

## Human Rights of Disabled People in Relation to Health by Rowena Daw

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Lady Hale, a member of the House of Lords stated, in a public lecture:

*"... human dignity is all the more important for people whose freedom of action and choice is curtailed, whether by law or by circumstances such as disability. The Convention is a living instrument ... We need to be able to use it to promote respect for the inherent dignity of all human beings but especially those who are most vulnerable to having that dignity ignored. In reality, the niceties and technicalities with which we have to be involved in the courts should be less important than the core values which underpin the whole Convention."*<sup>1</sup>

### 1. Some general themes

#### Introduction

Despite the diversity of impairments that are found among disabled people, as a group they share particular experiences and vulnerabilities from a human rights point of view. Firstly, a human rights approach to health for disabled people involves first the right of access to health care, which can only be indirectly obtained under human rights law. Secondly, it concerns the fulfilment of other rights, violations of which can have serious health consequences because of the disability. Thirdly, health policies and programmes can promote or they can violate human rights in the ways they are designed or implemented – this is more the subject of policy than enforceable rights, and where promoting a human rights culture can be beneficial.

At the outset it is important to be mindful of the social model of disability which locates disability in the barriers to equality which exist in a society that takes people without impairments as the norm. If the problem that denies a person his or her human rights is seen as belonging in the social structures, rather than in the individual, then responsibility is likely to rest with a public authority as well. In examining case law, however, we find, some few judgments aside, that the medical model of disability still reigns, accompanied by a degree of paternalism and misunderstanding at times

The aim of this article is first to highlight some relevant obstacles and opportunities that have been shown in the last decade for disabled people and then to consider the particular contribution made by emerging case law. I refer to some excellent papers but do not seek to replicate the material they cover.

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<sup>1</sup> British Institute of Human Rights Lecture, 2003.

## 2. Some obstacles

**Slowness to develop a human rights culture:** Given that the legal enforcement of rights to health have the inherent problems as other economic, social and cultural rights, campaigners for the human rights of disabled people looked particularly to the development of a human rights culture for their protection when the Human Rights Act was passed in 1998. However the Act has not proved a boon for disabled people. A British Institute of Human Rights (BIHR) investigation<sup>2</sup>, for instance, considered the Act's impact on 'people that are, or can at certain times in their lives, be considered vulnerable: children, disabled people, older people and refugees and asylum seekers'<sup>3</sup>. It found that the Act had 'simply not had an impact'.

little serious attempt by any organisation – whether in government or in the voluntary sector – to use the Human Rights Act to create a human rights culture that could in turn lead to systemic change in the provision of services by public authorities<sup>4</sup>.

Recent initiatives in England, such as the joint Department of Health/ BIHR project on a Human Rights Framework for Health and the recent Disability Rights Commission (DRC) Report on Health Inequalities (discussed below) are among initiatives seeking to set in motion the changes that were expected to follow the introduction of the Act.

**Access to the law:** "Disability was, until very recently, the forgotten dimension of human rights and unacknowledged as a subject for a right to equality".<sup>5</sup> There have been many obstacles to the fulfilment of disabled people's human rights through the courts and the case law. This has been the situation both generally and in relation to health care issues.

With the main exception of people detained as psychiatric patients, until recently the rights of disabled people as a minority group have not featured in Strasbourg cases, and only a few cases have involved people with mental or physical impairments. The exception illuminates one reason for both the invisibility and the dearth of case law since access to the courts is most difficult for this disadvantaged group and the court processes have been slow to respond.<sup>6</sup> This is a problem spared to patients in psychiatric hospital since Article 5 of the Convention requires a person who is deprived of liberty to have a right to legal representation. One prominent commentator has even taken the view that human rights legislation may further disadvantage many disabled people because it privileges both access to court and the substantive issues of those who are articulate and socially well placed.<sup>7</sup>

However, recent cases, both at Strasbourg and in the domestic courts, have shown a greater understanding of the particular needs and vulnerabilities of

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<sup>2</sup> Watson, J (2002) *Something for Everyone: The impact of the Human Rights Act and the need for a Human Rights Commission*: London, British Institute of Human Rights.

<sup>3</sup> *Ibid* at p5.

<sup>4</sup> *Ibid* at p8.

<sup>5</sup> Daw, R (2003) *The impact of the Human Rights Act on disabled people*, Disability Rights Commission: London

<sup>6</sup> For an excellent recent coverage of these issues see Clements and Read *Disabled People and European Human Rights*, A review of the implications of the 1998 Human Rights Act for disabled children and adults in the UK, Policy Press Bristol 2003

<sup>7</sup> Clements *Winners and Losers*, JOURNAL OF LAW AND SOCIETY, VOLUME 32, NUMBER 1, MARCH 2005

some disabled people and the need to use the Convention rights more expansively. Several of these have in turn had a beneficial impact on those who would be unable to take their own cases.

