get the screening they need and they encounter significant barriers in gaining access to basic

health services. For people with learning disabilities, the risks in particular include obesity and respiratory disease; for people with mental health problems, obesity, smoking, heart disease, high blood pressure, respiratory disease, diabetes and stroke.²⁸

Despite the higher risks experienced by these groups, the investigation revealed that they are actually less likely than other people to receive evidence-based checks and treatments. People with mental health problems receive standard cholesterol checks less often than others with heart disease, and breathing tests less often than others with respiratory problems. People with learning disabilities who have diabetes have fewer measurements of their body mass index, and those with stroke have fewer blood pressure checks; they also have very low cervical cancer screening rates. Both groups experience what is described as “diagnostic overshadowing”, that is, the interpretation of physical ill-health as an aspect of a known mental health condition or learning disability with the result that it is not investigated or treated properly.²⁹

To illustrate the extent to which people with learning disabilities and people with mental health problems had eluded targeted government intervention, the DRC report pointed out that there are more obese people with learning disabilities or mental health problems in England than there are obese people in Birmingham and Coventry combined. To address the problem of obesity among these groups would therefore have a greater impact than to do so across those two large Midlands cities. As the report pointed out:

“A national programme to tackle health inequalities in England would not ignore whole cities like Birmingham or Coventry and yet people with learning disabilities

and/or mental health problems have, to date, been ignored in national health inequalities programmes.”³⁰

More generally, the DRC concluded that the cause of health inequalities are “multiple and include deprivation, lifestyle, access to health assessments and treatments and side effects of anti-psychotic and mood stabiliser medication”.³¹ Especially striking was the link to social deprivation:

“Recent data (...) suggest that around 20-33% of the increased risk of poor health faced by children with learning disabilities in the UK can be attributed to their increased risk of exposure to socio-economic disadvantage. The health problems experienced by people with learning disabilities and/or mental health problems are shaped by broader social inequalities, and tackling poverty must form a key part of any efforts to address those problems.”³²

The DRC was specifically concerned, however, to focus on issues other than social deprivation and to identify the “disability penalty”.³³ That disability penalty was manifest, for example, in the fact that, even after accounting for social deprivation, people with schizophrenia and bipolar disorder who have major physical health problems are more likely to die sooner than other people with the same health problems. It was manifest also in the fact that someone with a learning disability or mental health problem might experience deprivation differently because of what the DRC called “compounding difficulties of social exclusion, discrimination and isolation”.³⁴ As the DRC put it, “[t]his is therefore rightly a matter of disability equality, to be addressed through the new Disability Equality Duty, which requires public sector organisations to work positively to promote equal outcomes for disabled people”.³⁵

The promotion of “equal outcomes” rather than the “equal treatment” of the report’s title had by the end emerged as the proposed objective.

3. A Decade of “Indifference”

The DRC formal investigation reinforced and dovetailed with an earlier campaign launched in 2004 by Mencap, the leading learning disability non-governmental organisation. The campaign, *Treat me right!*, which went beyond primary healthcare to include acute care in hospital as well, also aimed to focus attention on the finding that people with learning disability have poorer health than the general population.³⁶ According to Mencap, this is partly because they develop conditions that are directly related to their impairment or because they are generally poor and are therefore more likely to have unhealthy lifestyles. To that extent, the prevalence of high rates of morbidity can be isolated from what might be regarded as “prejudice” or “discrimination”. However, Mencap also suggests that a significant factor is the poor standard of treatment afforded to people with learning disability by the NHS, very often as a direct result of what it describes as “ignorance and prejudice among healthcare professionals towards people with learning disability”.³⁷

Mencap found that 75% of General Practitioners (GPs) said they had no training to help them treat people with a learning disability, and that 90% thought that a patient’s learning disability had made it more difficult for them to provide an accurate diagnosis. The lack of specific training increased the likelihood of diagnostic overshadowing and limited the ability of health professionals to understand the different ways that people with learning disabilities communicate.³⁸

