

## An Interest in Human Dignity as the Basis for Genomic Torts

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### INTRODUCTION

Dean Prosser's well-known view that the privacy tort is to be understood as comprising four sub-torts (focused on intrusion upon seclusion, disclosure of private facts, publicity placing the plaintiff in a false light, and appropriation of the plaintiff's name or likeness), with the set being held together by a general right to be let alone, has not gone unchallenged.<sup>1</sup> For the purposes of this present foray into the field of genomic torts, the most interesting challenge comes from writers such as Edward J. Bloustein, according to whom the interest in privacy is to be understood as an aspect of human dignity.<sup>2</sup> What makes Bloustein's analysis particularly apposite is that he sees dignity-based-privacy as playing a key role in enabling the law to make essential and appropriate responses to the questions raised by the development of new technology:

The identification of the social value which underlies the privacy cases [viz human dignity] will also help to determine the character of the development of new legal remedies for threats posed by some of the aspects of modern technology. Criminal statutes which are intended to curb the contemporary sophisticated electronic forms of eavesdropping and evidentiary rules which forbid the disclosure of the fruits of such eavesdropping can only be assimilated to the common law forms of protection against intrusion upon privacy if the social interest served by the common law is conceived of as the preservation of individual dignity.<sup>3</sup>

At the time that Bloustein published his paper, modern genetics had scarcely got underway. However, forty years on, it is clear that innovations in biotechnology, and especially developments in modern genetics, are presenting the law with a regulatory challenge (also an opportunity) every bit as significant as that presented by the long-range camera and various forms of surreptitious listening device. Faced with this challenge, some commentators are again turning not

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1. William L. Prosser, *Privacy*, 48 CAL. L. REV. 383 (1960).

2. Cf. Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 31 (Mark A. Rothstein ed., 1997). See generally Edward J. Bloustein, *Privacy as an Aspect of Human Dignity: An Answer to Dean Prosser*, 39 N.Y.U. L. REV. 962 (1964).

3. Bloustein, *supra* note 2, at 1005-06.

only to privacy,<sup>4</sup> but specifically to a dignitarian analysis of privacy, as the foundation for the law's response.<sup>5</sup>

From a traditional English law perspective, such moves might seem both strange and ill-advised. In England, there has been a notorious reluctance to recognise a common law tort of privacy as such;<sup>6</sup> and, even after the enactment of the Human Rights Act 1998, which broadly speaking incorporates the European Convention on Human Rights (ECHR) into English law, the balance of opinion is that a cause of action in a dispute between private parties cannot be founded directly on the right to privacy (as provided for by Article 8 of the ECHR).<sup>7</sup> Moreover, the idea that, if we did recognise a right of privacy, we should found it on respect for human dignity would elicit a sceptical response<sup>8</sup> — for this would be seen as standing one uncertain idea (privacy) on a foundational idea (dignity) having even less certainty. It follows that many English lawyers would echo (with reference to legal discourse) the remarks of the bio-ethicist Helga Kuhse, who has said:

[T]he notion of human dignity plays a very dubious role in contemporary bioethical discourse. It is a slippery and inherently speciesist notion, it has a tendency to stifle argument and debate and encourages the drawing of moral boundaries in the wrong places. Even if the notion could have some use as a short-hand version to express principles such as “respect for persons,” or “respect for autonomy,” it might, given its history and the undoubtedly long-lasting connotations accompanying it, be better if it were for once and for all purged from bioethical discourse.<sup>9</sup>

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4. See GRAEME LAURIE, *GENETIC PRIVACY: A CHALLENGE TO MEDICO-LEGAL NORMS* (2002). Laurie proposes a broad conception of privacy, with both a spatial and an informational dimension, as the most appropriate way of protecting interests (especially the interest in *not* knowing) threatened by the circulation of genetic information. Moreover, Laurie sets privacy alongside liberty and autonomy, all three concepts being seen as “adjuncts to a view of human dignity that is prevalent in our [Western] society.” *Id.* at 84.

5. See, e.g., June Mary Z. Makdisi, *Genetic Privacy: New Intrusion a New Tort?* 34 CREIGHTON L. REV. 965 (2001).

6. See *Home Office v. Mary Jane W.*, [2002] Q.B. 1334 (C.A. 2001); *Khorasandjian v. Bush*, [1993] Q.B. 727 (C.A. 1993); *Kaye v. Robertson*, [1991] F.S.R. 62 (C.A. 1990).

7. This is a thread that unites much of the academic commentary. For one of the earlier commentaries to this effect, see Ian Leigh, *Horizontal Rights, the Human Rights Act and Privacy: Lessons From the Commonwealth?*, 48 INT'L & COMP. L.Q. 57 (1999). For a more recent assessment, see Hugh Beale & Nicola Pittam, *The Impact of the Human Rights Act 1998 on English Tort and Contract Law*, in HUMAN RIGHTS IN PRIVATE LAW 131, 159 (Daniel Friedmann & Daphne Barak-Erez eds., 2001), who conclude that “it seems likely that there will be some ‘weak horizontal’ effect, in that the courts are likely to develop remedies against ‘private’ defendants which will protect the private equivalent of Convention rights.” Perhaps the closest that the courts have come to anything stronger than this is *Douglas v. Hello! Ltd.*, [2001] Q.B. 967 (C.A. 2000), particularly so in the judgment of Sedley L.J. Cf. *Mary Jane W.*, [2002] Q.B. at ¶ 42 (Woolf C.J.), ¶ 74 (Buxton L.J.) (taking a more cautious approach to the matter).

8. Cf. David Feldman, *Secrecy, Dignity, or Autonomy? Views of Privacy as a Civil Liberty*, 47 CURRENT LEGAL PROBS. 41 (1994).

9. Helga Kuhse, *Is There a Tension Between Autonomy and Dignity?*, in BIOETHICS AND BIOLAW VOLUME II: FOUR ETHICAL PRINCIPLES 61, 74 (Peter Kemp et al. eds., 2000).

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Within Europe more generally, however, the English are out of step on both these matters. Elsewhere in Europe, privacy rights are recognised and respect for human dignity is taken extremely seriously — indeed, the European Court of Human Rights has recently said that the “very essence of the [European Convention on Human Rights] is respect for human dignity and human freedom”;<sup>10</sup> and human dignity is the cornerstone of the “new bioethics”<sup>11</sup> as articulated, for example, in the Convention on Human Rights and Biomedicine.<sup>12</sup> Beyond Europe, too, respect for human dignity is perceived to be a fundamental value in relation to the legitimate practice of genetics. Witness, in particular, the Universal Declaration on the Human Genome and Human Rights,<sup>13</sup> which demands that research on the human genome, and its applications, should “fully respect human dignity, freedom and human rights.”<sup>14</sup>

Recently, the Human Genetics Commission in England has encouraged a change of direction by recommending that the Government should sign and ratify the Convention on Human Rights and Biomedicine,<sup>15</sup> Article 1 of which provides:

Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.

The Commission does not balk at the implications of this recommendation, treating the following principle (which it calls the principle of respect for persons) as fundamental to its thinking on the matter of personal genetic information:

Respect for persons affirms the equal value, dignity and moral rights of each individual. Each individual is entitled to lead a life in which genetic characteristics will not be the basis of unjust discrimination or unfair or inhuman treatment.<sup>16</sup>

In this article, I want to take this potentially radical turn in English politico-legal thinking several steps further. If we recognise that respect for human dignity is a fundamental value, then what would be the implications of incorporating this value, not simply into the back-

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10. *Pretty v. United Kingdom*, [2002] 35 Eur. H.R. Rep. 1, ¶ 65 (2002). This is now said despite the fact that the Convention itself does not explicitly mention human dignity.

11. *See infra* text accompanying notes 27-50.

12. *See generally* Convention for the Protection of Human Rights and Dignity of the Human Being With Regard to the Application of Biology and Medicine, Apr. 4, 1997, Eur. T. S. No. 164.

13. *See generally* Universal Declaration on the Human Genome and Human Rights, at <http://www.unesco.org/ibc/en/genome/projet/index.htm> (last visited Feb. 27, 2003) [hereinafter Universal Declaration], adopted by G.A. Res. 152, U.N. GAOR, 53rd Sess., U.N. Doc. A/53/625/Add.2 (1998).

14. *Id.* at pmb1.

15. *See* HUMAN GENETICS COMM'N, *INSIDE INFORMATION: BALANCING INTERESTS IN THE USE OF PERSONAL GENETIC DATA* (2002) [hereinafter *INSIDE INFORMATION*].

16. *Id.* at ¶ 2.20.

ground politico-legal rhetoric, but into the tort system? In particular, how well might explicit recognition of an interest in human dignity serve as the basis for a suite of tort claims responding to perceived injustices arising from developments in the new genetics (for example, where genetic discrimination is practised by employers and insurers, or by parents who wish to select the characteristics of their offspring)? To some extent, the incorporation of human dignity may prompt little more than a fresh application or an incremental adjustment of recognised causes of action; but, in other cases, if we are to follow our sense of what justice requires, we might need to be rather more innovative.<sup>17</sup>

My discussion in this paper is in five parts. In Part I, a distinction is drawn between two conceptions of human dignity, “human dignity as empowerment” and “human dignity as constraint.” Although much of the renewed interest in human dignity (at any rate, in Europe), and much of the dignity-based opposition to new biotechnology, fits with the conception of human dignity as constraint, my position and analysis is founded on human dignity as empowerment (which essentially makes a triple demand in the name of respect for human dignity, namely: (i) respect for one’s capacity as an agent to make one’s own free choices; (ii) respect for the choices so made; and (iii) respect for one’s need to have a context and conditions in which one can operate as a source of free and informed choice). In this respect, my approach is very much in line with the thinking of the Human Genetics Commission for which respect for persons, and acknowledging the dignity of others, entails respecting the autonomy of persons.<sup>18</sup>

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17. Support for the view that the common law does, and should, operate in this way is to be found in Lord Steyn’s judgment in *McFarlane v. Tayside Health Board*, [2000] 2 A.C. 59, 82 (H.L. 1999). Lord Steyn states:

[T]o explain decisions denying a remedy for the cost of bringing up an unwanted child by saying that there is no loss, no foreseeable loss, no causative link or no ground for reasonable restitution is to resort to unrealistic and formalistic propositions which mask the real reasons for the decisions. And judges ought to strive to give the real reasons for their decision. It is my firm conviction that where courts of law have denied a remedy for the cost of bringing up an unwanted child the real reasons have been grounds of distributive justice. That is of course, a moral theory. It may be objected that the House must act like a court of law not like a court of morals. That would only be partly right. The court must apply positive law. But judges’ sense of the moral answer to a question, or the justice of the case, has been one of the great shaping forces of the common law.

*Id.*; see also Lord Steyn, Perspectives of Corrective and Distributive Justice in Tort Law, John Maurice Kelly Memorial Lecture at University College Dublin, (Nov. 1, 2001) (published by the Faculty of Law 2002).

18. See INSIDE INFORMATION, *supra* note 15. The Commission states:

The principle of respect for persons requires that we acknowledge the dignity of others and that we treat them as ends in themselves and not merely instrumentally as means to ends or objectives chosen by others. This means that we must respect the autonomy of others.

*Id.* at ¶ 2.13.

With this analysis of human dignity, I turn to consider a (non-exhaustive) set of situations in which those who are aggrieved by the provision of genetic services or by the misuse of genetic information, and the like, might turn to the tort system for redress.<sup>19</sup> The first situations, which are dealt with in Part II of the paper, concern the kinds of substantive claims that might be made where there has been a failure to carry out a pre-natal genetic procedure as required (or a failure to warn as to a pre-natal genetic condition). To some extent, claims of this kind might fall within the law of contract. However, if they are to be pleaded in torts law, the existing jurisprudence invites claims for “wrongful birth,” “wrongful pregnancy,” or “wrongful life.”<sup>20</sup> Assuming a context of “designer babies” and the like, the two principal questions to be considered are (i) how far our existing forms of action might operate where a genetic intervention or selection misfires, and (ii) how far a dignity-based tort ought to go in such cases.

In Part III, the focus is on possible claims relating to the control of genetic information about oneself. On the one hand, such claims might concern the unauthorised *outward* transmission of genetic information (where, without X’s authorisation, Y obtains genetic information relating to X, or passes on such information to Z); on the other hand, such claims might seek to prevent the unwanted *inward* transmission of genetic information about oneself (where X is pleading privacy and confidentiality, or perhaps an interest in human dignity, as the basis for a right *not* to know). To some extent, one’s ability to control the outward flow of genetic information about oneself depends upon one’s ability to control access to tissue and samples from which information about one’s genetic make-up can be obtained.

This leads, in Part IV, to the vexed question of whether one can have property in one’s own body parts, especially proprietary rights in

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19. Other papers in this volume illustrate the breadth of possible action. For example, David Partlett points up the possibility of claims arising from negligent advice where a person’s genome has been misread or misinterpreted; Thomas Redick highlights the expanding scope of the duty to inform and warn once the interaction of particular environments with particular genetic features is more clearly understood; and Heidi Li Feldman suggests that the phenomenon of “market-driven manufacturing,” as it applies to the next generation of tailored drugs, will put pressure on the tort system to conceive of negligence claims in a more holistic way.

20. Here, I am adopting the terminology proposed by Justice Lax in *Kealey v. Berezowski*, [1996] 136 D.L.R. (4th) 708, 723-24 (1996). By a claim for “wrongful birth,” I refer to one brought by the parents of a child born with a birth defect. The pregnancy was planned. The wrong occurred post-conception. By a claim for “wrongful pregnancy,” I also refer to an action brought by the parents of a child (in some cases, perfectly healthy, in others, not). However, the pregnancy was unplanned and the child “not wanted.” The act complained of always arises pre-conception (e.g., a failed sterilization). By an action for “wrongful life,” I refer to a claim brought by a child born with birth defects. The burthen of the complaint is that the alleged tortfeasor breached a duty to give the child’s parents the opportunity to terminate the pregnancy. The breach might arise pre-conception (e.g., a failed sterilization) or post-conception (e.g., a failed abortion or improper genetic screening or testing). Quære: might there be a plausible variation on a wrongful life claim where a child claims that its mother has unreasonably failed to obtain, or act on, genetic tests which would have shown that a present or future child would be at risk of carrying a particular faulty gene?

one's own removed body parts. If one can, this might open up actions arising from property-based torts such as conversion or, of course, encourage new claims aimed at respecting human dignity if the empowerment conception supports such actions. Finally, in Part V, we consider the misuse of genetic information, focusing on claims arising from genetic discrimination, particularly where the discriminator is a potential employer or insurer. In the absence of dedicated protective legislation, a claim for wrongful genetic discrimination would fall to be pleaded in contract or tort. Lacking a general doctrine of good faith, the English regime of contract law might be unable to assist (particularly in relation to genetically discriminatory refusals to contract);<sup>21</sup> and, thus, the onus would be on tort law to respond. Once again, the background question is whether a newly recognised interest in human dignity would enable the tort system to respond in a calculable, coherent, and appropriate way to perceived injustice.

In the light of this last remark, which presupposes that calculability and coherence, and the like, are amongst the criteria for sound legal doctrine, a brief methodological note is called for. The general strategy in this paper involves three stages as follows. First, we observe that the concept of human dignity is enjoying a considerable revival in various discourses that touch on human genetics. In bioethical discourse, this tendency is especially pronounced. Second, we note that human dignity is a contested concept, and we align ourselves with one particular conception, "human dignity as empowerment." Third, we consider how far the recognition of intrinsic and individual human dignity (interpreted via "human dignity as empowerment") as an interest to be protected by the tort system would go in supporting various claims arising from the practice of new genetics.

Now, although judges in torts cases sometimes proceed straight from a declared moral principle to an equivalent legal principle,<sup>22</sup> there is generally some caution about converting moral principles into equivalent legal principles. For example, Laura Purdy having argued that "it is morally wrong to reproduce when we know there is a high risk of transmitting a serious disease or defect,"<sup>23</sup> goes on to say that this "is not, by itself, an argument in favour of *legal* prohibition of reproduction."<sup>24</sup> For one thing, there are enforcement costs once we

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21. See Roger Brownsword, *Freedom of Contract, Human Rights and Human Dignity*, in *HUMAN RIGHTS IN PRIVATE LAW*, *supra* note 7, at 195-98.

22. For instance, in *Schloendorff v. Society of New York Hospital*, 105 N.E. 92, 93 (N.Y. 1914), Justice Cardozo proceeds from the moral principle that adults of sound mind have the right to determine what shall be done with, or to, their bodies to the principle that "a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages."

23. Laura M. Purdy, *Genetics and Reproductive Risk: Can Having Children Be Immoral?*, in *BIOETHICS: AN ANTHOLOGY* 123, 124 (Helga Kuhse & Peter Singer eds., 1999).