**Resources:** As well as in mental health there has been one other area of case law in Strasbourg which has involved disabled people. Parents of disabled children have tried to use the right to education (Protocol 1, Article 2)<sup>8</sup> to get a mainstream or special school place for their disabled child but these have all failed. The education cases have demonstrated that governments have a large measure of discretion as how to make best possible use of the resources available to them in the interests of disabled children generally.<sup>9</sup> These cases make the wider point. The discretion relating to the use of resources is of course a central theme of human rights discourse, which has bedevilled attempts to use human rights law to improve disabled people's access to health care – to medication<sup>10</sup> and to facilities that will improve their general health and wellbeing. As Lord Hoffmann<sup>11</sup> has put it although:

"it is well arguable that human rights include the right to a minimum standard of living, without which many of the other rights would be a mockery" ... the human rights protected by the Convention "certainly do not include the right to a fair distribution of resources or fair treatment in economic terms — in other words, distributive justice. Of course distributive justice is a good thing. But it is not a fundamental human right."

Lord Walker of Gestingthorpe made the same point:<sup>12</sup>

"There is no general human right to good physical and mental health any more than there is a human right to expect (rather than to pursue) happiness."

### **An opportunity: The role of discrimination under the DDA and Article 14**

Disability discrimination law, with its duty on service providers to make reasonable adjustments for disabled people is however a productive source of rights for disabled people in health care. Unlike human rights law it has expressly obliged governments and service providers to allocate resources to the dismantling of barriers – physical or in policies and practices that impede equality.

***The formal investigation into health inequalities:*** The Disability Rights Commission recently undertook a groundbreaking formal investigation into the Health Inequalities for People with Learning Disabilities and/or Mental Health

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<sup>8</sup> "No person shall be denied the right to education. In the exercise of any functions that it assumes in relation to education and to teaching, the State shall respect the right of parents to ensure such education and teaching in conformity with their own religious and philosophical convictions"

<sup>9</sup> *P D v UK* Application 14137/88; *P and L D v UK* Application 14135/88. *Simpson v UK* (1989) 64 DR 188

<sup>10</sup> *R v Cambridge Health Authority ex p B* [1995] 1 WLR 898 at page 906: *R v North West Lancashire Health Authority, ex p A* [2000] 1 WLR 977

<sup>11</sup> *Matthews v Ministry of Defence* [2003] UKHL 4, [2003] 1 AC 1163, at para [26], *R (on the application of Razgar) v Secretary of State for the Home Dept* [2004] UKHL 27, [2004] 2 AC 368. Lord Bingham of Cornhill at para [9]

<sup>12</sup> *Ibid* at para [34]

Problems<sup>13</sup> found that there was serious systemic inequality for these groups. The Report found that in England and Wales, people with learning disabilities and people with mental health problems are much more likely than others to have significant health risks and major health problems. For people with learning disabilities, these particularly include obesity and respiratory disease; for people with mental health problems, obesity, smoking, heart disease, high blood pressure, respiratory disease, diabetes and stroke.

In primary care, these groups, although they are high risk are less likely to receive some of the expected, evidence-based checks and treatments than other patients “and efforts to target their needs specifically are ad hoc”. The Report states:

“Both people with learning disabilities and people with mental health problems experience ‘diagnostic overshadowing’, that is, reports of physical ill health being viewed as part of the mental health problem or learning disability – and so not investigated or treated. This could mean that levels of ill health are even higher than our figures suggest.

There is little or no evidence that information on the physical health needs of people with learning disabilities and/or mental health problems is either regularly collated or used locally by commissioners to develop improved services.

At government level, these groups have not been systematically targeted by programmes to reduce health inequalities which have mainly focused on socially deprived areas. Whilst important, this alone does not meet the needs of people with learning disabilities and/or mental health problems, who will only attain more equal health outcomes through targeted attention.” (p.3-4)

It called for urgent action at strategic levels, including primary care organisations and Governments, inspection and standard-setting bodies. Recommendations for staff training to reduce diagnostic overshadowing, effectively targeted health promotion, improved prescribing, monitoring, information and choice in relation to psychiatric treatment and the direct involvement of disabled people were included. This investigation was undertaken prior to the introduction of the disability equality duty and has provided an evidence base from which health authorities will be required to work when they set out to give effect to the new duty.

It is interesting to note that the formal investigation did not refer to human rights standards. This may be partly because, like the other equality commissions, the DRC does not have a mandate to deal with human rights law; but it also reflects a wider problem that the possible connections between human rights and discrimination are still not being explored. How the two laws may reinforce each other and provide added value is yet to be discovered. The same is the case, I understand, with the different legislative framework providing a duty to promote equality in Northern Ireland.

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<sup>13</sup> Equal Treatment: Closing the Gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems, DRC, September 2006.

***The new public sector duty to promote equality for disabled people (DED):*** While it does not enable individuals to enforce it, this duty imposes robust obligations on public authorities. A wide ranging and systemic response to inequality, these may be even more effective than individual judgments. The disability equality duty requires equality to be promoted through eliminating discrimination, promoting positive attitudes towards disabled people and their participation in public life, addressing harassment and bullying and treating disabled people more favourably than non disabled people where necessary. Public authorities such as the NHS and its local partners must draw up disability equality schemes. There is a legal obligation to involve disabled people in its preparation and implementation, the duty to collect evidence on disability, and a duty to undertake disability equality impact assessments. The first Disability Equality Schemes were due to be published by the Department of health and public health bodies in December 2006.