Mencap also found that care in hospital was particularly bad, often as a result of lack of understanding and training, or because of assumptions about the level of care that can be expected from family and care-home staff. In some instances, Mencap identified what it regarded as “blatant discrimination”, with healthcare staff seeming to make “arbitrary value judgments about people with a learning disability having less worth than people without a disability”.³⁹

In a follow-up report entitled *Death by Indifference*, Mencap published its findings on the deaths of six people with learning disability in NHS hospitals. According to Mencap, these six “shocking and tragic” cases demonstrate that there is “institutional discrimination” within the NHS against people with a learning disability, leading to neglect and even premature death.⁴⁰ Mencap identified what it considered to be six contributory factors: people with learning disability are seen to be a low priority; many healthcare professionals do not understand much about learning disability; many healthcare professionals do not properly consult and involve the families and carers of people with a learning disability; many healthcare professionals do not understand the law around capacity and consent to treatment; health professionals rely inappropriately on their estimates of a person’s quality of life; and the complaints system within NHS services is often ineffective, time-consuming and inaccessible.⁴¹

Mencap’s conclusions reinforced the findings of two separate investigations conducted by the health service regulator, the Healthcare Commission, into the alleged abuse of people with learning disabilities in the care of Cornwall Partnership NHS Trust and Sutton and Merton Primary Care Trust, respectively. In those cases, the Healthcare Commission found evidence that abuse had occurred in

part because learning disability services were such a low priority and attracted poor levels of management: “institutional abuse” prevailed mainly as a result of “lack of awareness, lack of specialist knowledge, lack of training and lack of insight”.⁴²

When the Health Service Ombudsman for England, Ann Abraham, investigated the six specific cases identified by Mencap, she too came to some stark conclusions.⁴³ The Ombudsman’s report illustrated “some significant and distressing failures in service across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care”.⁴⁴ The investigation found in some cases that there had been “maladministration and service failure for disability related reasons”, as a well as a failure “to live up to human rights principles, especially those of dignity and equality”.⁴⁵ The Ombudsman concluded that the death of one of the individuals concerned occurred as a consequence of the service failure and maladministration identified, and in another case that it was likely the death of the person could have been avoided if the care had not fallen so far below the acceptable standard. In one of those cases, the Ombudsman found that the individual concerned had not been fed for twenty-six days.⁴⁶

The Ombudsman’s findings were consistent with the broader findings of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities by Sir Jonathan Michael, published as *Healthcare for All* in 2008. That inquiry found “appalling examples of discrimination, abuse and neglect across the range of health services”, which it attributed to learning-disabled people being “not visible or identifiable” by health services; lack of awareness among staff; the needs of learning-disabled people not being a pri-

ority for the NHS; inadequate monitoring of compliance with the law; the tendency for learning-disabled people to slip through the regulatory and inspectorate net; insufficient knowledge and information on the part of staff to make reasonable adjustments; very limited training and education about learning disability for NHS staff; and ignorance and fear, negative attitudes and values.⁴⁷

These findings present a uniformly dispiriting picture of the experience of people with learning disabilities within the NHS. It is all the more dispiriting since it is now thirty years since an influential report of The King's Fund, *An Ordinary Life*, spelt out in 1980 the aspiration to end generations of social exclusion.⁴⁸ That aspiration was finally translated into government policy in 2001 when a government White Paper, *Valuing People*, constructed its central objectives around the principles of independence, rights, choice and inclusion;⁴⁹ and in a 2007 consultation report the aspiration to enable people with learning disabilities to lead ordinary lives and do the things most people take for granted was reasserted, although the then Secretary of State for Health, Alan Johnson, conceded that, despite some progress, for many people with learning disabilities "little has changed".⁵⁰ The 2009 sequel, *Valuing People Now*, whilst placing its trust in the concept of "personalisation", in the sense of adherence to a framework of person-centred planning, individualised services and individually managed budgets, and measures to support access to paid work, could not fail to acknowledge the continuing difficulties of implementing real change.⁵¹

This rather bleak analysis offers little comfort to those on either side of the law and policy divide. On the one hand, the experience of people with learning disabilities, both in healthcare and beyond, has proved largely

impervious to government policy aimed at promoting independence, choice and inclusion; on the other hand, whether because of the inaccessibility of the court process or because of the unwillingness on other grounds of disabled people to make use of it, that experience has almost entirely eluded the reach of individual law enforcement and the protection of rights through the civil court structure. A reasonable response might fall somewhere between frustration and despair.