24. *Id.* (emphasis added).

convert moral principle into legal prohibition as well as significant inroads into individual choice and freedom; and, although for practical purposes both law and morality demand some degree of closure and settlement, the integrity of morality is not threatened by ongoing debate, review, and adjustment of position. Bearing in mind caveats of this kind, my general position is that we should nevertheless conceive of law as an exercise in applied moral reason,<sup>25</sup> and that if human dignity is a landmark in moral reason, we should not be shy of integrating it within the legal landscape. However, in this present paper, my principal concern is to assess the kind of support that would be offered by human dignity if it became a protectable tort interest without assuming that, all things considered, its adoption would be the right thing to do.<sup>26</sup>

### I. TWO CONCEPTIONS OF HUMAN DIGNITY

Human dignity is an elusive concept, used in many senses by moral and political philosophers.<sup>27</sup> In modern debates, however, it regularly appears in two very different roles, in the one case acting in support of individual autonomy (human dignity as empowerment) and, in the other case, acting as a constraint on autonomy (human dignity as constraint).<sup>28</sup>

The conception of human dignity as empowerment is very closely linked with modern human rights thinking. In particular, human dignity is explicitly declared to be one of the foundational ideas in the Universal Declaration of Human Rights, 1948 (which, together with the International Covenant on Economic, Social and Cultural Rights, 1966, and the International Covenant on Civil and Political Rights, 1966, comprises the so-called “International Bill of Rights”). Thus, the Preamble to each instrument provides that “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world”; and Article 1 of the Universal Declaration famously proclaims that “[a]ll human beings are born free and equal in dignity and rights.” What this seminal cluster of preambular ideas amounts to is this: that each and every human being has inherent dignity; that it is this *inherent* dignity that grounds (or accounts for) the possession of

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25. See DERYCK BEYLEVELD & ROGER BROWNSWORD, *LAW AS A MORAL JUDGMENT* (1986).

26. The idea is not altogether without precedent. In the South African legal system, for example, there is a tortious action for impairment of human dignity. See Jonathan Burchell, *Beyond the Glass Bead Game: Human Dignity in the Law of Delict*, 4 S. AFR. J. ON HUM. RTS. 1 (1988).

27. See RONALD DWORKIN, *LIFE'S DOMINION* 233-37 (1993).

28. The terminology here comes from a previous collaboration with Deryck Beyleveld. DERYCK BEYLEVELD & ROGER BROWNSWORD, *HUMAN DIGNITY IN BIOETHICS AND BIOLAW* (2001).

*inalienable* human rights; and that, because all humans have dignity, they hold rights equally. So understood, human dignity is much more than a background implication that we can tease out of a number of particular rights relating to demeaning or degrading treatment or to privacy, it is the infrastructure on which the entire superstructure of human rights is constructed.<sup>29</sup>

Three substantive claims are distinctively associated with the idea of human dignity as empowerment. First, there is a demand for recognition as one who has the capacity to make one's own free (and informed) choices. As Joseph Goldstein has aptly remarked, to treat one who has such capacity for autonomous decision-making as an incompetent "constitutes the ultimate disregard of . . . human dignity."<sup>30</sup> If we want to talk about an "affront" to human dignity, this is as deep an affront as there can be. Second, there is a demand that one's own particular free choices be respected.<sup>31</sup> Third, there is a claim to the conditions in which an autonomous life can be lived. Sometimes, particular conditions (especially in places of work or penal correction) and practices (principally, slavery and apartheid) are condemned as demeaning and contrary to human dignity. This may speak to the need for conditions in which self-respect and self-determination are possible; but this does not exhaust the demand. If we are to respect the idea of human dignity as empowerment, we should be constantly striving to put in a place a supportive context for agents who are seeking to fulfill their autonomous potential.

By contrast, the evolving idea of human dignity as constraint lacks such a clear and unifying anchoring point. In modern European bioethics (the "new bioethics"), it is an idea that appeals to a coalition of Kantians, Catholics, and communitarians. In fact, both interpretations — human dignity as empowerment and human dignity as con-

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29. See ANDREW CLAPHAM, *HUMAN RIGHTS IN THE PRIVATE SPHERE* 143 n.22 (1993) (providing examples of the recurrent use of human dignity in international human rights declarations, covenants, conventions, and resolutions).

30. Joseph Goldstein, *For Harold Lasswell: Some Reflections on Human Dignity, Entrapment, Informed Consent, and the Plea Bargain*, 84 *YALE L.J.* 683, 691 (1975).

31. This aspect of human dignity is nicely brought out by the Nuffield Council on Bioethics in its report on *Genetics and Human Behaviour* (2002). The Council, having said that responsibility "is an essential ingredient in the conception of human dignity," goes on to relate this to "the presumption that one is a person whose actions, thoughts and concerns are worthy of intrinsic respect, because they have been chosen, organised and guided in a way which makes sense from a distinctively individual point of view." NUFFIELD COUNCIL ON BIOETHICS, *GENETICS AND HUMAN BEHAVIOUR: THE ETHICAL CONTEXT* ¶ 12.2 (2002) [hereinafter NUFFIELD COUNCIL]. The Council continues: "If it turns out to be an illusion to suppose that people are responsible for themselves, then their actions and thoughts do not belong together as part of the meaningful life of an individual; a moral subject. In which case, one of the most fundamental reasons which people have for treating each other as worthy of respect would have been undermined." *Id.* Happily, the Council concludes that, at any rate in the current state of the art, behavioural genetics does not undermine our dignity-based sense of responsibility; for the evidence is that "behaviour is complex, influenced both by genetic and environmental factors, and by our own decisions." *Id.* at ¶ 15.3 (emphasis added).

straint — can claim to be supported by the seminal writing of Immanuel Kant.<sup>32</sup> For, in Kant's work, we find not only the idea that humans have intrinsic dignity (which suggests a conception of human dignity as empowerment, albeit duty-driven rather than rights-driven),<sup>33</sup> but also that human dignity has no price and that humans owe themselves a duty of self-esteem (which might suggest a conception of human dignity as constraint). In *The Metaphysics of Morals*, Kant collects together the strands of his thinking as follows:

Every human being has a legitimate claim to respect from his fellow human beings and is *in turn* bound to respect every other. Humanity itself is a dignity; for a human being cannot be used merely as a means by any human being . . . but must always be used at the same time as an end. It is just in this that his dignity (personality) consists, by which he raises himself above all other beings in the world that are not human beings and yet can be used, and so over all *things*. But just as he cannot give himself away for any price (this would conflict with his duty of self-esteem), so neither can he act contrary to the equally necessary self-esteem of others, as human beings, that is, he is under obligation to acknowledge, in a practical way, the dignity of humanity in every other human being. Hence there rests on him a duty regarding the respect that must be shown to every other human being.<sup>34</sup>

In these much-quoted remarks, modern writers can (and do purport to) find support for a variety of supposed applications of Kantian morality, not just in practical matters generally but specifically within the fields of bio-science and bio-commerce.<sup>35</sup> For Kant's remarks, if taken literally, are an open invitation to claim that commercialisation of the human body is an affront to dignity (by putting a price on something that is beyond price); and the famous injunction against "using" or "instrumentalising" another (by treating another simply as a means and not, at the same time, as an end) can be invoked to condemn a range of practices from sex selection to human reproductive cloning.<sup>36</sup>

When we order our thinking about human dignity, we can fix on two different reference points. One reference point is the idea that human dignity speaks to what is special or specific about humans, that is to say, what is intrinsically and universally distinctive about humans.

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32. Compare the Kantian-inspired analysis of private law and its relationships offered by the Weinribs. See *infra* note 50.

33. For the significance of this distinction, see Deryck Beyleveld and Roger Brownsword, *Human Dignity, Human Rights, and Human Genetics*, in *HUMAN GENETICS AND THE LAW: REGULATING A REVOLUTION* 69 (Roger Brownsword et al. eds., 1998).

34. IMMANUEL KANT, *THE METAPHYSICS OF MORALS* 209 (Mary J. Gregor trans. & ed., Cambridge University Press 1996) (1797).

35. See, e.g., Werner Wolbert, *The Kantian Formula of Human Dignity and Its Implications for Bioethics*, 4 *HUM. REPROD. & GENETIC ETHICS* 18 (1998).

36. Significantly, the special UN task force that brought forward the unprecedented (and, as events proved, soon-to-be-rejected) proposal that human reproductive cloning should be banned in all 190 member states was led by Germany and France (in both of which countries, there is strong support for human dignity as constraint). See Richard Willing, *UN Plan Would Ban Cloning to Create Human Baby*, *USA TODAY*, Sept. 23, 2002, at A3.

As Francis Fukuyama has recently put it, the demand made in the name of human dignity is one for equal recognition which implies “that when we strip all of a person’s contingent and accidental characteristics away, there remains some essential human quality underneath that is worthy of a certain minimal level of respect.”<sup>37</sup> This reference point is to be contrasted with the idea that human dignity speaks less to what is special about humans qua humans and more to what is special about a particular community’s idea of civilised life and the concomitant commitments of its members. Here, appeals to human dignity draw on what is distinctively valued concerning human social existence in a particular community — indeed, on the values and vision that distinguish the community as the particular community that it is, and relative to which the community’s members take their collective and individual identity.

In principle, whichever starting point we take, we can generate a conception of human dignity as empowerment as well as human dignity as constraint. In practice, though, human dignity as empowerment, as we have said, is closely associated with human rights movements that are designed to ensure that persons are recognised as special by virtue of having the capacity to make their own choices as well as being entitled to enjoy the conditions in which they can flourish as self-determining authors of their own destinies. By contrast, in the new bioethics, human dignity as constraint combines a view of what is distinctive about humans (their dignity) with views about what defines life as civilised (and, thus, respectful of human dignity) in a particular community.

We do not need to look very long to find examples of the potential tension between human dignity as empowerment and human dignity as constraint.<sup>38</sup> For instance, in the famous French dwarf-throwing (“lancer de nain”) case,<sup>39</sup> the Conseil d’Etat, having affirmed that respect for human dignity is one of the constituents of

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37. FRANCIS FUKUYAMA, *OUR POSTHUMAN FUTURE: CONSEQUENCES OF THE BIOTECHNOLOGY REVOLUTION* 149 (2002). According to Fukuyama, although “many would list human reason and human moral choice as the most important unique human characteristics that give our species dignity, I would argue that possession of the full human emotional gamut is at least as important, if not more so.” *Id.* at 169.

38. Cf. David Feldman, *Human Dignity as a Legal Value: Part I*, 16 *PUB. L.* 682, 685 (1999). Feldman rightly observes that human dignity can cut both ways:

[W]e must not assume that the idea of dignity is inextricably linked to a liberal-individualist view of human beings as people whose life-choices deserve respect. If the state takes a particular view on what is required for people to live dignified lives, it may introduce regulations to restrict the freedom which people have to make choices which, in the state’s view, interfere with the dignity of the individual, a social group or the human race as a whole. . . . The quest for human dignity may subvert rather than enhance choice. . . . Once it becomes a tool in the hands of lawmakers and judges, the concept of human dignity is a two-edged sword.

*Id.*

39. *Ville d’Aix-en-Provence*, 1996 *Daloz* 177 (Conseil d’Etat) req. nos. 143-578; *Cne de Morsang-sur-Orge*, 1995 *Daloz* 257 (Conseil d’Etat) req. nos. 136-727.

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ordre public, confirmed a municipal police power to prohibit any spectacle that represented a threat to such respect. Accordingly, it was held that, where police powers had been exercised in Morsang-sur-Orge and Aix-en-Provence to ban the attraction of dwarf-throwing in local clubs, such steps were lawfully taken in order to secure respect for human dignity and ordre public. However, the legality of the bans was challenged by, among others, one of the dwarfs, one Manuel Wackenheim, who argued that he freely participated in the activity, that the work brought him a monthly wage (as well as allowing him to move in professional circles) and that, if dwarf-throwing was banned, he would find himself unemployed again. To this, the Conseil d'Etat responded that the dwarf compromised his own dignity by allowing himself to be used as a projectile, as a mere thing, and that no such concession could be allowed.<sup>40</sup>

On the one side, the dwarfs were relying on the conception of human dignity as empowerment. For the dwarfs, the central issue was whether others were acting against their (the dwarfs') dignity. Their argument was that they were *not* being treated as mere things; others were not disregarding their capacity to control the situation. It was only to the extent that the dwarfs freely chose to participate that the activities took place. Moreover, from the dwarfs' viewpoint, to be deprived of their status as employed persons was to undermine the conditions in which they experienced a sense of their own dignity. So interpreted, it was the well-meaning paternalism of the Conseil, rather than the actions of the dwarf-throwers, that represented a threat to the dignity of the dwarfs.

On the other side, the Conseil d'Etat was operating with a conception of human dignity as constraint. Central to this conception is the idea that the dwarfs might compromise *their own* dignity and/or, with that, the dignity of fellow humans as understood in contemporary France. This is the idea of human dignity as an overriding value (whether grounded in individual humans or in groups of humans), a value to be respected by all members of human society. On this view, the fact that the dwarf-throwers did not intend to demean or degrade the dwarfs, or that the dwarfs freely consented to their participation, is immaterial: ordre public (including respect for human dignity) sets limits to autonomy — certain expressions of free choice are, quite simply, out of bounds. As for undermining the conditions in which the dwarfs recovered a sense of self-esteem, presumably the Conseil judged that this must be a case of false consciousness; for, surely, no

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40. See Marie-Christine Rouault, Note, *L'interdiction Par un Maire de L'attraction Dite de Lancer de Nain*, 11 LES PETITES AFFICHES 30, 32 (1996). And, for reflections on the case, with dignity being interpreted as the essence of humanity, see B. Edelman, *La Dignité de la Personne Humaine, un Concept Nouveau*, RECUEIL DALLOZ 1997, 23E CAHIER, CHRONIQUE, 185, 187-188.

genuine sense of self-esteem could be derived from participation in dwarf-throwing when the activity could not stand alongside respect for human dignity.<sup>41</sup>

Although these two competing conceptions of human dignity tend to structure modern debates — at any rate, they do so where human dignity is treated as focal for those debates — they do not exhaust appeals to human dignity or cognate terms. In particular, claims concerning “undignified” conduct or circumstances are very commonly advanced. It is tempting to dismiss such usage as relatively unimportant. After all, there is surely a fundamental difference between intrinsic and inalienable human dignity as the foundation for human rights and the occasional act of undignified behaviour. Equally, even if human dignity is understood as giving a community its particular cultural identity (as one might read the approach of the Conseil d’Etat in the dwarf-throwing case), this is surely a very different matter to mere undignified conduct (dwarf-throwing, the Conseil might protest, was not merely undignified, it went much deeper than this by compromising human dignity).

We might also worry that equating the infliction of an “indignity” with “undignified” conduct or circumstances might be both dangerous in practice and distorting in principle. For instance, the claim that the right to “death with dignity” should be recognised and respected would be dangerous if it invited the termination of life wherever the circumstances of the living were judged to be undignified (that is, whenever the circumstances of, say, Tom’s life were judged, not by Tom, but by Dick or Harry, to be so undignified as to warrant the termination of Tom’s life);<sup>42</sup> and the idea that death with dignity equates to death in dignified circumstances threatens to distort the principle that dignity demands the right to choose, that it is the right to choose, not the right to die, that is focal. Nevertheless, the virtue of living with dignity, as exemplified by the likes of Socrates and Nelson Mandela, is hard to deny. There is a positive to be accentuated here and, in a brave new genetic world, living with dignity might prove to be a virtue of the first importance.<sup>43</sup>

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41. Wackenheim, the dwarf, took his claim to the UN human rights committee where it was ruled that “the ban on dwarf-tossing was not abusive but necessary to protect public order, including considerations of human dignity.” Stefanie Nebel, *Projectile Dwarf Case Thrown Out*, INDEP., Sept. 28, 2002, at 17. The cross-fertilisation, within the UN, of the two conceptions of human dignity is a significant indicator of growing European influence on this matter. See also *supra* note 36.

42. A point forcibly made by John Finnis, in Bland: *Crossing the Rubicon?*, 109 L.Q. REV. 329, 336 (1993).

43. Cf. FUKUYAMA, *supra* note 37, at 173. Fukuyama, having opposed utilitarian thinking on a number of familiar grounds, adds the following objection:

The utilitarian goal of minimizing suffering is itself very problematic. No one can make a brief in favor of pain and suffering, but the fact of the matter is that what we consider to be the highest and most admirable human qualities, both in ourselves and in

Putting these rival views about human dignity into a larger picture, it seems to me that three broad bio-ethical perspectives dominate current thinking about the regulation of genomics. These are:

- utilitarian cost/benefit thinking,
- the human rights perspective (grounded on human dignity and emphasising the importance of individual autonomy and choice), and
- various rights-restricting, duty-based, appeals to human dignity (as articulated by a “new dignitarian” alliance, especially so in Europe).