Although this new duty can only be enforced by the DRC as a systemic response to inequality for disabled people, it is the nearest we have to a freestanding human right to non discrimination, which complements Article 14 of the ECHR.

***Relationship with Article 14:*** Has Article 14, the right to non-discrimination in the enjoyment of other rights<sup>14</sup>, been a productive source of rights for disabled people? Although it lacks the power of a freestanding right to equality, potentially Article 14 combined with the right to life (Article 2), the right to be free of inhuman and degrading treatment (Article 3) and the right to private and family life (Article 8) could yield some tangible benefits. Disability is not listed as a prohibited ground of discrimination in Article 14 although it is acknowledged to be included as any other status<sup>15</sup>. It is not clear how the status of disability will be defined. It is unlikely, (but not impossible), that the European Court of Human Rights, if called upon to decide the point might defer to each state's definition of disability. If on the contrary they were to take their own approach to disability it could avoid all the technical restrictions on the definition of disability that can hamper claimants under the DDA.

The failure to realise the potential of Article 14 is a general one which has been deprecated in the European Court of Human Rights itself. Judge Bonillo, in a dissenting opinion in a race discrimination complaint<sup>16</sup> stated:

“I consider it particular disturbing that the Court, in over fifty years of pertinacious judicial scrutiny, has not, to date, found one single instance of violation of the right to life (Article 2) or the right not to be subjected to

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<sup>14</sup> The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

<sup>15</sup> *Botta v Italy* (1998) EHLRL 486 proceeded on the basis that disability can fall within Article 14 but the point was not specifically raised. In *Pretty v DPP* (2002) 1 AC 800 it was acknowledged by one of the Law Lords that “other status” could include physical or mental capacity even though Mrs Pretty did not succeed in her claim that she was discriminated against compared with people who were physically capable of committing suicide.

<sup>16</sup> Judge Bonello, *Anguelova v Bulgaria* 38361/97; 13 June 2002

torture or other degrading or inhuman treatment or punishment (Article 3) induced by the race, colour or place of origin of the victim. Leafing through the annals of the Court, an uninformed observer would be justified to conclude that, for over fifty years democratic Europe has been exempted from any suspicion of racism, intolerance or xenophobia. The Europe projected by the Court's case law is that of an exemplary haven of ethnic fraternity, in which people's of the most diverse origin coalesce without distress, prejudice or recrimination."

This is equally relevant to disability. A developed concept of indirect discrimination, used in a similar way to the duty to promote reasonable adjustments would be helpful but has so far not emerged<sup>17</sup>. In this regard it is too soon to predict how far the law will be used. The European Court, faced with claims by disabled people for specific aids (a robotic arm) and particular accommodation required because of the person's disability have declined to assist.

On the other hand, judicial statements in *Price v UK*<sup>18</sup> point towards a more robust approach. In a case involving Article 3 of the Convention the judgement emphasises the "enhanced degree of protection which may be called for when the human dignity at stake is that of someone ... who is so disabled as to be critically dependent on the help of others for even the simplest and most basic tasks of day to day living. In order to avoid discriminating against the disabled one may need to treat the disabled differently precisely because their situation is significantly different from that of the able-bodied".<sup>19</sup> This is a central concept for the effective tackling of disabled people's exclusion from society.<sup>20</sup>

By contrast, the recent UN Convention on Rights of Persons with Disabilities provides in Article 5(3) "In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided".

## **International standards as a useful framework**

Sources for human rights standards relevant to disabled people and health care can be found in international human rights treaties and Conventions, most recently in the Convention on Rights of Persons with Disabilities which contains a specific article on health.

### **Article 25 – Health**

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without

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<sup>17</sup> In the case of *Thlimminenos v Greece* (2000), 31 EHRR 411 the ECtHR affirmed that the right is also violated when states without an objective and reasonable justification fail to treat differently persons whose situations are significantly different..

<sup>18</sup> *Price v United Kingdom* (2001) 34 EHRR 1285

<sup>19</sup> *The Queen (On the Application of (1) A (2) B v. East Sussex County Council* CO/4843/2001

<sup>20</sup> In this respect the Price decision built on the earlier decision in *Thlimminenos v Greece* (2000)

discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a. Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c. Provide these health services as close as possible to people's own communities, including in rural areas;
- d. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

This Article covers principles of service provision which are reflected domestically in NHS standards. The NHS statement of core principles 21 includes

- The NHS will shape its services around the needs and preferences of individual patients, their families and their carers
- The NHS will respond to the different needs of different populations
- The NHS will support and value its staff
- The NHS will help to keep people healthy and work to reduce health inequalities
- The NHS will respect the confidentiality of individual patients and provide open access to information about services, treatment and performance

Other sources of principle are found in the NHS specific health care targets and the National Service Frameworks.

The Article also deals with issues covered by the DDA and, to an extent, by the jurisprudence that is emerging under the ECHR.

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<sup>21</sup> NHS Plan 2000.