4. Anti-discrimination Law as a Critical Resource

As a counter to that counsel of despair it is possible to cite the most recent progress report compiled by the Department of Health, which indicates that the convergence of individual claims, referred in this instance to the Health Service Ombudsman, and a concerted critique of structural and systemic failings, is now producing tangible change on the ground. As the report indicates, there are now clear examples of health authorities taking innovative approaches, involving people with learning disabilities and their families in planning, assessing and delivering services, and so ensuring that their hospital ward, GP surgery or community service is fully accessible and actually working in the interests of disabled people. The report points also to improved leadership within the NHS to ensure the active engagement of disabled people and their families, especially through the strengthened role of Learning Disability Partnership Boards. In short, the report suggests that the abstractions of "empowerment" and "choice" are increasingly being made a practical reality.⁵²

Moreover, an important contributor to those encouraging signs has been the legal framework, both in its role as the creative purveyor

of interpretive concepts, such as “discrimination” and “reasonable adjustment”, and as a focal point for enabling critical but mutually reinforcing processes to occur, such as, precisely, the DRC formal investigation and the investigation of individual grievances by the Health Service Ombudsman. To that extent, the experience of people with learning disabilities in the NHS warrants further reflection on how the anti-discrimination legal framework has played its part, notwithstanding its identified limitations. Such an exercise is especially valuable since the part played by the law is not that of straightforward enforcement most readily recognised by those, especially within a common law jurisdiction, who measure success by the number of cases brought to court, the achievement of court judgment in those cases, and whenever possible the appearance of those judgments in the law reports as properly promulgated legal precedent. In this instance, it has been more a question of mobilising or “giving force to” the law, by a variety of means, than of “enforcement” more strictly conceived.

First, throughout the various inquiries cited, the language of disability-rights law offers the primary vehicle for some of the most far-reaching conclusions and recommendations. It is not just the campaigning voice of Mencap that speaks in terms of “discrimination”. The official report of Sir Jonathan Michael and the investigation of the DRC speak quite explicitly of discrimination and prejudice being a significant factor. The Health Service Ombudsman adopted the language of the DDA when she identified maladministration and service-deficiency that had occurred for “disability-related reasons”. The use of the language of discrimination brings to these observations a sense of urgency and entitlement that would otherwise be missing. It also relates the experience of disabled people to the broader tradition of human rights

implementation in a way that makes the evasions of the past harder to sustain.

Secondly, these various reports take for granted something that apparently could not be taken for granted in the negotiations that led to the UN Convention, namely, that in the case of disability rights, the failure to make reasonable adjustments is itself an instance of discrimination and not merely the regrettable omission of an optional extra.⁵³ It is no exaggeration to say, in fact, that much of the substance of the various reports is directed towards realising in practice the full potential of the reasonable adjustment duty and of doing that in a context where the failure to make such adjustments carries with it a measure of opprobrium. The failure to make adequate provision for routine health checks, to adapt screening processes to ensure coverage of those who might otherwise not take advantage of them, to take additional steps to ensure adequate communication with patients whose media and styles of communication are unusual, to provide training targeted at the distinctive needs of disabled people – these steps, variously identified by the DRC, the Health Service Ombudsman and Sir Jonathan Michael, are all in their different ways examples of adjustments to standard policies and practices deemed necessary to ensure equal recognition for people with learning disabilities. In such instances, it is the legal concept of reasonable adjustment that lends cogency and immediacy to what might otherwise be seen as empty exhortation or counsel of perfection. In the case of disability rights, different treatment is quite simply the primary condition of equality.