Elsewhere,<sup>44</sup> I have suggested that, if for some time the principal tension in bioethics and biolaw has been between utilitarian and human rights perspectives, with the latter at least seeking to qualify the former,<sup>45</sup> one of the most striking developments of recent years has been the reassertion of the importance of respect for human dignity. In Europe alone, as we have said, the Council of Europe’s Convention on Human Rights and Biomedicine advances respect for human dignity as its cornerstone principle; and it is noteworthy that the Charter of Fundamental Rights of the European Union<sup>46</sup> opens with human dignity in Article 1.<sup>47</sup> To the extent that this revival of interest in human dignity is simply a more pronounced articulation of the basis of human rights (as seems to be the case with human dignity as empowerment), bioethics remains a straight contest between the utilitarian and human rights perspectives. However, to the extent that a new dignitarian alliance is forming around the idea of the duty not to compromise human dignity (as in the notion of human dignity as constraint), an important new perspective is brought into play. Moreover, this third perspective creates a genuinely triangular contest because it is as much opposed to utilitarian consequentialism as it is to the prioritisation of individual autonomy.

In this larger setting, if we reject a utilitarian perspective (as I would), then is it with human dignity as empowerment or human dignity as constraint that we should work? For reasons that I have ex-

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others, are often related to the way that we react to, confront, overcome, and frequently succumb to pain, suffering, and death. In the absence of these human evils there would be no sympathy, compassion, courage, heroism, solidarity, or strength of character. A person who has not confronted suffering or death has no depth. Our ability to experience these emotions is what connects us potentially to all other human beings, both living and dead.

*Id.* (footnote omitted). We might say that, in the absence of these negative features of the human condition, there would be little opportunity for the virtue of human dignity to develop.

44. Roger Brownsword, *Bioethics Today, Bioethics Tomorrow: Stem Cell Research and the ‘Dignitarian Alliance,’* 17 NOTRE DAME J.L. ETHICS & PUB. POL’Y 15 (2003).

45. See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (3d ed. 1989) (attempting to accommodate these two perspectives in a framework of four values).

46. 2000 O.J. (C 364) 1 (as declared at the Nice European Council on Dec. 7, 2000).

47. See generally BEYLEVELD & BROWNSWORD, *supra* note 28, at 29-42 (discussing the new dignity-based bioethics).

plained elsewhere, my view is that human dignity as empowerment is the more defensible conception. However, we need to replace the qualifying condition “human” with the qualifying condition “agent.”<sup>48</sup> By an agent, I simply mean a being (whether human, modified human, or definitely non-human) having the developed capacity for free and purposive action. If we can believe anything, we can believe that adult humans generally fit this description but, in principle, the category of agency might be instantiated by others (provided that they are beings with the relevant capacities). It is the capacity for free and purposive action, for making one’s own independent decisions and choices, that equates to the dignity of agents (and humans insofar as they are agents).

To this model of freely choosing individuals (dignity as agent empowerment), three qualifiers should be noted. First, this is a model that comes with both negative and positive rights: thus, agents, as individuals, have rights but also positive responsibilities. Second, to repeat, some agents might identify themselves with a certain style of life (and death) captured by the virtue of human dignity. This life style, if not quite celebrating human finitude and adversity, would at least value a balanced approach to coping with such limitations and difficulties. Third, agents in families, groups, and larger collectivities might agree to forego options or opportunities that would otherwise be available to them as individuals. The reasons for such forbearance might be of various kinds, but the outcome will be a sense of collective identity (possibly of solidarity)<sup>49</sup> and distinctiveness. For example, in an ideal-typical case, the agents who comprise a society might agree that, even if there is ordinarily a right to decline to do business with a bad risk contractor, no bad risk judgments should be made on the basis of genetic information about individuals. In other words, this (hypothetical) society distinctively agrees that adverse genetic information should not enter into any contractual calculations (quite possibly, with knock-on effects for the position it takes in relation to genetic testing in contractual contexts).

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48. Subject to this qualification, I would endorse the Lasswellian view that “[the] ultimate goal of the law [is] to respect the dignity of each person as a human being.” Goldstein, *supra* note 30, at 698.

49. Interestingly, the Human Genetics Commission identifies a concept of “genetic solidarity and altruism” to be taken into consideration alongside its basic principles. See *INSIDE INFORMATION*, *supra* note 15, at ¶ 2.9. The idea is formulated as follows:

We all share the same basic human genome, although there are individual variations which distinguish us from other people. Most of our genetic characteristics will be present in others. This sharing of our genetic constitution not only gives rise to opportunities to help others but it also highlights our common interest in the fruits of medically-based genetic research.

*Id.* at ¶ 2.11.

With these two conceptions of human dignity in tension with one another, we must expect that the competition will run on into the tort system if we recognise that claimants are entitled to be compensated for violations of, or impairments to, their human dignity. Nevertheless, having declared ourselves to be on the side of human dignity as empowerment (and, with that, the general human rights perspective), our principal interest is in seeing how a regime of tort law *self-consciously and explicitly* equipped with such a conception of human dignity might respond to the perceived wrongs generated by developments in the new human genetics.<sup>50</sup>

## II. GENETIC WRONGS IN THE PRE-NATAL CONTEXT: BABIES BY DESIGN AND “DESIGNER BABIES”

English law, broadly speaking in line with other European legal systems, takes a sceptical stance in relation to claims for wrongful life, and it takes a fairly tough view, too, in relation to wrongful pregnancy claims.<sup>51</sup> With regard to the former kind of claim, *McKay v. Essex Area Health Authority*<sup>52</sup> is the leading case. With regard to the latter, the leading case is *McFarlane v. Tayside Health Board*.<sup>53</sup> In both cases, a unifying thread is the importance of the value of human life (the sanctity of life) — whether viewed negatively in the sense that we do wrong to regret the addition of a life, or positively in the sense that we should celebrate a birth — and, for our purposes, this is where we find an obvious connection with conceptions of human dignity. We can start by sketching the case-law, and then we can draw on the concept of human dignity to speculate about some hypotheticals involving genetic selection (in one type of case, negative selection to secure a healthy child, in the other type of case, positive selection, to secure a child that is not only healthy, but also is one having certain desired or enhanced attributes).<sup>54</sup>

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50. Some commentators already conceive of private law in terms of this kind. For example: The person in private law is a self-determining agent characterised solely by the capacity for purposive action without being obligated to act for any purpose in particular. This capacity for purposiveness is the basis for ascribing dignity to every self-determining agent and is presupposed in the law's notions of imputability and entitlement. By virtue of one's self-determining agency, a person has the normative status to assert one's dignity in relation to others and therefore to be an end and not merely a means for them. Rights are the juridical embodiments of the dignity inherent in self-determining agency. Correlatively, a duty is the restraint that the existence of another's right imposes on the exercise of one's freedom.

Lorraine E. Weinrib & Ernest J. Weinrib, *Constitutional Values and Private Law in Canada*, in *HUMAN RIGHTS IN PRIVATE LAW*, *supra* note 7, at 47.

51. *See supra* note 20.

52. [1982] Q.B. 1166 (C.A. 1982).

53. [2000] 2 A.C. 59 (H.L. 1999).

54. In principle, the distinction between negative (therapeutic) and positive (enhancement) selection is clear. As the Nuffield Council on Bioethics puts it:

The way to distinguish between those interventions which count as ‘therapies’ and those which count as ‘enhancements’ is by reference to the condition that is to be al-

A. *The Case-Law*

In *McKay*, Mary McKay was born disabled, her mother having contracted rubella (German measles) during the early months of the pregnancy. Blood samples had been taken for testing, but the first samples were seemingly mislaid and the results of the second samples misinterpreted. At all events, the mother was not warned that her baby might be infected with rubella and, not being alerted or advised as to the possibility of having an abortion, she continued with the pregnancy. Following the birth of Mary, claims were brought against both the health authority and its doctor, alleging various breaches of duty arising from the bungling of the blood tests. Amongst these claims, it was pleaded on behalf of Mary that she should be compensated for having been born, raising for the first time in the English courts the question of whether an action for wrongful life should be recognised. In fact, this question very nearly did not get raised because, had Mary been born about a year later, any such action would have been barred by the Congenital Disabilities (Civil Liability) Act 1976.<sup>55</sup> Mary's wrongful life claim, novel though it was, was duly struck out by the Court of Appeal as disclosing no reasonable cause of action. One of the reasons for striking out the claim was that the calculation of damages would be not just difficult, but impossible. After all, even metaphysicians would have difficulty in putting a figure on the difference in value between a life of severe disability and no life at all. However, Stephenson L.J. rejected the prospect of any such claim for broader reasons of public policy. As he put it: "To impose such a duty towards the child would, in my opinion, make a further inroad on the sanctity of human life which would be contrary to public policy."<sup>56</sup> Of course, this left open the possibility of the plaintiffs recovering compensation for the defendants' failures insofar as these were claims by the child for a failure to take reasonable care to reduce the likelihood of further rubella damage in the womb and, concomitantly, by the mother for the additional burden of caring for a disabled child.

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tered: therapies aim to treat, cure or prevent diseases and to alleviate pathological conditions which place someone outside the normal range, whereas enhancements aim to improve already healthy systems and to advance capacities which already fall within the normal range.

See NUFFIELD COUNCIL, *supra* note 31, at ¶ 13.41. In practice, however, the line between disorder and normality shifts and, as the Council is well aware, the way in which we characterise particular conditions (e.g., shyness or aggression) is critical for their classification.

55. In *McKay*, the court accepted that it was the Law Commission's intention that wrongful life claims should be barred and that the Act was drafted, inter alia, with this objective in mind. Although it is now generally accepted that the Act does indeed have this effect, there is a view that the legislation does not quite close off a particular type of wrongful life claim, namely one that carefully focuses on the physician's negligent failure to advise on the (disabled) child's potential quality of life. See Jane Fortin, *Is the 'Wrongful Life' Action Really Dead?* 1987 J. Soc. WELFARE L. 306 (1987).

56. *McKay*, [1982] Q.B. at 1180.

*McFarlane v. Tayside Health Board* does not involve the birth of a disabled child. Quite to the contrary, Catherine McFarlane was a perfectly healthy child, the fifth child in the household, and one loved and cared for as a member of the McFarlane family. However, Catherine's parents, having assumed major financial commitments by moving to a larger home, had not planned this birth — Catherine was not a baby by design. In fact, Mr. McFarlane had undergone a vasectomy; and he and his wife had only resumed intercourse without contraception after he had been told that the operation had been successful and that his sperm count was negative. It was in these circumstances that Mrs. McFarlane became pregnant with Catherine. Following Catherine's birth, Mrs. McFarlane claimed damages for the pain, discomfort, and inconvenience of her pregnancy; and she and her husband claimed the cost of rearing Catherine.<sup>57</sup> Whilst the first claim succeeded, the second was regarded as much more problematic and, in due course, it was dismissed by the House of Lords.<sup>58</sup> So far as this second claim was concerned, a comparative review of the jurisprudence revealed three common responses: full recovery, limited recovery but excluding the costs of child rearing, and the offset/benefits approach whereby damages are reduced by the benefits of having a child.<sup>59</sup> The majority of the House favoured the limited damages approach.<sup>60</sup>

In ruling out full compensation, the House adverts on several occasions to the value of human life (and, by implication, human dignity). For example, Lord Steyn notes that, in Germany, the Constitutional Court has ruled wrongful pregnancy claims unconstitutional as subverting the dignity of the child (although this view has been rejected by the Bundesgerichtshof);<sup>61</sup> and he cites with approval Trindade and Cane's remark that wrongful pregnancy claims by parents along with wrongful life claims by the child are "equally repugnant to ideas of the sanctity and value of human life."<sup>62</sup> Lord Clyde also notes that the "sanctity of human life" can be put forward as a reason against awarding compensation, although this is to be set against the public policy in favour of calculable family planning.<sup>63</sup> Most emphatically, perhaps, Lord Millett says: "In my opinion the law must take the birth of a normal, healthy baby to be a blessing, not

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57. *McFarlane*, [2000] 2 A.C. at 76-77.

58. *Id.* at 76.

59. *Cf. Johnson v. Univ. Hosps.*, 540 N.E.2d 1370 (Ohio 1989).

60. *McFarlane*, [2000] 2 A.C. at 75.

61. *Id.* at 80.

62. *Id.* at 83 (citing FRANCIS TRINDADE & PETER CANE, *THE LAW OF TORTS IN AUSTRALIA* 434 (3d ed. 1999)).

63. *Id.* at 100; see also C.R. Symmons, *Policy Factors in Actions for Wrongful Birth*, 50 *MOD. L. REV.* 269 (1987).

a detriment. . . . It is morally offensive to regard a normal, healthy baby as more trouble and expense than it is worth.”<sup>64</sup> However, unlike his fellow Law Lords, Lord Millett believes that the logic of this view militates against both claims (including Mrs. McFarlane’s claim — although, interestingly, his Lordship would have been prepared to award £5,000 compensation for the loss of freedom, or opportunity, to limit the size of the family).

Since the decision in *McFarlane*, two unresolved, but related, questions have come before the Court of Appeal in a pair of cases involving failed sterilizations. Whereas, in *Parkinson v. St. James and Seacroft University Hospital NHS Trust*,<sup>65</sup> the question was whether there can be compensation for the *extra-ordinary* costs of rearing a disabled child, in *Rees v. Darlington Memorial Hospital NHS Trust*,<sup>66</sup> the question was whether there can be compensation for the *extra-ordinary* costs of rearing a healthy child, but where the parent is disabled. In *Parkinson*, after an exhaustive analysis of the speeches in *McFarlane*, the court agreed that compensation of this kind could be legitimately awarded<sup>67</sup>; in *Rees*, the court was divided, but the majority, with some hesitation, ruled that compensation could be awarded because the situation of able-bodied parents (as in *McFarlane*) was distinguishable from that of a disabled parent (as in *Rees*).<sup>68</sup> Quite clearly, here as elsewhere, the law is drawing a distinction between those who are disabled and those who are not. Is this compatible with respect for human dignity (if, for the sake of argument, we treat this as the deep principle underlying *McFarlane*)? In *Parkinson*, Hale L.J. offers this very significant response:

A disabled child needs extra care and extra expenditure. He is deemed, on this analysis, to bring as much pleasure and as many advantages as does a normal healthy child. Frankly, in many cases, of which this may be one, this is much less likely. The additional stresses and strains can have seriously adverse effects upon the whole family, and not infrequently lead, as here, to the break-up of the parents’ relationship and detriment to the other children. But we all know of cases where the whole family has been enriched by the presence of a disabled member and would not have things any other way. *This analysis treats a disabled child as having exactly the same worth as a non-disabled child. It affords him the same dignity and status.* It simply acknowledges that he costs more.<sup>69</sup>

So, there is a dignity to human life (which is commonly held by proponents of dignity as constraint) and all humans, whether able-bodied or

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64. *Id.* at 113-14.

65. [2002] Q.B. 266 (C.A. 2001).

66. [2003] Q.B. 20 (C.A. 2002).

67. *Parkinson*, [2002] Q.B. 266, at ¶ 50.

68. *Rees*, [2003] Q.B. 20, at ¶ 22.

69. *Parkinson*, [2002] Q.B. 266, at ¶ 90 (emphasis added).

disabled, enjoy the same intrinsic dignity (which is common to both conceptions of human dignity but which, as I have said, is axiomatic in dignity as empowerment).

Let us try to take stock of the ground rules for liability in this area before running them through a couple of test cases involving genetic selection. In brief, the position taken by English law is:

- There is to be no compensation for “wrongful life.”
- In a “wrongful pregnancy” claim, there is to be no compensation for the costs of rearing a healthy child; however, the extra-ordinary costs of raising a disabled child are recoverable (as are the extra-ordinary costs where the mother is disabled).
- There can be compensation for “wrongful birth” (so that disabilities caused by professional negligence, and cognate losses arising from such negligence, are to be compensated).

How would these ground rules play in our two test cases? And, how would a newly recognised deep principle of respect for human dignity impact in this area?

### B. *Two Test Cases*

As pre-implantation diagnosis (PGD) becomes more widely available and acceptable, the screening of embryos for genetic disorders (particularly single-gene disorders such as cystic fibrosis) will surely become more commonplace. Couples who are aware of the risk of a particular disorder being passed on to their children will want to de-select embryos that test positive for the gene in question. Such *negative* genetic selection is in every sense the most straightforward kind of case. Even so, the process of testing, selecting, and implanting embryos can go wrong; and it can do so for reasons that lie within the responsibility of the medical team. In such cases, if claims are not to be brought forward in contract, they may be pleaded in negligence (for example, as an action for wrongful birth where the lack of due care results in the implanted embryo carrying the defective gene).