### 3. Developments in human rights law applying to disabled people

A greater public awareness of disability and strong campaigning by disabled groups in very recent years has brought about developments in the law and practice of human rights in the European Court. The results have been mixed. Two central concepts which are very resonant for disabled people; autonomy and dignity have been brought in to play, particularly in the quality of life debate.

#### The “quality of life” debate

At the heart of the autonomy for disabled people is the value that is placed on the life of a person with severe impairments, the so called quality of life issues. Key issues include for instance the right of disabled people to life saving treatment. Cases where an infant is severely disabled and facing painful and intrusive treatment that will prolong life but not improve its quality have led the domestic courts to balance the suffering involved in the treatment with the respect for preserving life. Article 2 could improve consistency between the cases.

*Re Baby B* concerned a child with Downs Syndrome and an intestinal blockage that would have been fatal if not operated on. The parents would not consent to the operation as they considered that the child should be permitted to die. The court decided to override the parent’s view. It was clear that the baby would be severely mentally and physically disabled if she survived but that her faculties would not be destroyed. It was too early to offer any further prognosis. If the operation succeeded, the baby might have the normal life span of a child with Downs Syndrome. “It is not for us to say that a life of that description should be extinguished,” said one of the judges.<sup>22</sup>

In 2002, the General Medical Council issued guidance to health professionals on the withdrawal of life prolonging treatment, artificial nutrition and hydration. In the recent *Burke* case<sup>23</sup> certain provisions of that Guidance were considered in detail. The High Court judge held that some of those provisions were in breach of Articles 3 and 8 of the Convention and that the Guidance fails to acknowledge the heavy presumption in favour of life-prolonging treatment and that such treatment will be in the best interests of a patient unless the life of the patient, viewed from that patient’s perspective, would be intolerable. The case was appealed to the Court of Appeal, where it was held that the Guidance was not in breach of Convention rights, but commented that it should be clearer. The Court of Appeal also made it clear that disabled people should be accorded the same respect as non-disabled people with regard to medical decision making.

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<sup>22</sup> [1990] 3 All ER 3 All ER 927 at p. 929 per Templeman LJ.

<sup>23</sup> *R (on the Application of Burke) v The General Medical Council*, High Court judgment reported at [2004] EWHC 1879 and Court of Appeal judgment, yet to be reported, discussed at pp.39-40

In a recent admissibility decision by the European Court of Human Rights, *Glass v UK*,<sup>24</sup> the compatibility of ‘do not resuscitate’ notices with the Convention was considered. The doctor in question had issued a DNR notice in respect of a “severely mentally and physically disabled child” who had been admitted to hospital with a respiratory tract infection but had deteriorated to the point that it was believed he was dying. He was then ‘rescued’ by the family who vehemently opposed the notice and he recovered. The Court found that the decision had not proceeded on the ground that his quality of life would be lower than that of a non disabled person although clearly his disability was a factor in determining his chances of survival and the appropriate treatment for him. The Court observed that the notice was only directed against the application of vigorous cardiac massage and did not exclude other techniques such as the provision of oxygen to keep him alive. They also made clear that where a State has:

“made adequate provision for securing high professional standards among health professionals and the protection of the lives of patients matters such as errors of judgment are not in themselves sufficient to “call the State to account from the standpoint of its positive obligations under Article.”

While this case clearly acknowledged that the quality of life must not be based on an assumption that a disabled person’s life is less valuable to them than that of a non-disabled person, it could be criticised for leaving little room for quality of life arguments to succeed in the face of clear clinical judgments

### **The right to die?**

Two high profile cases in recent years have ruled on the right of a person to choose to end their life. In *Ms B*<sup>25</sup> the right of a competent patient to refuse treatment even when the result would be to end her life was upheld. In the case of *Ms. Pretty*,<sup>26</sup> a woman with motor neurone disease was totally reliant on others for her care and subsistence but was mentally unimpaired. She sought an assurance that her husband would not be prosecuted under the Suicide Act if he assisted her to die, asserting that Article 2 implied a right to die and that under Article 3 she had the right to be free of inhuman and degrading treatment. She argued that by denying her the opportunity of being released from suffering the State itself was imposing that degrading treatment upon her. The European Court of Human Rights disagreed, reluctant no doubt to endorse assisted dying with all the ethical dilemmas that entails.

The issue of euthanasia is particularly contentious for disabled people. Some strongly argue for the right to have their life shortened if it becomes unbearable to them. Others are concerned that the low value that the medical profession at times accords to disabled people’s lives already creates a danger of premature decisions to end life, and fear that acceptance of

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<sup>24</sup> Application NO 61827/00 18 March 2003

<sup>25</sup> (2001) 58 BMLR 87

<sup>26</sup> *Pretty v UK* [2002] EHRR 245

euthanasia increases this risk.

Disabled people have been very vociferous in their defence of the equal value of the life of the disabled person and have campaigned against assisted suicide and euthanasia.