Thirdly, and related in particular to the language of reasonable accommodation, there is the implicit recognition in all these reports that, as prescribed by the Disability Equality Duty (now the Equality Duty contained

in the Equality Act 2010, albeit subject to the potential relaxation of approach signalled by the draft regulations),⁵⁴ the onus, even in law, rests on the NHS not on individual and vulnerable disabled people. It is not just that the DRC's formal investigation anticipated and welcomed the imminent duty as an opportunity to reverse historic neglect. The very initiative of the various other reports and the tenor of their recommendations leave no room for the complacent assurance that in the absence of, and until, defeat in court, all can be assumed to be well. Notwithstanding the changes in the Equality Act 2010 and in the draft regulations, the very existence of a statutory duty, including the obligation to prepare and publish equality objectives, reinforces an approach to the legal framework that is more "positive" than the earlier reliance on retrospective individual litigation.

The Department of Health's own response to the Health Service Ombudsman's report indicates the range of positive initiatives in place: for example, the creation of the Health Self Assessment to improve collaboration between local people with learning disabilities, their carers and care professionals; the establishment of Learning Disability Partnership Boards to facilitate dialogue between health and social care decision makers; the nomination of Learning Disability Leads to demonstrate leadership and share good practice; and the identification of liaison and facilitation staff in acute and primary care to improve the patient experience of people with learning disabilities.⁵⁵ These steps can be seen as a response to the heightened expectations created by the new fifth generation duty. In practice, the signs are that the language of positive equality duty has begun to permeate the collective imagination, at least within the upper echelons of the NHS.

5. The Broader Legal Framework

Beyond the framework provided by the DDA as a piece of anti-discrimination law, two other legal instruments helped shape the critique of NHS practice in the process of public audit: the Mental Capacity Act and the Human Rights Act.

First, it is the Mental Capacity Act that reinforces the assumed capacity of disabled people to make decisions for themselves rather than the reverse, as in the past. As Mencap discovered, that change of mindset has yet to be achieved in full across the NHS. Even the Department of Health in its follow-up to the Health Services Ombudsman's report concedes that more needs to be done to improve the skills and understanding of mainstream staff in various ways, including in respect of mental capacity, consent and "best interest" decision-making.⁵⁶

This is not just a technical legal issue but something that goes to the heart of how far disabled people are recognised as autonomous individuals with, as a matter of fundamental principle, as much entitlement to direct their own lives as anyone else. Family carers should not have to explain to hospital staff their obligations; nor should "Do Not Resuscitate" notices be placed in patients' records without any conversation with the individuals concerned or their families. One patient experience cited by the Department for Health graphically illustrates the potentially inhumane treatment that the law is intended to remedy and for which it creates a language of protest:

"My son has a severe learning disability and challenging behaviour. I arrived at the hospital where he needed tests. I was asked 'How many people should I get? Four

or five?' It took a moment to realise the doctor meant the number of people required to hold my son down and force treatment on him. There was no question of speaking to him or me about the best way to explain the treatment or keeping him as calm as possible. I had to explain best interest decision making to her, and to her manager, before even the most basic principles of the law were followed."⁵⁷

Secondly, there is the language of human rights, given local flavour by the domestic Human Rights Act 1998 but in essence that of the European Convention on Human Rights, especially as articulated in Article 3, with its prohibition of inhuman and degrading treatment, and in Article 8, with its commitment to the value of private and domestic life.

Explicit, and implicit, in the public audit described is a deep suspicion that people with learning disabilities are simply not valued at all, or if they are, that the value placed upon their lives is less than that of other people. It is this underlying mentality that shapes quite explicitly the entire trail of policy development from The King's Fund report of 1980 and through its explicit adoption in the *Valuing People* agenda of 2001. It is inherent too in the repeated suggestions that people with learning disabilities have not been credited with full personhood, that they have been invisible to health service construction and data collection, that they have simply not been a serious enough priority to warrant targeted prevention and screening programmes.