The first of our two test cases focuses on *negative* genetic selection. However, it is negative selection with a twist. This twist, exemplified by cases such as those of the Nash<sup>70</sup> and the Hashmi<sup>71</sup> families, is that the couple (as in the straightforward case) want a child free of a particular inherited disorder; however, they do not want the child sim-

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70. Linda and Jack Nash (like Lee Ann Currie fifteen years earlier) had a six-year old daughter, Molly, suffering from Fanconi anaemia. Both families conceived more children in the hope of having a healthy child whose umbilical cord blood could be used to treat the sick child. The Nashes made the news because, in addition to using PGD to reject embryos carrying the Fanconi's gene, they also screened their healthy embryos to find a match for their daughter. Adam was the result. See generally GREGORY STOCK, REDESIGNING HUMANS: OUR INEVITABLE GENETIC FUTURE 124-25 (2002); DESIGNER BABIES: WHERE SHOULD WE DRAW THE LINE? (Ellie Lee et al. eds., 2002) [hereinafter DESIGNER BABIES].

71. For the facts of the Hashmis' case, see *infra* Test Case 1.

ply for its own sake, but specifically so that it can act as a donor for a sibling already having the disorder. In two respects, this twist makes the case more complex than the straightforward case of negative selection: first, because the procedure of selection must screen both for the defective gene (as in the straightforward case) and for a tissue match between the embryo and the sibling, there is an increased likelihood of something going wrong; and, secondly, the fact that the purpose of the selection is not directly to enhance the life-chances of the chosen embryo(s) but to benefit the third-party sibling, adds to the moral difficulty of the case.

The other test case focuses on *positive* genetic selection, where the parents want more than a healthy child; they want a child with a particular desired (and, as they view it, desirable) genetic profile. This, too, is much more complex than the straightforward case: first, because, in the present (and any reasonably foreseeable) state of the art, selecting the desired genetic make-up is likely to lie beyond, or right at the margins of, our knowledge and understanding (particularly if the technique of enhancement involves not merely selection of the most promising embryo, but also an element of genetic engineering); and, secondly, because there is a sense that the move from negative to positive selection crosses a fundamental moral boundary.

### 1. Test Case One

Our first test case concerns a couple from Leeds in the North of England, Shahana and Raj Hashmi. The Hashmis have a son, Zain, who suffers from the inherited blood disorder, thalassaemia. Having failed in their attempts to find a compatible bone marrow donor for Zain, the Hashmis sought permission from the UK Human Fertilisation and Embryology Authority (HFEA) to have their in vitro fertilised (IVF) embryos screened with a view to selecting an embryo that would be (a) non-thalassaemic and (b) a suitable tissue match for Zain. Amid a blaze of publicity, the HFEA indicated its general willingness to allow tissue typing in conjunction with PGD in December 2001, and the specific go-ahead for the Hashmis followed in February 2002 (however, at the time of writing, the legality of the approval given by the HFEA is being adjudicated in a judicial review brought by Josephine Quintavalle on behalf of the public interest group, Comment on Reproductive Ethics).<sup>72</sup> Quite apart from the legal complica-

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72. See *R in re Quintavalle ex rel. Comment on Reproductive Ethics v. Human Fertilisation & Embryology Auth.*, [2002] EWHC 2785 (Q.B. Admin. Ct. 2002). At first instance, Mr. Justice Maurice Kay held that embryo checking for tissue typing purposes falls within the scope of the framework legislation, but that the HFEA has no statutory authority to issue licences for such purposes. *Id.* at 2785-86. The HFEA has appealed successfully against this ruling to the Court of Appeal, but the case is likely to go to the House of Lords. Seemingly, though, the HFEA was already having second thoughts about using PGD for tissue typing. For, following criticism from

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tions, the odds against this procedure being successful are fairly long (of fourteen embryos produced so far, none has been a match); and, if it fails because no suitable embryo is identified, or because the re-introduced embryos do not develop as they should, this will be a disappointment, but it hardly stacks up to a tort claim. However, if the failure to bring about a successful pregnancy were to be caused by a lack of professional care and attention in carrying out the procedure, might there be a claim by the parents who have been deprived of (i) a healthy (non-thalassaemic) child who is (ii) a potentially life-saving sibling for Zain? Moreover, might there be a claim by Zain for professional negligence?

Consider a variation on this scenario: let us suppose that there is a failure in checking the embryos to be selected — perhaps something along the lines of one of the textbook IVF mix-ups.<sup>73</sup> As a result, an embryo that is thalassaemic is implanted and carried successfully to term. Zain has a brother; but the Hashmis' troubles have been doubled rather than solved. What claims might be put here?

Then, consider this variation: again, let us suppose that the failure is in checking the embryos to be selected. As a result, an embryo that is non-thalassaemic, but which is not a good tissue match for Zain, is implanted and carried successfully to term. Zain has a brother, a perfectly healthy brother. Alas, this newly born child cannot assist Zain, and this is not the child that the Hashmis bargained for. Do they have a claim to be compensated for this baby by design whose design is not as specified? Does Zain have a claim?

What are the answers to these puzzles? Where the professional negligence results in no successful pregnancy, this is akin to a physician's negligence causing a miscarriage or a still-birth. In such cases

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the House of Commons Select Committee on Science and Technology, in August 2002, the HFEA declined to authorise a similar procedure for the Whitaker family. The Whitakers were hoping that the procedure would be licensed as a last hope for their son Charlie who suffers from the rare blood disorder, Diamond Blackfan anaemia. The principal reason why the HFEA judged that such a procedure would be unethical seems to have been that it accepted that there is a doubt about public support for procedures in which one embryo is chosen over another purely for tissue-typing reasons. See Rebecca Allison, *New Designer Baby Row as Watchdog Rejects Family's Plea for Treatment: Application for IVF and Licence*, GUARDIAN, Aug. 2, 2002, at 3. However, initial reports also suggested that, because it is not possible to screen for Diamond Blackfan anaemia, there was a risk that the designer child, although a suitable tissue match, would suffer from the same disorder as Charlie. Given such a risk (of assisting the conception of one damaged child to try in vain to save the life of another damaged child), this too was presented as a ground for the HFEA's judgment that it would be unethical to license such an attempt.

73. Perhaps the best-known mix-up of this kind was that which befell Donna Fasano and Deborah Perry-Rogers at a fertility clinic in Manhattan. Essentially, an embryo from the latter was mistakenly implanted in the former, who then went on to give birth to the child. Steven Morris, *U.S. Mother Forced to Make Heartbreaking Decision After Blunder Led to Legal Tussle*, GUARDIAN, July 9, 2002, at 3. Such mistakes, however, are not limited to the United States. See, e.g., Sarah Hall, *Two Women Given Wrong Embryos in IVF Mix-Up*, GUARDIAN, Oct. 29, 2002, at 2.

— whether of straightforward negative selection or of negative selection with a twist — what kind of a claim might the mother have in relation to this failed pregnancy? It is trite that the common law offers no compensation to the mother for her grief and sorrow as such; nor is there any longer compensation for loss of consortium (which never applied anyway to the parents of deceased children); and nor does the statutory award for bereavement damages apply unless the child is born alive. Faced with these barriers to compensation, Simon Brown J. suggested in *Bagley v. North Herts Health Authority*<sup>74</sup> that, where a mother has undergone “the burdensome, laborious process of carrying and bearing her child, only to be deprived at the final hour of her hopes and expectations of success and fulfilment,”<sup>75</sup> then this might be directly compensated. However, the idea that there might be a recognised head of compensation for “dashed hopes” was subsequently doubted in *Kerby v. Redbridge Health Authority*,<sup>76</sup> and, in our hypothetical, whilst there are certainly dashed hopes, would one equate the difficulties faced by the Hashmis with the burdens of a natural pregnancy and childbirth? Indeed, we might. In fact, some might think that the plight of the Hashmis is even more agonising — as Juliet Tizzard has remarked, “for couples at risk of having a child with a genetic disease . . . PGD is no picnic, physically or psychologically.”<sup>77</sup> Nevertheless, in the current state of English law, if one wanted to find a more promising way of compensating for, effectively, wrongful non-birth, one would be looking to recognised claims for psychological injury and reasonably foreseeable consequential losses (such as the additional costs to be incurred in trying to deliver a life-saving brother for Zain).<sup>78</sup>

Clearly, to the extent that Zain is aware of his circumstances, the negligent failure of the procedure will be a cause for disappointment and, quite possibly, anxiety. To be sure, it is arguable on the particular facts that Zain’s parents should have taken steps to shield him from all this, so that his hopes were neither raised nor dashed (although, given the publicity attending the case, this would have been difficult indeed). At all events, if we put to one side any arguments about contribution and causation, is there any basis, other than negligently inflicted dashed hopes, on which Zain might seek to be compensated? One thought is that he (like his parents) might have a claim for any

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74. [1986] 136 NEW L.J. 1014 (1986).

75. *Id.* at 1015.

76. [1993] 4 MED. L. R. 178 (1992).

77. Juliet Tizzard, ‘Designer Babies’: *The Case for Choice*, in DESIGNER BABIES, *supra* note 70, at 29, 35 (2002).

78. *See, e.g., Kralj v. McGrath*, [1986] 1 All E.R. 54 (Q.B. 1985).

psychological injury occasioned by the negligence of the professional team.<sup>79</sup>

With regard to this thought, where English courts are invited to compensate claimants who have been adversely affected by negligent defendants in novel circumstances, the focal question becomes whether the defendant owes a duty of care to the claimant. This question can be expressed in many different ways. Famously, in *Anns v. Merton London Borough Council*,<sup>80</sup> Lord Wilberforce tried to capture the position in the following terms:

[T]he position has now been reached that in order to establish that a duty of care arises in a particular situation, it is not necessary to bring the facts of that situation within those of previous situations in which a duty of care has been held to exist. Rather the question has to be approached in two stages. First one has to ask whether, as between the alleged wrongdoer and the person who has suffered damage there is a sufficient relationship of proximity or neighbourhood such that, in the reasonable contemplation of the former, carelessness on his part may be likely to cause damage to the latter — in which case a prima facie duty of care arises. Secondly, if the first question is answered affirmatively, it is necessary to consider whether there are any considerations which ought to negative, or to reduce or limit the scope of the duty or the class of person to whom it is owed or the damages to which a breach of it may give rise.<sup>81</sup>

On the face of it, this two-stage test did not threaten to over-expose defendants to liability; and, indeed, Lord Wilberforce himself was a relatively cautious incrementalist in the matter of extending liability. However, the test came to be associated with an over-extension of liability (particularly in relation to claims by commercial contractors who sought to recover purely economic loss via tort actions rather than contractual actions), and further hurdles were put in the way of recognising a duty of care. Most importantly, perhaps, the courts sought to regain control by declaring that the overriding question is whether it would be “fair, just and reasonable” to recognise a duty in the particular circumstances.<sup>82</sup>

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79. Another thought is that professional “rescuers” who carelessly aggravate a situation might be liable for the increased loss. See, e.g., *Capital & Counties Plc. v. Hampshire County Council* [1997] Q.B. 1004 (C.A. 1997). However, on reflection, this seems like a poor thought. In what sense have the medical professionals aggravated the situation? Zain’s condition is not made worse because of the failure of the medical people. Or, possibly putting this another way, what is Zain’s loss if we are minded to compensate him?

80. [1978] A.C. 728 (H.L. 1977).

81. *Id.* at 751-52.

82. The House of Lords, having already shown some nervousness post-*Anns* about general principles, almost arrived at this test in *Governors of the Peabody Donation Fund v. Sir Lindsay Parkinson & Co.*, [1985] A.C. 210, 241 (H.L. 1983-84), where Lord Keith said “in determining whether or not a duty of care was incumbent upon a defendant it is material to take into consideration whether it is just and reasonable that it should be so.” This, it should be emphasised, signalled a test fixed firmly on the facts of each particular case. In *Caparo Industries Plc. v. Dickman*, [1990] 2 A.C. 605 (H.L. 1989-90), the House of Lords completed the return to a more

For a variety of reasons, English courts will sometimes hold that it is not fair, just, and reasonable to treat the defendant as having a tortious duty of care. As I have said, claims in which recovery is sought for purely economic loss, like claims which look as though they should be pleaded in contract rather than tort, are particularly susceptible to this objection; and, although the reservation is not normally expressed in quite these terms, the same cautious approach applies to claims for psychological injury. If we assume that the claims made by the Hashmis and by Zain were for psychological distress, then they would fall to be judged by the precedents on "nervous shock." In what is a highly unsatisfactory body of law, a distinction is drawn between claims made by "primary victims" (roughly, those who are themselves within the area of risk and, thus, directly at risk of injury) and "secondary victims" (roughly, those who are not directly at risk of injury but who suffer psychological injury as a result of their concern for a primary victim). It is generally recognised that the law in relation to claims made by secondary victims is in a considerable mess.<sup>83</sup> However, any claims made by the Hashmis and Zain would have to be presented as those of primary victims.

Here, following a split decision by the House of Lords in *Page v. Smith*,<sup>84</sup> the law is relatively favourable for claimants. In *Page*, the claimant was involved in a road traffic accident caused by the defendant's carelessness. Although the claimant was not physically injured, he did suffer psychological injury (a renewed onset of myalgic encephalomyelitis which, prior to the accident, had been in remission). Taking the view that some sort of personal injury was reasonably foreseeable, and that personal injury must include both physical and psychological injury, the majority of the House ruled that the claimant could recover compensation even though no physical injury was suffered.<sup>85</sup> To appreciate the pro-claimant nature of this decision, one only has to put the result in the following slightly more specific terms: the claimant was held to be entitled to compensation for psychological injury which was not reasonably foreseeable in circumstances where physical injury, which was reasonably foreseeable, did not actually result. On the other hand, of course, one might say that it would be absurd to insist upon some trivial physical injury actually being in-

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cautious approach. As Lord Bridge put it, after *Anns*, "[w]hat emerges is that, in addition to the foreseeability of damage, necessary ingredients in any situation giving rise to a duty of care are that there should exist between the party owing the duty and the party to whom it is owed a relationship characterised by the law as one of 'proximity' or 'neighbourhood' and that the situation should be one in which the court considers it *fair, just and reasonable* that the law should impose a duty of a given scope upon the one party for the benefit of the other." *Id.* at 617-18 (emphasis added).

83. See generally LAW COMM'N, REP. NO. 249, LIABILITY FOR PSYCHIATRIC ILLNESS (1998).

84. [1996] A.C. 155 (H.L. 1995).

85. *Id.* at 197.

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curred in order to open the door to a claim for psychological injury. In the light of the pro-claimant attitude of the majority in *Page*, and assuming that the risk of psychological injury is reasonably foreseeable, then compensation for this kind of injury must be a real possibility.

To move on to the first variation on the hypothetical, where a child is born but it has thalassaemia, there is an action for wrongful birth; but there is no action by the child for wrongful life. This applies, of course, to both straightforward negative selection and negative selection with a twist, such as that presented by the Hashmis' case. In the latter, what we have just said above would apply to a possible claim brought by Zain.

Moving on to the further variation in the hypothetical (where the child that is born is perfectly healthy, but not a tissue match for Zain), clearly this has no application to the case of straightforward negative selection. However, what would be the position in the more complex case of the kind exemplified by the Hashmis? Under the present law, there can be no action by the parents for wrongful pregnancy or wrongful birth; and, on these varied facts, a claim for psychological damage might be more difficult to maintain — particularly if the court took the view that the standard is set by couples of “reasonable fortitude” and that such persons would cope with adversity of this kind. Such considerations would not reduce the prospects of a successful action by Zain. After all, from Zain's perspective, it makes no difference whether the newly-born child is an unsuitable donor because it, too, has thalassaemia or because it does not have the required tissue type. Zain's legal prospects, therefore, would be as they are in the previous hypotheticals and what we have said above would apply.

So much for utilising English torts law as it currently stands. What would be the position if we imagined that English law were to recognise a claim for impairment of human dignity? From the perspective of human dignity as constraint, even straightforward negative testing would be seen as problematic (because the de-selection of an embryo is equated with the destruction of human life). *A fortiori*, it would be seen as wrong to conceive of children for third-party purposes (even life-saving purposes) for this would involve the “instrumentalisation” of the donor child (even if that child was not in any way physically affected by the use of its cord blood). For these reasons, it would be inappropriate for the State to encourage such conduct and, thus, there would be no compensation if the parties' attempts to assist Zain were to misfire. As we have said, however, the perspective favoured in this paper is that of human dignity as empowerment, and so the question is how a tort protecting that conception of

an interest in human dignity would respond in these hypothetical cases.