“Many activists see these practices as dangerous to disabled people, because they may create a double standard in which healthy non-disabled people seeking suicide are offered support and counselling, while disabled people and health problems are seen as “better off dead”. Furthermore, many disability-rights advocates argue that it is wrong to offer death as a solution to people whose problems stem largely from an unsupportive, inaccessible society. As long as support services and other necessary resources are still unavailable to many disabled people euthanasia should not be an option.”<sup>27</sup>

The Disability Rights Commission has stated

“the DRC takes very seriously the principle of autonomy expressed in the phrase the right to die. However we believe there is an overriding principle of the right to live. Alongside the wishes of people like Reginald Crew and Dianne Pretty we hear the voices of disabled people who express a real fear that their lives will be put at risk if voluntary euthanasia or assisted suicide were legalized .... We are not aware of any country that has managed to frame a law that allows assisted suicide or voluntary euthanasia ... whilst ensuring that disabled people are protected from coercion and involuntary euthanasia.”<sup>28</sup>

## Parenthood

Laws permitting abortion when it is necessary to protect the mother’s health or life circumstances will, according to current case law, be compatible with Article 2.<sup>29</sup> While the foetus does not have the right to life in the same way as a person, it may have some rights as the pregnancy proceeds<sup>30</sup>. Under the Abortion Act s.1 (1) (d) an abortion is lawful if there is a "substantial risk that if the child were born it would suffer some physical and mental abnormalities so as to be seriously handicapped". Disability rights activists have questioned whether this is compatible with Articles 2 and 14. If a father sought to challenge a mother’s decision to have an abortion, by contending that the provisions of the Abortion Act are incompatible with the Convention the key issue is likely to involve the competing rights in the mother and the rights of the foetus would be directly raised.

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<sup>27</sup> “The application of the ECHR in British Courts in relation to disability issues” Caroline Gooding, Disability Rights Commission 2004

<sup>28</sup> As quoted by Gooding “ The application of the ECHR in British courts in relation to disability issues” Unpublished DRC paper, 2004

<sup>29</sup> *Paton v UK* (1980) 19 DR 244; *H v Norway* 17004/90 (1992).

<sup>30</sup> Most recently discussed in *Vo v France*(2005) 40EHRR 259

Article 12 (the right to marry and found a family) also has implications for some disabled people who are routinely discouraged by health authorities of social services from becoming parents. This may take the form of pressurising pregnant women with a disability to have an abortion. Either their disability is seen as an obstacle to effective parenting or it is feared that their disability is hereditary.

“Disabled people are generally regarded by society as inappropriate parents. If a disabled woman becomes pregnant she is likely to encounter attitudinal discrimination at different levels and from a variety of professional associations. Physical barriers when using antenatal services are massive. Once the child is born, another series of barriers come into play.”<sup>31</sup>

For instance, a local authority might put pressure on the woman to have her child fostered and no support offered in order that she may keep the child.<sup>32</sup> Similarly, disabled adults may be considered inappropriate adoptive parents because of their disability. While these decisions can sometimes be justified, the assumptions behind these attitudes are often mistaken and discriminatory.

An individual with mental capacity to make decisions for him/herself has the right to marry and found a family. This may require public authorities, such as residential homes, to take positive steps to ensure sufficient privacy to enable sexual relations to happen.

**Fertility treatment:** Article 12 does not guarantee to anyone a positive right to fertility treatment but the denial of fertility treatment to a person with a disability might involve Article 12 together with Article 14. In the UK, some health authorities provide for treatment on the NHS and others do not; candidates for fertility treatment are selected according to criteria laid down in the Human Fertilisation and Embryology (HFE) Act and the Code of Practice. The HFE Act does not exclude any category of women from being considered for treatment but two criteria listed in the Code of Practice have the potential to discriminate against disabled parents. They are: the prospective parents’ medical histories and the medical histories of their families; and any risk of harm to the child or children who may be born, including the risk of inherited disorders.<sup>33</sup>

**Sterilisation:** Sterilisation of young women with learning difficulties is a contentious issue. It usually arises when a parent applies to a court for a sterilisation order on the grounds of the young woman’s best interest. Courts have become more reluctant to make orders for sterilisation in recent years probably in the light of the ECHR. They require a definite risk of pregnancy rather than a theoretical possibility before an order can be made. Article 12 and Article 8 will reinforce the current approach and possibly extend it as

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31 Response by BCODP, National Centre for Independent Living, to White Paper “Modernising Social Services”, Cm 4169 (1998).

32 Ibid. p.5. The paper “Modernising Social Services” deals with these issues.

33 HFE Act Code of Practice 3.17.

more research is done in the area. *The following case demonstrates the dilemmas.*

*X, aged 31, was physically able but had severe learning difficulties. She had regularly attended an adult training centre where she enjoyed and desired physical contact and had developed a close relationship with a male user of the centre. She expressed a desire to have a baby. Evidence established that she lacked the capacity to make a decision about sterilisation due to her degree of mental impairment and that she would never have such a capacity. In the view of her family and the consultant psychiatrist the process of pregnancy and childbirth would be frightening and upsetting to her and she would be unable to care for a baby.*