It is the human rights language of dignity or worth that animates these discussions and creates a framework within which a critique of accepted practice can be mounted. The Health Service Ombudsman speaks of

the human rights principles of dignity and equality; Mencap, of inappropriate "quality of life" assessments by health professionals; Sir Jonathan Michael, of ignorance, fear and negative attitudes. Underpinning the sense of indignation that permeates these various reactions is the realisation that those with learning disabilities have simply not been accorded fully human status; and at root it is that intuition that founds the basis of all indignation against inequality and disadvantage. Equality emerges in these reports as at root a human rights value, alongside fairness, respect, dignity and autonomy (the FREDA values, adopted by the Department of Health).⁵⁸

6. Beyond Law: Dignity, Universalism and "the Good Life"

This narrative of the experience of people with learning disabilities suggests three broad conclusions about the way in which a legal framework, based on the model of anti-discrimination law, can extend its reach beyond the conventional forum of individual court-based litigation. Firstly, even in a sphere such as healthcare, which does not readily lend itself, at least in the UK context, to individual anti-discrimination litigation, the legal framework, by creating expectations and creating a language in which those expectations can be articulated, can play a decisive part in constructing the critique of services that invites audit and investigation by non-litigious means. In that way, the legal framework emerges as a powerful, albeit indirect, resource for interpreting the experience of disadvantage and inequality, and as the conveyor of a sense of urgency and insistence that might otherwise be diminished.

Secondly, court action does not exhaust the process of invoking the legal framework. The

devices of audit and inquiry, especially when embedded in grass-roots non-governmental organisation action, can effectively invoke the law and create an environment in which the values underpinning the law are given expression. The role of ombudsman emerges also as a potentially important resource. Although frequently lacking enforcement powers and essentially quasi-judicial in character, ombudsmen, whether with general or specialist mandates, have the ability to provide ease of access to adjudicative processes, to the invocation of the law even if not to its strict application, and to the recommendation of a suite of remedies that exceeds the narrower range very often available to the civil courts.

Thirdly, it is important for anti-discrimination law to coalesce with other law, so that it becomes part of a broader legal framework based on common values and objectives. In the examples cited, the laws relating to mental capacity and domestic human rights law were invoked by protagonists to capture those experiences of disadvantage and degradation that largely eluded anti-discrimination law in the particular circumstances encountered by disabled individuals and their families. It was that coalition that lent breadth, depth and precision to the critique of services that all agreed were falling short of acceptable standards. It is, furthermore, a legacy that has wide application but, in a narrower UK context, is especially salient when government policy may yet have a regressive impact on the obligation actively to plan ahead rather than contemplate remedial action after the event.

The narrative of a decade's experience also invites three further reflections, of even broader application. The first concerns the nature of "dignity". A recurrent theme has

been the fact that people with learning disability are denied dignity by being ignored, undervalued and excluded from recognition in the ordinary conduct of daily life, on hospital wards and in GPs' surgeries. The recurrence of this sort of misrecognition is an indication that it is deeply rooted in the way in which equality and dignity itself are construed. As Martha Nussbaum has argued, the dominant tradition of thinking about human personhood has mistakenly taken its distinguishing characteristic to reside in rationality, as something quite separate from the needs that human beings share with each other. The practical extension of the equality principle to people with learning disabilities, however, compels the realisation that an approach to human dignity based exclusively on cognitive factors is inadequate to the task.⁵⁹