Where the tort is geared to protecting human dignity as empowerment, the dominant concern is to ensure that agents are given the proper opportunity to choose and that their choices, once made, are protected. As at present, the primary function of contract would be to protect the post-choice expectation, and the primary function of tort would be to protect the pre-choice status quo. From the perspective of human dignity as empowerment, there is no reason, in principle, to object to simple negative selection. If couples choose to make use of the latest reproductive technology to have children (as with IVF), then why not also choose to use that technology to improve the chances of having a child that is free of some serious disability or disease? Taking this one step further, respect for human dignity gives us no reason to think that parents should not conceive with a view to saving the life of their born child; and, nor is there any reason why they should not be permitted to avail themselves of the most modern technologies for this purpose. They do not instrumentalise anyone by doing so. The donor child is not treated *simply* as a means; as in any co-operative exercise, the other party is also treated as an end (or, at any rate, in a way that is compatible with respecting the well-being of a potential agent).<sup>86</sup> From this perspective, therefore, there is no background negative colouring the actions of the parents. They are entitled to do what they are doing. How would this impact on the group of test-cases that we have been discussing?

First, where no child is born (and, assuming that, but for the negligence of the medical team, a suitable child would have been born), the human dignity tort would at least match the current (limited) remedial repertoire. However, might it also go beyond this by compensating for dashed hopes or unfulfilled expectations? If a legal regime denies compensation for dashed hopes where standard pregnancies fail as a result of professional negligence, it is unlikely to compensate for such disappointment in a negative selection case — even with human dignity in play. In principle, though, human dignity as empowerment seeks to improve the conditions in which agents can choose their purposes and have some prospect of attaining their ends. If the co-operative engagement between couples such as the Hashmis and the medical team with which they are working can be read as generating an expectation of success, then we might be closer to grounding

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86. It is worth emphasising that the second formulation of the Kantian categorical imperative, much favoured by the dignitarian alliance, does not prohibit treating others as a means; the injunction is against treating others as a mere means and not also as an end. The Human Genetics Commission, in articulating its principle of respect for persons, however, gets the Kantian imperative absolutely right. *See supra* note 15.

liability. However, the expectation must not be so strong that the case is classified as “contract or nothing.” Given the focus of human dignity as empowerment, a *tort* claim might target the parties’ disappointment in one of two ways. One way would be to focus on the parties’ raised hopes. When the project fails because of the negligence of the medical team, it is arguable that they leave the couple worse off than they were before embarking on the treatment. Another way would be to formulate an appropriate expectation in something like the following terms: namely, that the medical team, mindful of the importance of the project to the Hashmi family, assume the obligation of taking reasonable care in carrying out the procedures, including not occasioning disappointment to the couple.<sup>87</sup> By either of these routes, the Hashmis might argue for compensation directed at the negligent wrecking of their project. Such compensation would not be for psychological damage; rather it would be the product of a dignity-based claim for impairment of the Hashmis’ purposes.

Second, where the child that is born has the gene for thalassaemia, this is a wrongful birth case attracting the package of compensation that goes with that. Once again, as in the first case above, human dignity might be argued as a way of opening up some further liability relating to the disappointment experienced by the parents.

Third, where the child that is born is perfectly healthy but not a match for Zain, we perhaps see one of the clearest contrasts between the bearing of the rival conceptions of human dignity. In such a case, human dignity as constraint would emphatically deny any case for compensation. However, human dignity as empowerment would see such a case as one in which an agent’s known purpose had been frustrated through the negligent performance of one who had agreed to assist in achieving that purpose. To treat the latter as assuming a strict compensatory obligation should the project fail would be to contractualise the case; but to treat the latter as assuming the lesser obligation to take reasonable care and compensate in relation to the specific project, should carelessness undermine that project, would seem an appropriate tortious response to the need to respect human dignity (as empowerment).

Finally, what about claims made by Zain? If the additional compensation delivered by respect for human dignity as empowerment centres on the protection of an agent’s chosen purposes, Zain falls beyond the circle of protection. The life-saving purposes of Zain’s

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87. For articulation by the House of Lords of the idea of “voluntary assumption of obligation” as the foundation for a duty of care in tort, see, e.g., *Henderson v. Merrett Syndicates Ltd.*, [1995] 2 A.C. 145 (H.L. 1994); *White v. Jones*, [1995] 2 A.C. 207 (H.L. 1993). See also Simon Whittaker, *The Application of the ‘Broad Principle of Hedley Byrne’ as Between Parties to a Contract*, 17 *LEGAL STUD.* 169 (1997).

parents certainly touch and concern him; but the purposes are essentially those of his parents. If, through professional negligence, those purposes are not realised, or are realised in a distorted way, any dignity-driven additional compensation will be for Zain's parents rather than for Zain himself.

## 2. Test Case Two

In some future world, where the mathematics of genetic enhancement no longer look so daunting, let us suppose that we have the capacity to use PGD to select embryos for sex and beauty, for intelligence and creative talent, and so on, as well perhaps as the technology to genetically engineer embryos for such desired features. Even though such a scenario seems to be some considerable way into the future, we are already debating the ethics of enhancement.<sup>88</sup> One concern, expressed by Lee Silver amongst others, is that enhancement would be available for purchase only by the wealthy, leading to the further accentuation of social and economic inequalities.<sup>89</sup> If this proved to be so, with clinics for designer babies operating in the private sector, we can take it that claims (for non-enhancement as per the parents' specification) would generally sound in contract rather than tort. However, if access to enhancement could be broadened, and if tort claims were to be utilised, how might they look? Let us assume that a child is born perfectly healthy, but it is not what either the parents or the doctor ordered. Suppose, for instance, that the family is musical, that the parents have specified a child with a musical ear, but as a result of professional negligence by the genetic team the child born has neither perfect pitch nor an ear for music. Would the parents have a claim? Would the child have a claim for something approaching wrongful life with damages being assessed by reference to the difference in value between the life of the child as born and its value had it been born according to the design specification?

From the perspective of an agency-based moral theory, an important distinction might be drawn between those characteristics that are agency-relevant and those that are agency-irrelevant. Whereas characteristics of the former kind are essential for agency (without these characteristics, one lacks the capacity to act in a free and purposive way), characteristics of the latter kind do not cut so deep — a being can have or lack such characteristics and still be an agent. On this

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88. Generally, the view in Europe is that enhancement would be unethical — the shadow of "eugenics" is a long one. However, the Nuffield Council on Bioethics draws an interesting distinction between selective termination using (i) pre-natal diagnosis (where the pregnancy is already established) and (ii) PGD. If a choice of technique has to be made, the Council prefers the latter. See NUFFIELD COUNCIL, *supra* note 31, at ¶ 13.66.

89. LEE M. SILVER, *REMAKING EDEN: CLONING AND BEYOND IN A BRAVE NEW WORLD* (1998).

basis, we can say that whether or not one has musical talents does not affect whether or not one is an agent. Thus, in the above hypothetical, although the procedure has gone wrong, it has not done so in a way that concerns agency-relevant characteristics. The child, musical ear or not, is nonetheless an agent. There is also the thought, to which we will return very shortly, that an agency-based liberal theory might have grave reservations about the musical family's project. Bruce Ackerman, for example, has argued persuasively that the fundamental liberal principle of (what he calls) "neutrality" militates against recognising a parental right "to design their children in the way they find most pleasing [i.e., in accordance with the parents' own conception of the good]."<sup>90</sup>

Subject to this liberal caveat, we might nevertheless think that this focus on agency-relevance allows too much margin for negligent error. After all, even though we are dealing with agency-irrelevant characteristics, should we not offer some protection against professional negligence? Following this approach, the obvious move is to distinguish between those impacts that would be compensated if they were negligently caused in relation to born agents, and those impacts that would not. How should we make such a comparison?

Let us suppose that we start from the premise that the intended remedial function of the tort system is to compensate where wrongs, such as negligence, cause a victim to be made worse off (and, indeed, to compensate just to the extent that the victim has been made worse off). On this basis, it is easy to compensate a working musician, who is injured by the negligence of the defendant, for his pain and suffering, and loss of earnings and the like. It is a bit more difficult, but still possible, to fix a compensatory figure for an aspirant musician whose hopes of a musical career are cut short by the defendant's negligence. But does it make sense to offer compensation to either the parents or their child in relation, not to a talent that is not able to fully flower, but to one the seeds of which are not even present? Are we moving into the area once again of compensating for dashed hopes and expectations? If so, is it the parents alone who are eligible claimants (as the progenitors of the purpose that has failed)?

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90. BRUCE A. ACKERMAN, *SOCIAL JUSTICE IN THE LIBERAL STATE* 123 (1980). According to Ackerman, the core principle of liberalism is that power plays cannot be justified by reasons that assert either that the power holder's conception of the good is superior to conceptions of the good held by others or that the power holder is intrinsically superior to others: this is the so-called principle of neutrality. *Id.* at 11. Applying this principle, Ackerman argues that it would be illiberal not only for the State to design a "master race" in its own image of the good, but equally so for parents to impose their own conception of the good on their children (whether genetically or environmentally). *Id.* at 114-15. See generally Deryck Beyleveld & Roger Brownsword, *Liberalism in Quest of Itself*, 45 *MOD. L. REV.* 104 (1982) (reviewing ACKERMAN, *supra*).

Let us return to (relatively speaking) terra firma. Suppose that a child is born deaf as a result of medical negligence. For most purposes, the child is worse off than it should have been as an agent-to-be, and compensation puts no strain on the mission of the tort system. So far, so good. However, what do we say about members of the deaf community who could avoid having a deaf child but who, in fact, go out of their way to conceive a child carrying the deafness gene? Of course, in such a case, the parents have no complaint. However, should we recognise a claim made by an aggrieved child *against its parents* for their deliberate disadvantaging of the child as an agent-to-be in any community other than the deaf community in which it will be raised? If we think that this might be an appropriate case for compensation, what do we make of the musical child, born (successfully) with its parents' design specification, but who would have preferred a different specification? Does the disappointed child have any redress against the delighted parents? As we have said, liberal principles argue against permitting parents to design particular futures for their children by imposing their own favoured conception of the good on their offspring. Applying such principles, it follows that the musical child has good reason to complain about the parents imposing this specification, but not that the parents should have designed in some other specification (now favoured by the child) — to keep faith with liberal principles, the parents should have eschewed any kind of design reflecting a particular conception of the good.<sup>91</sup> And, to return to a previous question, if the musical family's project miscarries because of professional negligence, the liberal caveat suggests that this is *not* an appropriate case for compensation.

What does human dignity have to say about these hypothetical scenarios? From the standpoint of human dignity as constraint, we can take it that claims of this kind would be given short shrift. Attempts at enhancement would be seen as a straightforward compromising of human dignity.<sup>92</sup> Accordingly, even if the state permits it,

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91. For a dialogue between parents who have selected for a daughter who is relatively good at chemistry but relatively weak on aesthetics — the aggrieved daughter hates chemistry and aspires to be a great artist — see ACKERMAN, *supra* note 90, at 122-23.

92. Compare the Nuffield Council on Bioethics, where the Council constructs an objection to pre-natal selection based on "natural humility." NUFFIELD COUNCIL, *supra* note 31, at ¶¶ 13.71-.78. The essence of this conservative objection, which is pitted against the right to reproductive autonomy, is that parental love involves accepting one's children as one finds them: "[t]his attitude is an important feature of parental love, the love that parents owe to their children as individuals in their own right; for this is a love that does not have to be earned and is not dependent on a child having characteristics that the parents hoped for." *Id.* at ¶ 13.74. The Council, while not entirely persuaded by the conservative objection, nevertheless considers that the case for pre-natal selection remains to be made. Accordingly, it recommends that PGD, which is currently used to select against embryos with a serious disease or disorder, "should not be extended to include behavioural traits in the normal range such as intelligence, sexual orientation and personality traits." *Id.* at ¶13.78.

there should certainly be no safety-net for those who take their chance with enhancement and, thus, no support through compensation.

Human dignity as empowerment, on the other hand, would take a much less damning view. From this perspective (which is essentially a liberal viewpoint), the distinction between agency-relevant and agency-irrelevant characteristics would seem to be the right starting point. However, if the category of agency-relevant characteristics is limited to those capacities or features that are essential for *minimal* functioning as an agent, this would allow for little or no positive enhancement. Granted, compensation might be made available where agents act with a view to conceiving a child who is born generically disadvantaged *as an agent* (for example, deaf, or blind, or one-armed),<sup>93</sup> but failed attempts to enhance beyond this level would not attract compensation.

Against such a restricted view, it might be argued that, because the model of agency that is fundamental to this view of human dignity is one of individual agents making their own choices and then assuming responsibility for the choices that they have made, positive enhancement is not off limits, provided that it relates to the power of choice. In other words, enhancement that tries to make a future agent's choices for it is off bounds, but not enhancement that is geared to improving a future agent's ability to make its own choices. In this sense, enhancement must be consistent with the liberal principle of neutrality; or, as some might prefer to put it, enhancement must leave the agent-to-be with an "open future."<sup>94</sup> So, for example, it might be consistent with human dignity as empowerment to positively enhance for intelligence, but not for a particular talent such as musical ability — even though parents, with greater or lesser success, might continue to sit their infant children in front of a piano from an early age. If this latter reading of human dignity as empowerment is adopted, who and what might be compensated? Once again, the principal eligible claimants would be the parents whose design project has not been treated with sufficient respect by the negligent parties. The parents are entitled to have their birth project treated seriously and failure to do so implies a lack of respect for their own dignity as agents. For a child, able to function as an agent, but under-enhanced relative to the par-

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93. But note the claim made that "many people who are born deaf, particularly when they have had the advantage of learning and using sign language from an early age, regard themselves as a cultural and linguistic minority, not in any way 'disabled' or damaged." Agnes Fletcher, *Making it Better? Disability and Genetic Choice*, in *DESIGNER BABIES*, *supra* note 70, at 15, 23. See, too, Ackerman's arguments based on the idea of "genetic domination." ACKERMAN, *supra* note 90, at 115-16.

94. Cf. NUFFIELD COUNCIL, *supra* note 31, at ¶¶ 13.72-.73; DENA S. DAVIS, *GENETIC DILEMMAS: REPRODUCTIVE TECHNOLOGY, PARENTAL CHOICES, AND CHILDREN'S FUTURES* (2001).

ents' specification, a claim for compensation seems more problematic. And, given the increasingly speculative nature of this discussion, it is perhaps best to leave it to some future time when the relevant jurisprudence of dignity-based claims has begun to take shape.

### III. PRIVACY AND CONFIDENTIALITY, CONTROL, AND COMMUNICATION IN A WORLD OF GENETIC INFORMATION

If we treat genetic information as akin to medical information (although not only relevant in medical contexts), then we will probably start with a relatively protective approach towards the nature and flow of that information.<sup>95</sup> Essentially, this is confidential information; and, in consequence, the person whose genome the information relates to should be in control of who should have access to that information (not just initially, but second and third hand and so on). Writing about genetic counsellors, Barbara Bowles Biesecker points out that such confidentiality could be breached in more than one way:

Confidentiality may be infringed in two distinct ways: deliberate breach and inadvertent disclosure. Genetic counselors may be party to either. They may be responsible for a disclosure or involved with the consequences when a third party is responsible (including other family members, health care providers, insurers, and employers). Deliberate breach by genetic counselors is morally and legally justifiable only when averting serious harm to a third party. The risk of inadvertent disclosure is a risk of clinical practice, record keeping, and teaching and may be reduced by certain safeguards.<sup>96</sup>

Infringements of this kind, whether deliberate, reckless, or negligent, whether direct or indirect (via third parties), involve a *prima facie* violation of the privacy interest in general and the confidentiality interest in particular,<sup>97</sup> in the sense that the subject of the information has not had the opportunity to control the outward flow of genetic information about him or herself.

95. The Human Genetics Commission recommends that "consideration be given to the creation of a criminal offence of the non-consensual or deceitful obtaining and/or analysis of personal genetic information for non-medical purposes." *INSIDE INFORMATION*, *supra* note 15, at ¶ 3.60. Note that (i) the Commission takes this so seriously that it is contemplating the creation of a *criminal offence* to deter wrongful use of genetic information; and (ii) the appropriation and misuse is in *non-medical* contexts. The Commission gives three examples of the kind of misuse that might fall outwith current protective legislation, namely: (i) "X takes Y's beer glass and obtains an analysis of his DNA. He or she then sells to a newspaper the information that Y has a particular genetic condition"; (ii) "X de-encrypts anonymised genetic information about Y from a research study [which X then uses] for some wrongful purpose"; and (iii) "X obtains a [DNA] sample from child A, for whom he has no parental responsibility, in order to ascertain whether he is" A's father. *Id.* at ¶ 3.50.

96. Barbara Bowles Biesecker, *Privacy in Genetic Counseling*, in *GENETIC SECRETS*, *supra* note 2, at 108, 115.

97. The difference and relationship between privacy and confidentiality will, of course, depend upon how we set the base terms. However, so long as privacy protects a range of interests that include, but also go beyond, informational interests, and so long as confidentiality is exclusively concerned with the protection of informational interests, privacy will have a broader sweep than confidentiality.