*In deciding to make an order of sterilisation, in her best interests, the judge considered the degree of risk of pregnancy and harm to her if that occurred and the alternative methods of contraception. He stated that her inability to care for the baby was not a reason for justifying a sterilisation. Nor was a risk that the baby may be of impaired mental capacity relevant. The only issue was the psychological damage of pregnancy and the likelihood that she would need a caesarean birth, which would be no less invasive than the sterilisation. The judge commented that sterilisation would protect her from risk but also indirectly allow her more freedom to enjoy a sexual relationship, as the adults who cared for her would not need to restrict her independence as much as they did at present. *Re X (Adult Sterilisation)*<sup>34</sup>*

### **Standards of care in institutions**

When a person is detained in prison or under mental health legislation the state has direct responsibility for the person and the courts will impose a higher standard of care under Article 3 (protection against inhuman and degrading treatment) or under Article 8 which protects a person's physical integrity. In general the European Court has begun to apply stricter standards under this article.<sup>35</sup> Whilst these cases have involved disabled prisoners, the reasoning applies to disabled people in other institutions, particularly when they are vulnerable because of mental illness or conditions such as Alzheimer's or when they have significant learning disabilities

Claims can arise because of conditions generally, the length of solitary confinement, or the excessive application of prison rules or practices. In the case of people detained under mental health legislation forcible treatment against the patient's wishes could potentially breach their human rights, although so far there have only been dicta to that effect.<sup>36</sup> Forced treatment with medication for people who refuse treatment has recently been scrutinised by the Joint Committee on Human Rights in comments on the Mental Health Bill 2006.<sup>37</sup> A curious situation is emerging. It is established case law that the patient must be kept in a therapeutic environment to satisfy Article 5 but

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<sup>34</sup> (2000) All ER (D) 204.

<sup>35</sup> *Selmouni v France* [2000] 29 EHRR 403

<sup>36</sup> For instance in *R (Wilkinson) v Broadmoor Hospital* [2002] 1 WLR 459

<sup>37</sup> Joint Committee on Human Rights, 4<sup>th</sup> Scrutiny Report 2006-7

there is no duty to provide treatment.<sup>38</sup> Indeed if the patient retains capacity there may in some circumstances no right to treat unless there is a “medical necessity”. Forced treatment may in some circumstances amount to inhuman or degrading treatment and be a disproportionate interference with Article 8 rights.

Disability in itself may exacerbate the normal deprivations of prison life and that in turn can adversely affect the impairment. In one case the Court held a breach of Article 3 in relation to a prisoner whose detention conditions led to a flare up of his eczema and to a deterioration in his mental health.<sup>39</sup> Unnecessary handcuffing may be considered inhuman and degrading treatment under Article 3, particularly for a person with a physical disability or a user of sign language.

Restraining a non-disabled person to the applicant’s level of ability to move and assist herself even for a limited time would amount to inhuman and degrading treatment – possibly torture. In a civilised country society considers it not only appropriate but a basic humane concern to try to ameliorate and compensate for the disabilities faced by a person in the applicant’s situation. In my opinion these compensatory measures come to form part of the disabled person’s physical integrity

Prison life itself may bring about further impairments. These are complex issues, potentially involving the state in significant resources and changes of practice, which the courts have been wary about imposing. Detainees have had success only in the most clear cut cases.

In *Keenan v United Kingdom*<sup>40</sup> the European Court stated:

"It is relevant in the context of the present application to recall also that the authorities are under an obligation to protect the health of persons deprived of liberty. The lack of appropriate medical treatment may amount to treatment contrary to Article 3. In particular, the assessment of whether the treatment or punishment concerned is incompatible with the standards of Article 3 has, in the case of mentally ill persons, to take into consideration their vulnerability and their inability, in some cases, to complain coherently or at all about how they are being affected by any particular treatment."

The case involved a prisoner with paranoid schizophrenia, who was known to be a suicide risk. His condition was not properly monitored or assessed, his medication was changed by a doctor with no psychiatric training, and he was placed in segregation in the punishment block. He received an extra 28 days sentence for disruptive behaviour which was a symptom of his illness. He committed suicide. The ECtHR held that this treatment fell below the standard of treatment required for a mentally ill person and violated Article 3.

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<sup>38</sup> *Aerts v Belgium* (2000) 29 EHRR 50

<sup>39</sup> *Robert Napier and the Scottish Ministers*, 26 April 2004, Outer Court of Session, P739/01

<sup>40</sup> (2001) 33 EHRR 913

The landmark decision for disabled people in relation to Article 3 is *Price v UK*.<sup>41</sup>

Ms Price was committed to prison for three days for contempt of court in the course of civil proceedings. She alleged that she suffered degrading treatment as a result of the prison's inadequate facilities which left her without full access to a toilet and on a bed that caused her considerable pain. She has all four limbs for-shortened as a result of thalidomide and had numerous accompanying health problems including defective kidneys. In finding that a breach of Article 3 was established the Court said:

"There is no evidence in this case of any positive intention to humiliate or debase the applicant. However, the Court considers that to detain a severely disabled person in conditions where she is dangerously cold, risks developing sores because her bed is too hard or unreachable, and is unable to go to the toilet or keep clean without the greatest of difficulty, constitutes degrading treatment. The applicant's disabilities are not hidden or easily overlooked. It requires no special qualification, only a minimum of ordinary human empathy, to appreciate her situation and to understand that to avoid unnecessary hardship-- that is, hardship not implicit in the imprisonment of an able-bodied person -- *she has to be* treated differently from other people because her situation is significantly different."