Instead, what emerges is the need for the principle of equality to be rooted not solely or even primarily in cognitive attributes but very firmly in the bodily nature of the human person, in the fundamental capabilities that lie at the core of the good life for human beings. It is a realisation that reaffirms the status of the equality principle as one aspect of a broader framework of value that includes human rights but that does not deny the inevitability of human need, vulnerability and interdependence as a component of human dignity and source of human solidarity. In the end, the language of duty and restraint gives way to more positive language and to a notion of shared human dignity broadly conceived.⁶⁰ It is a language, too, that invites the reasonable accommodation of different need as a means of reaching beyond concerns about formal equality and process to something more substantive, to a model of liberalism grounded "very much on judgments about what makes a good life".⁶¹

The second reflection concerns the status of disabled people as a minority group. The translation from the deontological to the teleological, i.e. from notions of duty to notions of the good life, forces the recognition that, although disability has made ground in recent years as a minority group issue, in reality it is scarcely a minority group issue at all. As one commentator has remarked:

“While anti-discriminatory legislation is central to the response, for example, to discrimination on the basis of race or gender, it need not be for discrimination on the grounds of disability (...) the universalising thesis, in which disability is treated as part of the normal, is both the most intellectually satisfactory and the most effective, and (...) has the consequence that anti-discrimination legislation might not always be the most effective legal response to disability discrimination.”⁶²

That recognition is especially acute in the context of healthcare. The experience of healthcare for those who are disabled and for those who are not is invariably an encounter with need, vulnerability and dependence. Moreover, the components of good healthcare will be the same in both cases: the sort of “personalisation” that can facilitate good care and dignity for disabled people is the sort of care to which non-disabled people also aspire.

The experience of healthcare, conceived as more than just another consumer service and instead as a basic public response to shared human need, highlights the fact that disability is a continuum, a difference of degree not of kind, extending across various levels of ability and impairment, mediated by social circumstance and environment, and fluctuating in degree through every individual life, from

cradle to grave.⁶³ The emergence of disability as a rights issue, although at first in the guise of a minority group concern and therefore as an aspect of identity politics, in fact suggests that a unified approach to equality will look beyond the language of minority groups and local identity to a form of universalism that unites rather than divides.

Thirdly, and finally, the experience of healthcare afforded to people with learning disabilities makes it clear that, as well as saying something about entitlement, a comprehensive equality principle must say something about the human qualities needed to overcome inequality in practice. Yet another recurrent theme has been the perceived absence of the personal and professional characteristics required to enable healthcare staff to provide the level of care needed by those with learning disabilities. Basic, everyday human qualities such as kindness, insight and practical know-how have repeatedly been in short supply.

Part of the response has been to recommend better training and more intrusive regulation. It is likely, however, that something more fundamental is also required, both the cultivation of personal “virtue” and the collective building up of those institutions and environments that can internalise such virtuous dispositions, making them natural and apparently effortless, rather than the outcome of a constant straining to meet some externally imposed standard of behaviour. It is, in other words, likely to be as much a matter of self-realisation as of external regulation, of the shared long-term development of character and virtuous disposition as the isolated absorption of occasional guidance and training.⁶⁴

When asked what would make a real difference, the families of people with learning disabilities have reported that the key attribute of staff is their ability to establish “warm, respectful and caring” relationships.⁶⁵ As one mother put it:

“Often – not always, but sometimes – the best people have been people who have come with the right values and attitudes and with no experience whatsoever. (...) That’s why it is so important that the person understands and has that ability to build a relationship, to see the person as a person. You can teach all the rest.”⁶⁶

This ethical and political language, rooted more in those traditions of thought associated with Aristotle than with Kant, has

not always been an obvious resource for an equality tradition that is more at home with notions of merit and desert, “the right” rather than “the good”.⁶⁷ It is, however, one aspect of the “new paradigm” created by inclusion of disability in the equality fold that such language should be part of a unified perspective on equality and human rights. The challenge posed by the experience of disability is not simply that of finding legal forms that will transcend the boundaries of equal opportunity, non-discrimination and identity. It is also the challenge of finding the language that will root those legal forms in a more comprehensive and positive set of values that can speak of the good life and of the good society, and of the part played by the equality principle in achieving both.