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With genetic information in wide circulation, however, a reverse problem arises. This is that the subject of the information may wish to remain ignorant about his or her genome (and, in this sense, regulate the inward flow of information). Within families, it may be very difficult indeed to protect those who are genetic information-averse (at any rate, in relation to themselves). Not only may there be special situations where the subject wishes to be informed about the genome of another (say, a pregnant woman who wishes to know about her fetuses' genome) without also knowing about her own genome, there will be cases where it is very difficult for the information-averse to avoid putting two and two together.

Beyond the family, there will also be situations where a person may prefer not to know the results of genetic tests. For example, an employer may require applicant employees to submit to a genetic test in order to establish whether they represent any kind of risk to fellow employees, but also whether they will be at risk himself or herself. If we assume that, at least for the safety of potential fellow employees, the applicant must submit to such a test, is it open to the employee applicant to elect not to be informed as to the outcome of the test? In such cases, is there a right not to know? And, if so, is a tort based on an interest in human dignity (protecting choice and autonomy) the right way to protect such a right?

To set the scene for the first of these two sets of questions (regulation of the outward flow and the inward flow of genetic information) we can review two recent English cases, *R. v. Dept. of Health ex parte Source Informatics Ltd.*<sup>98</sup> (*Source Informatics*) and *A Health Authority v. X.*<sup>99</sup> After that, we can turn to the second set of questions and, in particular, assess whether a right not to know might be protected via a human dignity tort.

#### A. *Regulating the Outward Flow of Genetic Information: The Recent Cases*

The background to the *Source Informatics* case was that the applicant company was seeking to collect data about the prescribing habits of general practitioners, thinking that such information would be of commercial value to drug companies (the companies using the information to promote their products and fine-tune their marketing). Its plan was to supply pharmacists with software enabling the name of the general practitioner, together with the identity and quantity of the drug prescribed, to be downloaded onto disk. For this service, pharmacists would be paid a fee. As for the patients for whom the drugs

98. [1999] 4 All E.R. 185 (1999), *rev'd*, [2001] Q.B. 424 (C.A. 1999).

99. [2001] 2 F.L.R. 673 (2001), *aff'd*, [2002] 1 F.L.R. 1045 (C.A. 2001).

had been prescribed, the software was designed in such a way that patients could not be identified. The applicant's plans, however, were thwarted by advice concerning the confidentiality of patient information issued by the Department of Health. According to this advice, anonymisation of patient data would not negate the duty of confidence.<sup>100</sup> Crucially, because "[t]he patient would not be aware of or have consented to the information being given to the data company . . . [a]nonymisation of the data (with or without aggregation) would not obviate a breach of confidence."<sup>101</sup> Faced with this difficulty, the company sought a declaration that this guidance was in error and that "disclosure by doctors or pharmacists to a third party of anonymous information, that is information from which the identity of patients may not be determined, does not constitute a breach of confidentiality."<sup>102</sup>

At first instance, Latham J. dismissed the application, taking a strongly protective approach towards any unauthorised use of confidential information. Putting the issue at its simplest, the question for the court was this: on the assumption that anonymity could be guaranteed for the patients, then what possible harm could there be if the information abstracted from the prescriptions was processed as the applicants proposed (albeit an unauthorised use)? To this, Latham J. responded as follows:

The majority of patients would, I suspect, be unconcerned by the prospect that statistical information obtained from their prescriptions was being used in this way, recognising that, if anonymity is guaranteed, their privacy would not be invaded, and that the commercial value of their prescriptions would individually be infinitesimal. But I recognise that, for some, the sensitivity, as they would see it, of the information may be such that they would feel that any use of the information without their consent, would be unconscionable. In other words it would be a breach of the trust which they were reposing in the pharmacist.<sup>103</sup>

Having said this, Latham J. concluded:

this type of situation [is] one in which there is a public interest in ensuring that confidences are kept. It is important that those who require medical assistance should not be inhibited in any way from seeking or obtaining it. . . . I believe that there may be some patients who will feel very strongly that the pharmacist should not give any information obtained from the prescription without their consent. This will enable them to make a decision as to whether to allow the information to be used.<sup>104</sup>

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100. *Source Informatics*, [2001] Q.B. at 430-31.

101. *Id.* at 431 (quoting a Department of Health policy advice document).

102. *Id.*

103. *Source Informatics*, [1999] 4 All E.R. at 195.

104. *Id.* at 196.

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Drawing on the larger bioethical picture as sketched earlier in this paper, if this were a matter for debate, one might expect the following three angles to be pleaded. Utilitarians would focus on the costs and benefits of allowing anonymised information to be used; rights theorists would major on whether the use of anonymised information involved any prima facie violation of right and, if so, whether patients had given their informed consent to such use; and duty theorists would focus on whether pharmacists could comply with their duties to the patients while passing on the anonymised information. In Latham J.'s judgment, each of these perspectives finds an echo. His concluding comments about the public interest are suggestive of a longer term and general utilitarian calculation and, when he speaks of a breach of trust and unconscionable conduct by the pharmacists, this might be read as a duty perspective. However, a great deal of what Latham J. says indicates a concern with the rights of patients. Even if, because of anonymisation, patients cannot be harmed in the sense that another will have identifiable information about them, Latham J. is reluctant to allow that there is, therefore, no breach of right. Yet, if this is so, what right might this be? The obvious answer is that Latham J. must be presupposing some species of proprietary right. In other words, one reading of this judgment is that patients have a right to prevent the processing and use of their prescription information because, quite simply and conclusively, the information is theirs.

On appeal, the Court of Appeal reversed Latham J.'s decision. In short, the court said that, once the information was anonymised, no harm could be done to the patients, no rights could be violated. Once again, the three value perspectives fed into the decision. Early in his judgment, Simon Brown L.J. (with whom Aldous and Schiemann L.JJ. concurred) noted that the Department was concerned that more targeted marketing by the pharmaceutical companies would affect prescribing habits and, in turn, add to the National Health Service (NHS) drug bill. The applicants disputed this interpretation of the impact of targeted marketing. But, it was not an issue that was seen as central to whether or not passing on the anonymised information would involve a breach of confidentiality. Having reviewed the case-law, Simon Brown L.J. articulated the focal question in duty terms as follows:

To my mind the one clear and consistent theme emerging from all these authorities is this: the confidant is placed under a duty of good faith to the confider and the touchstone by which to judge the scope of his duty and whether or not it has been fulfilled or breached is his own conscience, no more and no less. One asks, therefore, on the facts of this case: would a reasonable pharmacist's conscience be troubled by the proposed use to be made of the patients' prescriptions? Would he think that by entering Source's

scheme he was breaking his customers' confidence, making unscientific use of the information they provide?<sup>105</sup>

Of course, the qualifier "reasonable" (as in reasonable pharmacist) entails that this is not simply a matter of a clear conscience, subjectively speaking, and it raises the question: relative to what would a pharmacist reasonably so believe? This cues the significance of the patient's rights (or interests). For, if the processing of the information infringes no rights (or interests) of the patient, then the pharmacist could reasonably believe that no wrong is done to the patient. It is at this stage of the reasoning that Simon Brown L.J. departs most obviously from the line taken by Latham J. In response to the question, "What interest of the patient is the law seeking to protect?," Simon Brown L.J. says:

In my judgment, the answer is plain. The concern of the law here is to protect the confider's personal privacy. That and that alone is the right at issue in this case. The patient has no proprietary claim to the prescription form or to the information it contains. . . . [The patient has] no property in the information and no right to control its use provided only and always that his privacy is not put at risk.<sup>106</sup>

So, insofar as the patient has a right to control the outward flow of personal information, this suggests that we should distinguish between: (a) information of which the person is a source, but which has been anonymised so that he cannot be identified with the information; and (b) information of which the person is a source and to which he can be linked and identified. According to Simon Brown L.J., the law need not worry about information in the former category; but the latter is protected information because it touches and concerns the person's privacy interest.

This decision has attracted considerable criticism.<sup>107</sup> At one level, as Graeme Laurie has put it, the Court of Appeal has "succeeded only in replacing the amorphous concept of public interest as a limiting factor on the existence of a duty with the equally unclear concept of fairness as a measure of the scope of the duty."<sup>108</sup> Moreover, in responding to the question of fairness, the court, by treating privacy (narrowly understood) as the only interest at stake,

ignores other perfectly valid claims that individuals might make over their personal information. These might emerge either as part of a richer concept of privacy, or as an aspect of individual autonomy, or indeed as a reflection of a property interest that individuals might have in their own information. But, having delivered a minimalist view of privacy, the court rejected out of hand any prospect

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105. *Source Informatics*, [2001] Q.B. at 439 (C.A. 1999).

106. *Id.* at 440.

107. See Deryck Beyleveld & Elise Histed, *Betrayal of Confidence in the Court of Appeal*, 4 *MED. L. INT'L* 277 (2000).

108. LAURIE, *supra* note 4, at 225.

that individuals might have a property interest in personal information, or that there might be wider autonomy issues at stake.<sup>109</sup>

If (contrary to the Court of Appeal) we were to take a proprietary approach, such as we might attribute to Latham J., we would need to distinguish between information that fell within a person's proprietary right and information that fell outwith that right. In *Source Informatics*, the patients put the information into circulation, just like a person who declares what their shopping preferences are puts that (marketing) information into circulation (the cases are comparable are they not, even if one class of information is typically more sensitive than the other?). Without this information, there would be no prescription and no marketing-relevant information to abstract. If the patient has a proprietary right in the information first put into circulation (because it is information about the patient's medical condition), then the patient must have the right to control the subsequent use of that information, *including the right to control whether or not the information is anonymised*. To say, as Simon Brown L.J. holds, that the patient cannot be harmed once the information is anonymised is, from a proprietary perspective, to miss the point: if the information is anonymised without the patient's consent, the harm has already been done.

Let us suppose, however, that we follow the Court of Appeal's non-proprietary approach. As we have said, such an approach invites classifying information according to whether or not the data subject can be identified. However, a simple two-category approach may fail to do justice to the practical complexities associated with anonymising data in general, and genetic information in particular.<sup>110</sup> At one end of the spectrum, we will have data that has been anonymised in such a way that there is absolutely no possibility of the data subject being identified; at the other end of the spectrum, we will have data that has not been anonymised; and, in between, we will have various degrees

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109. *Id.* at 225-26. Laurie treats confidentiality as a cousin of privacy. As for privacy, this has its roots in a moral value system which places considerable emphasis on the protection of the rights and interests of individuals and presupposes such social norms as respect for individuals. In this it is allied to the related concepts of liberty and autonomy, and all three combine to perform essentially the same function — they prescribe the way in which individuals are to be treated in Western society, and they operate to establish and maintain boundaries between the individual and society. *These constructs are all adjuncts to a view of human dignity that is prevalent in our society.*

*Id.* at 84 (emphasis added). Such a prevalent view of human dignity, it seems, is human dignity as empowerment.

110. See *INSIDE INFORMATION*, *supra* note 15, at ¶ 5.9.

There are particular problems with the anonymisation of DNA. Because an individual's unique identity is embedded within DNA, this identity could be revealed if an anonymised sample were matched up with another sample that has not been anonymised. Such situations are likely to be rare, but the possibility has to be borne in mind when addressing claims to anonymisation.

*Id.*

of anonymisation and potential identifiability. In its recent report, the Human Genetics Commission works with three categories of information — irreversibly anonymised, reversibly anonymised, and linked or personalised information — as follows:

Irreversible anonymisation entails breaking the link between the identifiable individual and the information in such a way as to prevent this ever being re-established. Reversible anonymisation involves giving samples and information a coded identity. This code can be linked with an individual's name, provided there is access to the original encoding. For practical purposes, a researcher dealing with coded data will not be able to link the data with any identifiable individual. By contrast, personalised [or linked] data still has its identifying information attached to it, and a researcher dealing with a sample of this nature will be able to tell from whom the sample or the information is derived.<sup>111</sup>

Of these three categories, irreversible anonymisation most protects the privacy interest. However, if there is any risk of cross-matching an irreversibly anonymised DNA sample with a sample that has not been so protected, the individual's identity could be discovered. In this light, the assumption in *Source Informatics* that, at least for the purposes of the hearing, the data could be, and would be, anonymised in such a way that there was no possibility of the patient's identity being linked to the data looks a touch too comfortable. On this (comfortable) assumption, the Court of Appeal was satisfied that there was no threat to the patients' privacy rights, and that sufficed to give the green light to the use of the data. However, if that assumption had not been made (and, in the case of genetic information, there is a real question mark about whether such an assumption can ever be made) so that the anonymisation did not carry such an identity-proof guarantee, how would the case have been decided? This is a question to which we will return shortly.

The second case, *A Health Authority*,<sup>112</sup> suggests a precautionary approach to the protection of privacy. There, a health authority, having grounds to investigate matters of malpractice at a NHS general practice,<sup>113</sup> sought disclosure of certain documents. The doctors concerned sought to co-operate by obtaining, as far as reasonably practical, the appropriate consents from their patients whose records would be passed over to the health authority. However, with two patients not giving their consent, the court's guidance was sought. In a careful judgment that, inter alia, explored the views of the European Court of

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111. *Id.* at ¶ 5.11.

112. [2001] 2 F.L.R. 673 (2001), *aff'd*, [2002] 1 F.L.R. 1045 (C.A. 2001).

113. The questions to be investigated related, inter alia, to over-dispensing medicines, inappropriate delegation of clinical responsibility, and consent to a sterilisation.

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Human Rights in similar cases,<sup>114</sup> Munby J. held that the records could be released, but subject to extensive restrictions designed to prevent the identity of the patients being disclosed. The Court of Appeal upheld this decision.

Munby J.'s starting point was noticeably defensive of the interests of patients in maintaining the confidentiality of their medical records:

[A doctor's] duty, like that of any other professional or other person who owes a duty of confidentiality to his patient or client, is to assert that confidentiality in answer to any claim by a third party for disclosure and to put before the court every argument that can properly be put against disclosure. All the more so when, as in the present case, he knows, because he has asked, that his patient or client is refusing to consent to disclosure.<sup>115</sup>

The (unsuccessful) argument on appeal was, essentially, that Munby J. had overstated the doctor's duty to his patient and that the free exchange of information within the health service would be disrupted if patient confidentiality were to be taken so seriously. As to the safeguards against abuse of confidentiality (in order to protect the privacy of the patient), Munby J. drew guidance from the jurisprudence of the European Court of Human Rights. Typically, the required safeguards are:

- (a) the maintenance of the confidentiality of the documents themselves — the documents should not be read into the public record or otherwise put in the public domain;
- (b) the minimum public disclosure of any information derived from the documents; and
- (c) the protection of the patient's anonymity, if not in perpetuity then at any rate for a very long time indeed.<sup>116</sup>

Adopting this guidance, Munby J. ordered disclosure of the documents, but on terms that, *inter alia*, required that all references to persons other than the doctors should be obliterated and that nothing should be published that might lead to the identification of the patients.

Recalling the different approaches to confidentiality in *Source Informatics*, would the two patients in *A Health Authority* who refused to consent to disclosure have any cause for complaint? If we followed the Court of Appeal's line in *Source Informatics*, we would say that, because the records were anonymised (indeed, scrupulously anonymised by virtue of the terms of Munby J.'s order for disclosure), there was not even a *prima facie* violation of the patients' privacy rights. However, if we took the most robust proprietary version of Latham J.'s approach in *Source Informatics*, we would say that disclo-

114. *See* *Z v. Finland*, [1998] 25 E.H.R.R. 371 (1997); *MS v. Sweden*, [1999] 28 E.H.R.R. 313 (1997).

115. *A Health Auth.*, [2001] 2 F.L.R. at ¶ 9.

116. *Id.* at ¶ 53.

sure without consent involved a prima facie violation of the patients' rights. It would not follow, even on this approach, that disclosure could not be justified. Justification, here, would depend on the strength of the competing rights (or public interests) on the other side; but, because of the proprietary nature of the patients' rights, the countervailing interests would need to be weighty. Significantly, though, on this latter approach, the fact that the records were anonymised and that the patients could not be identified could not in any sense assist the justification for disclosure — anonymisation would be seen as being beside the point.

If the two non-consenting patients in *A Health Authority* were to put their case in terms of a protected interest in human dignity, how would this play? Would it be plausible for them to argue that they were seeking protection of a species of property?

Whilst one of the articles of faith of dignity as constraint is that it compromises human dignity to recognise property in the body or body parts (at any rate, where the body or its parts might be commodified or commercialised),<sup>117</sup> dignity as empowerment starts from a different, potentially permissive, position. We can defer further discussion of this permissive potential, however; for, in the next part of the paper, we discuss the question of whether we might recognise property in tissue or samples that hold the key to genetic information. Suffice it to say, here, that if we were to take a property approach then (i) property in our own body parts would seem to entail property, too, in the genetic information about ourselves held in those body parts; and (ii) the tough points concerning degrees of anonymisation would not be relevant.