This case was later distinguished in a case<sup>42</sup> involving a woman with a severe physical impairment as a result of a stroke. Her local authority housing for her and her family was not adapted for wheelchair use and as a result she was confined to one room, was rendered doubly incontinent as she could not reach the toilet and could neither go out nor act as a parent and partner to her family. The local authority knew they have a duty to re-house but failed to act until the court action was begun. The court awarded compensation on the grounds of Article 8 rather than Article 3. They held that there had been no intention to degrade or humiliate her and that the higher standard of care required when someone was under the complete control of prison authorities was not applicable.

**Article 5: deprivation of liberty:** The application of human rights principles to those detained under mental health law is a subject in itself and cannot be attempted in this paper. However no paper would be complete without mentioning the immensely significant Bournemouth judgment<sup>43</sup> which is transforming the level of protection and care to be given to people with mental impairments who are detained informally in residential institutions

HL has profound autism associated with frequent episodes of very challenging behaviour. He lacks capacity to decide any of the major issues which affect his

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<sup>41</sup> *Price v United Kingdom* (2001) 34 EHRR 1285

<sup>42</sup> *Morris v LB Newham* [2002] EWHC 1262

<sup>43</sup> *HL v. UK* (2004) 3

life, including where to live. After many years in a psychiatric hospital he went to live with two dedicated carers. Three years later, when temporarily away from them and as a result of a crisis, he was taken to a psychiatric unit where he was kept without contact with his carers for over three months, without procedural rights under Article 5 or the proper assessments required under mental health legislation. It was held in the ECtHR that he was deprived of liberty despite the fact that he was not objecting to his situation and that as a result he should have proper mental health assessments and procedural rights to challenge the deprivation of liberty.

Some later cases have sought to define the circumstances in which Article 5 would apply, with mixed results for disabled people.<sup>44</sup> The particular importance of these judgments for the purposes of this discussion is that for those who are found to be detained greater supervision and arguably better care will be needed. For the thousands who are languishing in care homes, often highly medicated and without concerned and articulate relatives to watch over their health and well being this judgment is a beacon of hope. Legislative changes to implement the judgment are forthcoming in England and Wales under the Mental Health Bill 2007.

### **Use of Article 8 rights**

***The extent of positive obligations:*** The other fruitful source of rights for disabled people is Article 8. The cases have explored the limits of the article to require positive action to overcome barriers to equality experienced by disabled people because of their impairments. The case of *Botta v Italy*<sup>45</sup> concerned the rights to a social life on an equal basis. It was heralded as a landmark decision for disabled people even though it did not succeed (and some say it has put the rights of disabled people back rather than forward<sup>46</sup>).

In *Botta v Italy* the applicant was a disabled wheelchair user. On holiday at a seaside resort he was unable to gain access to a private beach because they were not equipped with disabled facilities. Relying on Article 8 he complained of impairment of his private life and the development of his personality because the Italian State had failed to take measures to remedy the inaccessibility of the private bathing establishments. The Court reiterated that the positive duty under Article 8 may involve the State adopting measures to secure respect for private life even in the sphere of the relations of individuals between themselves ...

“Such positive obligations may exceptionally arise in the case of the handicapped in order to ensure that they are not deprived of the possibility of developing social relations with others and thereby developing their own personalities. In this regard, the Commission

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<sup>44</sup> In *HM v Switzerland* (200226 February 2002) an 84 year old woman was forcibly removed to a care home, following concerns about her self-neglect. Although not under lock and key it was clear that she was not permitted to leave the care home. The Court concluded that she was not “detained”. In *JE v DE (1) Surrey CC* (February 2007) a man who repeatedly requested to return to his home but did not try to leave was held detained.

<sup>45</sup> (1998) EHLRL 486.

<sup>46</sup> OLIVIER DE SCHUTTER ‘Reasonable Accommodations and Positive Obligations in the European Convention on Human Rights’

observes that there is no water-tight division separating the sphere of social and economic rights from the field covered by the Convention. This is an area in which a wide discretion must inevitably be accorded to the national authorities. Nevertheless, the crucial factor is the extent to which a particular individual is so circumscribed and so isolated as to be deprived of the possibility of developing his personality.”

Because Mr Botta was seeking the right of access to the beach far from his normal residence, there was “nothing to indicate that the applicant's life as a whole is so circumscribed and isolated that the occasional inconveniences and troubles he suffered ... amounted to a violation of his private life”.<sup>47</sup>

Later cases have made clear how limited the obligations are. In *Marzari v Italy*<sup>48</sup> the applicant suffered from metabolic myopathy. Cold temperatures and changes in temperature caused him intense muscular pain and forced him sometimes to use a wheelchair. He complained that, in breach of Italian law, the local authorities had failed to provide him with an apartment adequate to the needs arising from his impairment. However, the Court noted that the authorities were willing to carry out works on the apartment allocated to him. No positive obligation on local authorities to provide the applicant with a specific apartment could be inferred from Article 8. A suitable apartment had been offered to the applicant. He had refused it on the ground that it did not meet his needs, despite an assessment to the contrary by a Commission for the study of metabolic diseases.