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² United Nations, *From Exclusion to Equality: Realizing the rights of persons with disabilities – Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*, Geneva, 2007, available at: <http://www.ohchr.org/Documents/Publications/training14en.pdf>.

³ *Ibid.*, p.1.

⁴ Hammarberg, T., *Inhuman treatment of persons with disabilities in institutions*, 2010, available at: http://commissioner.cws.coe.int/tiki-print_blog_post.php?postId=93.

⁵ *Ibid.*

⁶ See above, note 2.

⁷ Gooding, C., *Disabling Laws, Enabling Acts: Disability Rights in Britain and America*, Pluto Press, 1994. On Europe, see Waddington, L., *From Rome to Nice in a Wheelchair: The Development of a European Disability Policy*, Europa Law Publishing, 2006.

⁸ See Fredman, S., “Disability Equality: A Challenge to the Existing Anti-Discrimination Paradigm”, in Lawson A. and Gooding, C., (eds.), *Disability Rights in Europe: From Theory to Practice*, Hart Publishing, 2005, pp. 199-218.

⁹ See above, note 4.

¹⁰ Hamilton Krieger, L. (ed.), *Backlash Against the ADA: Reinterpreting Disability Rights*, The University of Michigan Press, 2003.

¹¹ Equality and Human Rights Commission, *Triennial Review 2010: How Fair is Britain? Equality, Human Rights and Good Relations in 2010*, 2010, available at: http://www.equalityhumanrights.com/uploaded_files/triennial_review/how_fair_is_britain_-_complete_report.pdf.

¹² Sen, A., *The Idea of Justice*, Penguin, 2009, p. 259.

¹³ See, for example, Disability Rights Commission, *Equal Treatment: Closing the Gap*, 2006, and the research justifying investigation cited at Appendix 3, pp. 109-111.

¹⁴ Michael, Sir J., *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, 2008, p. 7.

¹⁵ *Ibid.* See also Parliamentary and Health Service Ombudsman, *Six Lives: the provision of public services to people with learning disabilities*, 2009.

¹⁶ See Disability Discrimination Act 1995, s. 21 for the duty as originally conceived.

¹⁷ Any such cases commenced in the county court would routinely go unreported, and there are no reported cases in the higher or appellate courts. Neither the Equality and Human Rights Commission nor the predecessor commission, the Disability Rights Commission, has drawn attention to any such cases. See, for example, Disability Rights Commission, *DRC Legal Achievements: 2000-2007*, 2007.

¹⁸ Leverton, S., *Monitoring the DDA 1995, Phase 2*, 2002, available at: <http://research.dwp.gov.uk/asd/asd5/IH91.pdf>.

¹⁹ The Disability Rights Commission was a statutory body in Britain, established in 2000 and dissolved in 2007 when it became merged within the Equality and Human Rights Commission.

²⁰ Disability Rights Commission, *DRC Legal Achievements: 2000-2007*, 2007, p. 142.

²¹ *Ibid.*, pp. 123-5.

²² *R. v East Sussex County Council ex parte A, B, X and Y* [2003] CO/4843/2001 High Court.

²³ *R. (on the application of Burke) v General Medical Council* [2005] EWCA Civ 1003 CA.

²⁴ Disability Discrimination Act 1995, Section 49A (as amended by Disability Discrimination Act 2005).

²⁵ Hepple, B., "The New Single Equality Act in Britain", *Equal Rights Review*, Vol. 5, 2010, pp. 11-24; cf. McCruden, C., "Foreword", in Blanck, P. (ed.), *Disability Rights*, Ashgate, 2005, pp. xiv-xv. Note now, however, that the new general and specific duties in s. 149 of the Equality Act 2010, which comes into force in April 2011, and the UK Government's draft regulations, contained in The Equality Act 2010 (Statutory Duties) Regulations 2011, mark a potential retreat from the more anticipatory and proactive aspects of the earlier disability duty.

²⁶ Disability Rights Commission, *Equal Treatment: Closing the Gap*, 2006, p. 2.