If we take a non-property approach, the scope of the privacy right has to be clarified and, at the same time, the costs associated with minimising the risk of identification have to be addressed. However, the thrust of dignity as empowerment must be towards precaution.<sup>118</sup>

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117. This is reflected in Article 21 of the European Convention on Human Rights and Biomedicine, which provides that “[t]he human body and its parts shall not, as such, give rise to financial gain.” See *infra* section IV(C). More specifically, Article 4 of the UNESCO Universal Declaration on the Human Genome and Human Rights provides that “[t]he human genome in its natural state shall not give rise to financial gains.”

118. Precaution also requires us to consider “access to justice” issues. As the Human Genetics Commission points out,

in most cases, people concerned about a breach of confidentiality will be unwilling or unable to engage in complex and expensive legal actions. They may, of course, use complaints procedures, which provide some degree of remedy. In practice, redress for a breach of confidence, either through the courts or complaints procedures will be expensive, time-consuming, and may provide satisfaction in only a few cases.

INSIDE INFORMATION, *supra* note 15, at ¶ 3.42. We might interject that headline-making claims by celebrities such as Michael Douglas and Catherine Zeta-Jones, *supra* note 7, and Naomi Campbell, *infra* note 122, encourage the view that actions for breach of confidence are, like the Ritz, “open to all.” This prompts the Commission to consider further protection through the criminal law. Although the Commission rejects the idea of an offence covering unauthorised

### 1. A Note on Data Protection

In the *Source Informatics* case, in addition to hearing argument on the question of breach of confidence, the Court of Appeal gave some consideration to the potential bearing on the issue of European data protection principles.<sup>119</sup> At the heart of these principles is the European Community Data Protection Directive,<sup>120</sup> which regulates the processing of personal data, requiring inter alia that such data be fairly and lawfully processed. Article 2(a) defines personal data as “any information relating to an identified or identifiable natural person (‘data subject’); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity”; and Article 2(b) defines the processing of personal data as “any operation or set of operations which is performed upon personal data, whether or not by automatic means, such as collection, recording, organization, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, blocking, erasure or destruction.” Article 8 regulates the processing of personal data concerning health. Crucially, processing of such data is not prohibited where the data subject explicitly consents (not so in *Source Informatics*) or where such processing “is required for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of health-care services, and where those data are processed by a health care professional.”<sup>121</sup> On the facts of *Source Informatics*, two questions arose from these provisions: (i) whether the act of anonymising the prescription information (which, pre-anonymisation, is clearly personal data) falls within the definition of processing; and (ii) whether, if so, such processing of personal data concerning health falls outside the prohibition in Article 8.<sup>122</sup>

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disclosure of personal genetic information, it is more attracted to a broader offence relating to breach of medical confidence (this applying to both genetic and non-genetic medical information). *INSIDE INFORMATION*, *supra* note 15, at ¶¶ 3.47-48.

119. *R. v. Dept. of Health ex parte Source Informatics Ltd.*, [2001] Q.B. 424, 428 (C.A. 1999).

120. Council Directive 95/46/EC, 1995 O.J. (L 281) 31.

121. *Id.* art. 8.3.

122. In the United Kingdom, the Data Protection Act 1998 (DPA) purports to implement the Directive. Although the Act, like the Directive, is designed to protect (informational) privacy and, where appropriate, balance privacy against other interests such as freedom of expression, its provisions are extraordinarily complex. Indeed, in the first case on its interpretation, Morland J. likened it to a “thicket.” *Campbell v. Mirror Group Newspapers*, [2002] EWHC 499, ¶ 72 (Q.B. 1999). On appeal in the same case, Lord Phillips MR described the Act as “a cumbersome and inelegant piece of legislation.” *Campbell v. MGN Ltd.*, [2002] EWCA Civ 1373, ¶ 72 (2002).

Briefly, medical data, qua information as to a person’s physical or mental health or condition, is brought by section 2(e) of the DPA within the special category of sensitive personal data. However, the head category of personal data is defined by section 1(1) in such a way that pre-

Despite being reluctant to give a definitive ruling on these questions, the court took the view that common sense and justice appeared to favour the line that an act of anonymisation would *not* count as processing.<sup>123</sup> Certainly, the natural reading of Article 2, reinforced by Recital 26 to the Directive (which states, *inter alia*, that “the principles of protection shall not apply to data rendered anonymous in such a way that the data subject is no longer identifiable”), is that data *once securely anonymised* is no longer protected data. This invites the argument that, if anonymised data is not personal data, then the act of anonymising personal data is not processing. And, the court seems to have accepted this argument. However, it is an argument that involves some sleight of hand. The key point to hold on to is that the data that is being anonymised is still personal data. In other words, we are talking about an act of some kind (if we call it an act of adaptation or alteration, it is explicitly covered by the definition of processing) being performed on personal data. Moreover, once the data has been anonymised, the data subject loses the protection of the data protection regime. It is arguable, therefore, that common sense and justice points to a precautionary approach here.

Why did the Court of Appeal not see the need for precaution? Presumably, the court continued to operate on the assumption that

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supposes that identification of the person to whom the information relates is possible; so, once what would otherwise be personal data is securely anonymised, it seems to fall outside the protection of the legislation.

Section 4(4) of the DPA provides that “it shall be the duty of a data controller to comply with the data protection principles in relation to all personal data with respect to which he is the data controller.” Schedule 1 sets out the data protection principles. The fundamental principle is that personal data “shall be processed fairly and lawfully and, in particular, shall not be processed unless (a) at least one of the conditions in Schedule 2 is met, and (b) in the case of sensitive personal data, at least one of the conditions in Schedule 3 is also met.”

Under section 13(1) of the DPA, “[a]n individual who suffers damage by reason of any contravention by a data controller of any of the requirements of this Act is entitled to compensation from the data controller for that damage.” And, under section 13(2), provision is made for compensation for *distress* caused by reason of such a contravention if damage has also been suffered or if the contravention relates to the processing of personal data for journalistic, literary, or artistic purposes.

In *Campbell*, which was the first case of its kind in England, Morland J. awarded the fashion model £2,500 damages (plus £1,000 aggravated damages) for distress occasioned by the newspaper’s publication of stories and pictures concerning her attendance at meetings of Narcotics Anonymous. The claim was successful both under common law breach of confidence and under section 13(2) of the DPA. However, this decision was reversed by the Court of Appeal. Here, it was conceded that Campbell “by mendaciously asserting to the media that she did not take drugs, . . . had rendered it legitimate for the media to put the record straight.” *Campbell*, [2002] EWHC at ¶ 36. In other words, it was conceded that the newspaper did not breach confidentiality or infringe privacy *simply* by reporting that Campbell had a drug problem. Given this concession, the court ruled that the context surrounding the core story was either not significant or justifiable as a matter of journalistic presentation. As for the parallel claim under the DPA, it held that the exemption for journalistic material (in section 32 of the DPA) applies to both collection and publication and that, on the facts, the exemption applied because the newspaper reasonably believed that publication was in the public interest. Rising above the detail, the court’s approach seems to have been that the newspaper (as Campbell conceded) was entitled to put the record straight, and that the journalistic package by which it had done this was reasonable enough. *Id.* at ¶ 38.

123. *Source Informatics*, [2001] Q.B. 424 (C.A. 1999).

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the patients' only interest was in their privacy. On this premise, the act of anonymising the prescription information would not harm the patients — hence a precautionary approach backed by a robust interpretation of “processing” was unnecessary. If, however, we think that the patients might have other interests at stake, bearing on the use to which the prescription information might be put (albeit in an anonymised form), then this presents the issue in a different light. And, from the perspective of human dignity as empowerment, the interest of the patients in having some choice and control about the use of their prescription information (whether for commercial or non-commercial purposes) cries out for recognition.

B. *Regulating the Inward Flow of Genetic Information:  
A Right Not to Know?*

The idea of a “right not to know” is a relatively novel one, but it is already debated in the literature and, indeed, it is recognised in various international instruments. For instance, Article 10(2) of the Convention on Human Rights and Biomedicine provides that “the wishes of individuals not to be so informed [i.e. about their health] shall be observed.” Article 5(c) of the UNESCO Universal Declaration states that “[t]he right of each individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected.” However, what is the scope of such a right?

Putting the issue in the context of a woman fearing that she might have the Huntington's gene, Laura Purdy offers a plausible approach to the matter:

Some people think that we should recognize a right “not to know.” It seems to me that such a right could be defended only where ignorance does not put others at serious risk. So if people are prepared to forgo genetically related children, they need not get tested. But if they want genetically related children, then they must do whatever is necessary to ensure that affected babies are not the result. There is, after all, something inconsistent about the claim that one has a right to be shielded from the truth, even if the price is to risk inflicting on one's children the same dread disease one cannot even face in oneself.<sup>124</sup>

This approach might be generalised to other contexts (for example, that of employment) so that the right not to know should be respected provided that others are not exposed to risk. Where the implications of a genetic test concern only the party tested, the right not to know would mean that the test itself would be optional; and, where the implications potentially affect both the party to be tested

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124. Purdy, *supra* note 23, at 127-28.

and others, then the option would not be as to the test itself, but as to being informed (or not) about its results.

To recognise a right not to know involves a considerable turn-about in tort regimes that have been shaped around the principle of *informed* consent.<sup>125</sup> Tort regimes, at any rate in the health care context, are designed to secure that information is given, not withheld. It is true, of course, that such regimes also recognise a “therapeutic privilege,” protecting physicians against liability where they have withheld information that they judge not to be in the patient’s best interests to have.<sup>126</sup> However, if we recognise a right not to know, this goes a good deal further, implying that the physician (and others) have a duty not to inform, or a duty to take care not to inform where the rights-holder has indicated a wish not to know (cf. an advance directive). In other words, we are contemplating more than an occasional *permission* not to inform, but an occasional *duty* not to inform. And, indeed, in some legal systems (but not in the UK), there is already liability where a health care professional “over-informs” another.<sup>127</sup>

How might such a duty *not* to inform operate? We might start by reasoning that, in principle, the relevant party might be information-averse, information-neutral, or information-eager. If we are to adopt a default position, which of these information attitudes should we take to be typical? Perhaps we can be more focused. For example, if the information concerns a genetic condition for which there is currently no treatment or preventive action, the person who is given this information might respond in more than one way. Some might welcome the opportunity to plan around the genetic condition, but others might be distressed and would prefer not to have known. All things considered, we might judge that a default position protecting the right not to know is appropriate in this class of case. On the other hand, if the information concerns a genetic condition for which there is some treatment, or in relation to which preventive action can be taken, we might think that a different default position is appropriate. Granted, even here, those who are given the information will not react in a uniform way; some will be positive, others negative. Nevertheless, we might judge that, all things considered, where the recipient of the information will have the option of protecting his or her well-being (in light of that information), and assuming that this option would not

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125. See generally, RUTH R. FADEN & TOM L. BEAUCHAMP, *A HISTORY AND THEORY OF INFORMED CONSENT* (1986).

126. Of course, as the doctrine of informed consent gains ground and becomes associated with patient autonomy, the scope of the therapeutic privilege is narrowed. So, for example, in a high-water informed consent case such as *Canterbury v. Spence*, 464 F.2d 772, 789 (D.C. Cir. 1972), the exception applies only if “risk-disclosure poses such a threat of detriment to the patient as to become unfeasible or contraindicated from a medical point of view.”

127. See LAURIE, *supra* note 4, at 272.

otherwise be available, then the default position should not expose informers to liability.<sup>128</sup> Clearly, though, if the informer is aware that the potential recipient would prefer not to know, then that special knowledge would change the default position.

Perhaps an attempt to articulate relatively straightforward (strict liability) default rules along the lines just indicated is not the best way of handling the problem. Perhaps the basic liability rule should be that informers are to compensate recipients where they have failed to take reasonable care in bringing unwanted information to the latter's attention. Objectively, factors such as the current (or imminent) availability of therapies, the degree of risk, the immediacy of the risk (i.e., when is the adverse condition likely to materialise?), and so on would need to be taken into account. Subjectively, it would be a matter of whether the informer knew that the recipient would prefer not to know or would react badly or the like. This approach would offer some general guidance but, in the end, the reasonableness of the informer's actions would be judged in the circumstances of each case. Let us try some test cases.

### 1. Test Case One

Alice, who is pregnant, is aware that there has been a history of Huntington's disease in her family. She is worried that her baby might have the Huntington's gene. If it does, she would want to terminate the pregnancy. However, Alice does not wish to know whether she herself has the Huntington's gene.<sup>129</sup> In fact, Alice very definitely does *not* want to know about her own condition. Her medical advisers believe that, in the present state of the art, two types of test can be carried out: a mutation test<sup>130</sup> which will establish conclusively whether or not the fetus has the defective gene on chromosome four, or an exclusion test<sup>131</sup> which is a linkage test targeting genetic markers that are close to the site of the mutation. Whereas the mutation test is designed to establish whether or not the fetus has the defective gene, the exclusion test is designed to establish whether or not a chromosome four from the affected side of Alice's family has been transmit-

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128. But, what about the case where A withholds information thinking, *wrongly*, that B would rather not know? Is A to be liable to B for mistakenly acting on B's right not to know? If not, where the default position permits disclosure (by shielding informers against liability) it must also permit non-disclosure (by shielding non-informers against liability).

129. For a Gewirthian analysis, see Deryck Beyleveld et al., *Generic Consistency in the Reproductive Enterprise: Ethical and Legal Implications for Exclusion Testing for Huntington's Disease*, 3 *MED. L. INT'L* 135 (1998).

130. See B. Bonke et al., *Favourable Mutation Test Outcomes for Individuals at Risk for Huntington Disease Change the Perspectives of First-Degree Relatives*, *HUMAN GENETICS* 111 (2002).

131. A. Tyler et al., *Exclusion Testing in Pregnancy for Huntington's Disease*, 27 *J. MED. GENETICS* 488-95 (1990).

ted to the fetus. In relation to the right not to know, the difference between these two tests is extremely significant. If the result of a mutation test is negative, there are no implications for the status of the mother; but, if the result is positive, the mother will have the Huntington's gene. By contrast, whatever the result of the exclusion test, whether positive or negative, there are no implications for the mother — she already knows that she is at risk, and irrespective of the result of the exclusion test, she will know no more and no less than this about her own status. If Alice is to prioritise her interest in not knowing whether she has the Huntington's gene, she will opt for the exclusion test.

Is there any problem with Alice opting for the exclusion test? The concern about this test is that, with a positive result, Alice will terminate the pregnancy. Understandably, she does not want to take the chance that she will pass on the Huntington's gene (if she has it). However, the exclusion test only establishes whether or not the fetus is at risk. It is perfectly possible, therefore, that Alice will elect to abort a fetus that does not actually have the Huntington's gene. Accordingly, the price that is paid for respecting Alice's right not to know is that we might abort a fetus that is perfectly healthy. In a legal system such as that in the United Kingdom, where the law permits the abortion of perfectly healthy fetuses on so-called "social grounds," this would be relatively unproblematic; however, in legal systems where abortions are only permitted in exceptional circumstances (or not at all), this would be a complication.

Should the law require the doctors to inform Alice about the full range of the testing options, including exclusion testing? Would it be a breach of Alice's right not to know if the doctors failed to give her the opportunity to have an exclusion test? If so, we are treating the duty not to inform as including a duty to take reasonable steps to avoid situations where there is a risk of the unwanted information being communicated. Ironically, in Alice's case, this means that Alice must be given information about the testing options in order to protect her right not to be informed as to her genetic make-up.

As a rider to this first test case, consider the following hard case as formulated by Graeme Laurie:

If a health care professional is aware of a genetic disorder in a family through tests on patient A, yet does not wish to offer a pre-natal test to pregnant patient B, a relative of A, for fear of alerting her to A's afflicted status, if no test is done and a baby is born with a debilitating condition, might an action lie in negligence?<sup>132</sup>

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132. LAURIE, *supra* note 4, at 270.

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Let us suppose that, as a result of their dealings with Alice, her doctors are aware that there is a risk that she has the Huntington's gene. Alice's doctors are now looking after one of her relatives, Betty, who is either thinking about starting a family or is already pregnant. Unlike Alice, Betty is not aware that there is a history of Huntington's in the family. If the doctors decline to put Betty on notice as to the risk she might be running with her present or future pregnancy, they will respect the confidential information that they have about Alice, as well as (arguably) respecting Betty's right not to know. However, if the doctors so withhold the information, and if Betty's child has the Huntington's gene, might they be liable in negligence to Betty? Without being able to erect Chinese walls between Alice and Betty, is there any practical way out of this dilemma for the doctors? If not, whose interests, those of Alice or those of Betty, should be prioritised?