In *Sentges v the Netherlands*, the applicant had a disease characterised by progressive muscle degeneration. As a result, he had to rely on assistance from other people for all his actions, including eating and drinking. A robotic arm would have greatly reduced his dependence on the constant presence of carers and would have enabled him to continue living at home for a longer period of time. The health insurance fund rejected his request for the robotic arm as it was not covered by any social insurance scheme. Mr Sentges alleged that he was not free to establish and develop relationships with other human beings of his choice. He contended that ‘private life,’ encompassed notions pertaining to the quality of life, including personal autonomy, self-determination and the right to establish and develop relationships with others. However, it was held that even if Article 8 were applicable, the Court must consider the fair balance to be struck between the competing interests of that individual and the community as a whole, and must also have regard to the margin of appreciation granted to States in determining how to comply with the Convention. In light of the fact that this margin is particularly wide where the issues involve the allocation of limited State resources, the Court ruled that the Netherlands were within this range of acceptable responses.<sup>49</sup>

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<sup>47</sup> Cases following Botta have also failed because they could not demonstrate an immediate and direct link between the measures sought and the private life of the applicant. This link appears to relate exclusively to the applicant's immediate surroundings or every day activities. *Marzari v Italy* (4 May 1999) App. No. 36448/97; *Zehlanova & Zehnal v. Czech Republic* (14 May 2002) App. No. 98621/97.

<sup>48</sup> *Marzari v Italy* (4 May 1999) Application No 36448/97.

<sup>49</sup> *Sentges v the Netherlands* (8 July 2003) Application No 27677/02.

### **Manual lifting**

An application of Article 8 principles occurred because of local authorities' policies on manual handling of physically disabled people. Local authorities have insisted that staff not lift clients and that appropriate equipment is needed for that purpose. As a result some disabled people are being confined to their homes and others have great restrictions on their activities.

In *The Queen (Application of A and B) v East Sussex County Council*<sup>50</sup> two physically disabled adults with learning difficulties and their family carers had their lives blighted by the local authority's policies on lifting. They were unable to take part in their favourite pastimes – shopping, swimming and horse riding – because none of these could occur without their being manually lifted.

The DRC intervened in the case, arguing that the local authority's legitimate concern for the safety of its staff had not been balanced against a recognition of the impact that such a policy had on the quality of disabled people's lives. Under Health and Safety at Work legislation employers must ensure, "in so far as reasonably practicable", the safety of employees. This involves a balance, in which the amount of risk is placed on one scale and the sacrifice involved in the measures necessary for averting the risk is placed in the other.

The Court ruled in favour of the applicants and against the local authority's blanket ban on lifting. The Judge reasoned that "human dignity" and the right of the disabled to participate in the life of the community were at the heart of "physical and psychological integrity" protected by Article 8. This is matched by the positive obligation of the State to take appropriate measures designed to ensure to the greatest extent feasible that a disabled person is not "so circumscribed and so isolated as to be deprived of the possibility of developing his personality".

This case was reported in the health and social work press, and has helped change attitudes throughout those professions. The DRC was contacted by scores of disabled people wanting copies of the judgement, to help them in their own battles with authority. The DRC has worked with the Health and Safety Executive to revise its guidance to reflect the decision.

### **Conclusion**

The cases have only begun to explore the potential of Articles 8 and 3 to improve the conditions of disabled people in the health system. Policy papers produced by the DRC on the Right to Independent Living,<sup>51</sup> Guidance relating to disability equality produced by the General Medical Council<sup>52</sup> and the BIHR Framework<sup>53</sup> together with the excellent reports produced by the Mental Health Act Commission contain a multitude of examples of situations which could involve human rights issues for patients and their families.

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<sup>50</sup> CO/4843/2001.

<sup>51</sup> Parker, Independent Living and the Human Rights Act 1998

<sup>52</sup> GMC Supplement to "Good Medical Practice"

<sup>53</sup> "Human Rights in Health care- a Framework for Local Action" Dept of Health 2007

Issues such as lack of confidentiality, mixed sex wards, lack of adequate information about medical treatments and inadequate medical record keeping, forced feeding, visiting rights, privacy for personal care and examination, forced treatment and restraint, access to health treatments and assistive devices are just some of the legions of issues.

This brings us back to where we started. To address these issues for people who lack ready access to legal remedies, in matters often involving scarce resources and difficult judgments about the role of the state a range of approaches is needed. Recent human rights case law has shown improved understanding of the realities of the lives of disabled people and occasionally made strides forward; the Disability Discrimination Act has proved helpful both as a systemic response and through individual cases; public bodies themselves are becoming more proactive in setting policy guidance. However, these are just beginnings in bringing the rights of disabled people into the mainstream of the human rights culture.