²⁷ *Ibid.*, p. 1.

²⁸ *Ibid.*, pp. 4-7.

²⁹ *Ibid.*

³⁰ *Ibid.*, p. 7.

³¹ *Ibid.*, p. 41.

³² *Ibid.*

³³ *Ibid.*, p. 42.

³⁴ *Ibid.*

³⁵ *Ibid.*

³⁶ Mencap, *Treat me right!*, 2004.

³⁷ Mencap, *Death by Indifference*, 2007, Appendix pp. 29-31.

³⁸ *Ibid.*, p. 29.

³⁹ *Ibid.*

⁴⁰ *Ibid.*, p. 1.

⁴¹ *Ibid.*, pp. 18-24.

⁴² *Ibid.*, p. 19.

⁴³ Parliamentary and Health Service Ombudsman, see above, note 15.

⁴⁴ *Ibid.*, Part One, p. 3.

⁴⁵ *Ibid.*

⁴⁶ *Ibid.*, pp. 22-24, 59.

⁴⁷ See above, note 14, pp. 7-8.

⁴⁸ The King's Fund, *An Ordinary Life*, 1980.

⁴⁹ Department of Health, *Valuing People: A new strategy for learning disability for the 21st century*, 2001.

⁵⁰ Department of Health, *Valuing people now: Consultation Report*, 2007.

⁵¹ Department of Health, *Valuing people now*, 2009.

⁵² Department of Health, *Six Lives – Progress Report*, 2010.

⁵³ On the UN negotiations, see Quinn, G. and Gombos, G., "Promoting a Paradigm Shift", *Equal Rights Review*, Vol. 2, 2008, pp. 83-93, especially p. 83.

⁵⁴ See above, note 25.

⁵⁵ Department of Health, *Six Lives Progress Report*, 2010.

⁵⁶ *Ibid.*, p. 36.

⁵⁷ *Ibid.*, p. 39.

⁵⁸ Department of Health, *Human Rights in Healthcare – A Framework for Local Action*, 2007, p. 3.

⁵⁹ Nussbaum, M., *Frontiers of Justice: Disability, Nationality, Species Membership*, Harvard, 2006.

⁶⁰ *Ibid.* See also Johnson, K. and Walmsley, J. with Wolfe, M., *People with Intellectual Disabilities: Towards a Good Life*, The Policy Press, 2010; and Burchardt, T., "Capabilities and disability: the capabilities framework and the social model of disability", *Disability and Society*, Vol. 19(7), 2004, pp. 735-51.

⁶¹ Taylor, C., "The politics of recognition", in Guttman, A. (ed.), *Multiculturalism: Examining the Politics of Recognition*, Princeton University Press, 1994, p. 61.

⁶² Aldridge, P., "Locating Disability Law", *Current Legal Problems*, Vol. 59(1), 2006, pp. 289-318, at p. 318. See also Bickenbach, J. E., "Minority Rights or Universal Participation: The Politics of Disablement", in Jones, M. and Basser Marks L. A. (eds.), *Disability, Divers-ability and Legal Change*, Kluwer Law International, 1999, pp. 101-116.

⁶³ See above, note 59, esp. Chapter 3. See also Nussbaum, M., *Hiding from Humanity: Disgust, Shame and the Law*, Princeton University Press, 2004, pp. 305-319 and Chapter 7.

⁶⁴ MacIntyre, A., *Dependent Rational Animals: Why Human Beings Need the Virtues*, Duckworth, 1999; Phillips A. and Taylor, B., *On Kindness*, Penguin, 2009.

⁶⁵ Mansell, J., *Raising our sights: services for adults with profound intellectual and multiple disabilities*, 2010, p. 12.

⁶⁶ *Ibid.*

⁶⁷ Eagleton, T., "The Right and the Good: Postmodernism and the Liberal State", *Textual Practice*, 1994, pp. 1-10, reprinted in Regan, S. (ed.), *The Eagleton Reader*, 1998, pp. 294-303.