## 2. Test Case Two

Bob applies for a job. He is required to take a genetic test in order to establish whether he has a susceptibility to any occupational disease arising from his employment. Bob agrees to take the test, but he notifies his prospective employer that he does not wish to know the result. Is there any reason why the employer should not be under a duty not to inform Bob as to the result?

Suppose that Bob's test result is positive. His employer takes reasonable care to prevent Bob having access to the results. Nevertheless, in light of the arrangements made for Bob at work, he is able to make an educated (and correct) guess that his result is positive. Is the employer liable? Would the employer be liable if Bob confronted him with his educated guess, and, with the employer refusing to confirm or disconfirm Bob's best guess, Bob took the employer's refusal as a confirmation? In such a case, the employer seems to be in an impossible position: if he confirms Bob's guess, he might be liable (unless Bob's conduct is taken to be a consent to being informed); if he refuses to respond, he might be liable for the inference drawn from his silence; and, presumably, "telling a white lie" is not an option.

Again, suppose that Bob tests positive and that there are precautionary measures that an employer could take in order to provide a safe system of work for Bob. However, these measures cannot be implemented without Bob's knowledge and cooperation. If, in order to respect Bob's right not to know, the employer declines to take such

precautionary measures, does Bob waive the standard negligence claim that he would have in such circumstances?<sup>133</sup>

### 3. Test Case Three<sup>134</sup>

Carol, a woman in her thirties, is conscious that there has been a lot of breast cancer in her immediate family. She is asymptomatic, but she nevertheless seeks genetic testing. The result shows that she has the BRCA1 gene, which is thought to be responsible for some five to ten percent of female breast cancers. Carol decides that she will have a full mastectomy as a precautionary measure, but she does not know what she should say to her younger sister Doris who is prone to bouts of depression; nor does she know whether she should advise her elder cousin Ethel. Carol decides to tell Ethel but to try to conceal what is happening from Doris. In the event, Ethel is badly upset by this news and tells Carol that she would rather not have known; and, despite Carol's attempts to conceal the facts from Doris, the latter finds out what is going on anyway. Is Carol in breach of a duty not to inform Doris and/or Ethel?

Does an interest in human dignity support a right not to know?<sup>135</sup> Given human dignity as empowerment, the paradigm, surely, is a case where one person, A, has made it unequivocally clear to another, B, that he or she does not wish to have genetic information of any kind or of some specified (limited) kind (for example, information about a genetic condition for which there is no therapy, or information about a risk that is not imminent, and so on). Where the potential informant has an advance directive of this kind, then to insist on giving the information notwithstanding seems to be a clear failure (whether maliciously or with the best of intentions) to respect the choice made by the recipient and, with that, a failure to respect the recipient's dignity.<sup>136</sup> In this sense, dignity as empowerment, possibly supported by

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133. Cf. *INSIDE INFORMATION*, *supra* note 15, at ¶ 8.20. The Human Genetics Commission reports an argument that was put to it to the effect that an employer has a duty of care *not* to employ a person whose genotype makes them more susceptible to lead. This argument was based on *Paris v. Stepney Borough Council*, [1951] A.C. 367 (H.L. 1950), where an employer who failed to supply goggles and insist upon their use by a one-eyed mechanic was held liable in negligence. The Commission is not inclined to respond to susceptible genotypes by discriminating against them. However, it concedes that there are issues here calling for fuller consideration. Compare *INSIDE INFORMATION*, *supra* note 15, at ¶¶ 8.19-8.23 with *NUFFIELD COUNCIL*, *supra* note 31.

134. For a not dissimilar scenario, see *LAURIE*, *supra* note 4, at 239.

135. Laurie argues that the right not to know is best supported by an extended conception of privacy. However, he says that "it is entirely meaningful to ground privacy in the same value system as autonomy and, indeed, confidentiality — that is, respect for persons and their dignity." *Id.* at 248.

136. Compare Goldstein, who says that respect for dignity amounts to "respect for the individual's competence and right to determine for himself what he needs to know (*including that he does not want to know anything*) in order to choose what he thinks is best for himself." Goldstein, *supra* note 30, at 686 (emphasis added).

the old case of *Wilkinson v. Downton*,<sup>137</sup> underpins a protected right not to know where that election has been clearly signalled; and it would only be if the informer was seeking to protect a more compelling right of another agent that giving the information could be justified (as the lesser of two evils). Moreover, in a case such as Alice's, the legally protected right not to know would also imply a right to be informed as to options that would avoid the relevant (unwanted) information being given. What, however, of those cases where no such signal has been given?

First, what does respect for human dignity indicate in cases where we do not know whether the recipient would wish to assert the right not to know? And, secondly, what does it indicate about cases where the information is communicated inadvertently?

With regard to the first question, the law might follow the kind of track taken by medical law where, when consent cannot be obtained, a test based on "best interests" or "substituted judgment" is applied. However, to keep faith with human dignity as empowerment, any test of this kind would need to hang on to the fact that the choice to inform or not is being made in relation to a functioning agent who is perfectly capable of making his or her own choices. So, for instance, in Carol's case, we must not treat Ethel as though she is not an agent (because she quite clearly is), nor must we allow Carol simply to transfer her own preferences to Ethel (whether in the form of Ethel's supposed best interests or a substituted judgment as to what Ethel would choose in the circumstances). On the other hand, it would be harsh indeed if the law required Carol to compensate Ethel when she had agonised about the matter and eventually taken the action that she thought right in the circumstances. This would also be an open invita-

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137. [1897] 2 Q.B. 57 (1897) (allowing plaintiff recovery for shock induced by a statement made to her by the defendant). Reliance on *Wilkinson*, which itself was a case without precedent, looks most plausible if it is taken broadly (as in some parts of the common law world) as supporting compensation for distress caused by "extreme and outrageous conduct." However, the closer that the claim is required to fit the facts of *Wilkinson*, the more difficult reliance becomes.

In *Wilkinson*, the material facts were (i) that the content of the statement was "shocking," the defendant telling the plaintiff that her husband had been injured in an accident; (ii) that the statement was actually untrue but the plaintiff reasonably believed it to be true; (iii) that the defendant intended the statement as a practical joke; (iv) that the statement foreseeably shocked the plaintiff; and (v) that the statement actually caused such psychological harm to the plaintiff. *Id.* at 57. Notwithstanding the defendant's joking intention, Wright J. ruled that, by imputation, the statement must be treated as one calculated to produce a harmful effect on the plaintiff. *Id.* at 59. Applying this to the right not to know, the hypothetical case is stronger than *Wilkinson* to the extent that the statement is true (not simply believed to be true) and should the transmission of the unwanted information be calculated to produce harm or distress. However, where the information is intended to be beneficial rather than harmful, we would need to decide whether well-intentioned but ill-judged disclosure could be likened to an irresponsible practical joke.

If we are to be guided by recent precedents, the indications are that the courts are inclined to read *Wilkinson* very restrictively against claimants. See *Home Office v. Mary Jane W.*, [2002] Q.B. 1334, ¶¶ 41-51 (Lord Woolf, C.J.), ¶ 64 (Buxton, L.J.) (2001); *Wong v. Parkside Health NHS Trust*, [2001] EWCA Civ 1721 (2001).

tion for disingenuous claims to be brought forward by parties alleging that the receipt of unwanted information has distressed them. In light of these considerations, perhaps the appropriate legal test is one that hinges on whether the informer has acted in good faith, believing that the information transmitted will be judged by the recipient as relevant to its agency. If the informer satisfies this test, there can only be liability if the recipient shows that no reasonable agent could have so acted and so judged in the circumstances. Where the informer is following a professional code of practice or the like, the proposed test would almost certainly result in a denial of liability.

Turning to the second question, inadvertent communication might arise (a) in a context in which the source of the information knows that the recipient does not wish to know or (b) in a context in which the state of mind of the recipient is unknown. In both contexts, the assumption is that the informer has taken reasonable care to prevent the information getting through to the recipient. Whether or not the standard of care in the former context should be more demanding than in the latter, is a matter for debate; and, in a typically tort-like way, one can imagine that questions about standard and duty and foreseeability will become entangled as judges work from case to case, claim to claim. However, whatever the resolution of this point and its attendant questions, the principle seems clear: the informer has a duty to take reasonable care and, provided that such care has been taken, there can be no liability.

#### IV. PROPERTY IN ONE'S OWN BODY: KEEPING IN CONTROL OF THE KEYS TO GENETIC INFORMATION

As we have seen, there is some support for the idea that we each have *proprietary* rights in relation to information about ourselves. If it is plausible to think that we might have proprietary rights of this kind, then it must include *proprietary* rights in relation to genetic information concerning ourselves; and, from this point, it is but a short step to arguing that we have proprietary rights to those parts of our body that hold information about our genetic make-up — which is to say that we must have such rights in relation to pretty much the whole, and any part, of our own bodies. Alternatively, we might arrive at the same overall conclusion from the opposite direction: that is to say, we might start with the premise that we have property in our bodies and body parts from which we infer that we have proprietary rights in our genetic information. Whatever our path to such thoughts, if we accept that we do have proprietary rights in our genetic information-yielding body parts, what would be the practical significance of such a position?

Where our bodies are intact, the right to physical integrity protects us against unauthorised attempts to access and use our bodies or any part thereof. We also need a right against enslavement to protect us against being treated lock, stock, and barrel as a mere commodity. To add proprietary rights might seem unnecessary. However, with the emergence of modern genetics, it is clear that removed body parts might be of commercial value. Once tissue has been removed without violating our rights, appeals to rights relating to bodily integrity or enslavement will not operate to give us control over how that removed tissue is used. In some contexts, we might retain control by special contract. However, the obvious way of arguing for tissue sources to have control over who has access to removed tissue, as well as the purposes to which that tissue and its derivatives might be put, is to recognise a covering proprietary right. If we do this, property-based torts, such as conversion,<sup>138</sup> will be available to the source to protect the particular interest in their personal property.

The practical consequences of recognising that we each have property rights in relation to those parts of our own bodies, whether intact or removed, that hold genetic information about us are of capital significance. As James Boyle has rightly observed, there are conflicting interests at stake here:

On the one hand, property rights given to those whose bodies can be mined for valuable genetic information will hamstring research because property is inimical to the free exchange of information. On the other hand, property rights *must* be given to those who do the mining, because property is an essential incentive to research.<sup>139</sup>

Predictably, therefore, there is a real pressure against recognising property rights of this kind, an opposition which can be put in either conceptual or normative terms. In short, is it conceptually coherent to recognise property in our own body parts; and, if so, do the moral arguments, especially the arguments from respect for human dignity, support or oppose such recognition?<sup>140</sup> We can start our discussion with that most familiar of cases, that of John Moore.

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138. In *MCC Proceeds Inc. v. Lehman Brothers International*, [1998] 4 All ER 675, 685-86 (C.A. 1997), it was agreed that conversion is a form of strict liability for any wrongful interference with the right to possession of a chattel. At common law, "conversion lies for any act of wilful interference with the chattel which is committed without lawful justification, is inconsistent with the right of another and operates to deprive that other of the use and possession of the chattel." 45(2) HALSBURY'S LAWS OF ENGLAND ¶ 542 (4th ed. 1999).

139. JAMES BOYLE, SHAMANS, SOFTWARE, AND SPLEENS: LAW AND THE CONSTRUCTION OF THE INFORMATION SOCIETY 24 (1996).

140. Some of the material in this section draws on earlier work co-authored by Deryck Beyleveld and Roger Brownsword. See Deryck Beyleveld & Roger Brownsword, *Articles 21 and 22 of the Convention on Human Rights and Biomedicine: Property and Consent, Commerce and Dignity*, in RESEARCH PROJECTS ON "BASIC ETHICAL PRINCIPLES IN BIOETHICS AND BIO-LAW" 33 (1998) (the Utrecht Working Papers for EU Project PL 950207); Deryck Beyleveld & Roger Brownsword, *My Body, My Body Parts, My Property?* 8 HEALTH CARE ANALYSIS 87-99 (2000); BEYLEVELD & BROWNSWORD, *supra* note 28, at 171-94.

### A. *The Case of John Moore*

The story in John Moore's case began in 1976 when he started having treatment for hairy cell leukaemia. Moore's doctors realised at an early stage that a cell-line established from his T-lymphocytes might be valuable commercially (through its ability to produce lymphokines). During the course of Moore's treatment, the doctors removed his spleen and other samples of tissue (which procedures were clinically justified). However, the doctors also developed a cell-line from Moore's spleen and samples on which, in 1981, the University of California obtained a patent, with the doctors listed as the inventors, and with the value of the potential products thought to be several billion dollars.

Crucially, at no time during this process did the doctors inform Moore that his tissue was commercially valuable, or that they intended to try to exploit it commercially. Consent to removal was obtained solely on the understanding that removal of his spleen was necessary to save his life. After the operation, further blood and other tissue samples were removed from Moore (which he was told were for tests), which were used for research and experiments to attempt to develop the desired cell-line, without informing him of any of these activities.

When Moore discovered what had happened, he filed suit (in 1984) in the California Superior Court against the doctors and the University of California, pleading: (1) breach of fiduciary duty or lack of informed consent; and (2) conversion (wrongful interference with his property), with the object of asserting a claim to a share in the profits generated by the patent. At first his legal action was unsuccessful. However, Moore appealed to the California Court of Appeals, which ruled in his favour.<sup>141</sup> By a majority, the court decided that Moore did own his cells. Two main reasons were cited:

- (a) The recognised rights and interests that persons have in their bodies are so akin to property that to call them anything else would be "subterfuge."<sup>142</sup>
- (b) Not to grant persons the right to control what happens to their tissue would lead to violations of rights to privacy and human dignity.<sup>143</sup>

On further appeal, however, the Supreme Court of California took a different view, ruling that Moore had no property rights in his cells, but that he had a case for breach of fiduciary duty (and this part of his claim was then settled out of court).<sup>144</sup> The main reasons given by the

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141. See *Moore v. Regents of Univ. of Cal.*, 249 Cal. Rptr. 494 (Cal. Ct. App. 1988).

142. *Id.* at 504-05.

143. *Id.* at 508.

144. See *Moore v. Regents of Univ. of Cal.*, 793 P.2d 479 (Cal. 1990).

supreme court against Moore's property rights (again by a majority) were:

- (a) that it was not necessary to recognise Moore's property rights to provide him with the appropriate remedy<sup>145</sup> (and, indeed, it would not be appropriate for the courts as against the legislature to decide on Moore's proprietary interest);<sup>146</sup>
- (b) that there was nothing unique about Moore's cells. Everyone has cells that produce lymphokines;<sup>147</sup>
- (c) to grant Moore a property right would inhibit medical research.<sup>148</sup>

With the Moore case highlighting both the commercial potential of tissue that might in an earlier time have simply been destroyed, and the questionable nature of proprietary rights in such tissue, we can look at the *conceptual* issue of *property* rights. In other words, what is the essence of a property right? And, is there any conceptual incoherence in recognising property in bodies and body parts even if, currently, rights in relation to such matter are not characterised in this (proprietary) way?

### B. *What is a Proprietary Right?*

The question of whether, in principle, an agent can have property in his or her own body, or its parts, is deeply contested in both legal and philosophical circles.<sup>149</sup> Nevertheless, most would accept that, where the institution of private property is recognised, then the existence of a proprietary right signals that the rights-holder has at least some of a set of certain (distinctively proprietary) entitlements — at least some of the sticks that, so to speak, comprise the property bundle — in relation to some particular property item.<sup>150</sup> Where a rights-holder has the complete set of distinctively proprietary rights (the equivalent of what Jim Harris calls “full-blooded ownership”),<sup>151</sup> then this will include having the right to control access to and use of the

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145. *Id.* at 501.

146. *Id.* at 493.

147. *Id.* at 490.

148. *Id.* at 494-96.

149. *See, e.g.*, STEPHEN R. MUNZER, *A THEORY OF PROPERTY* 37-58 (1990). Munzer rejects the “imperial” view that all body rights are property rights. Rather, he divides all body rights into “personal rights” and “property rights,” and then the latter are divided into weak and strong property rights. *Id.* at 48-49. Transferability is the key to property rights; and transfer for value (rather than gratuitous transfer) is the key to strong property rights.

Most body rights are personal rather than property rights; examples are rights not to be murdered, not to be searched without a warrant or just cause, not to be compelled to testify against oneself, not to be libeled or slandered, to speak freely, and to exclude others from sexual or other physical contact. Some body rights are property rights whether weak, such as the right to donate an organ upon death, or strong, such as the right of publicity or the right to sell blood or semen . . . .

*Id.* at 57.

150. *See, e.g.*, J.W. Harris, *Who Owns My Body?*, 16 *OXFORD J. LEGAL STUD.* 55, 59-62 (1996).

151. *Id.* at 59.

property in question. The implication of this conception is that questions about the range of entitlements that can belong to the set of (distinctively) *proprietary* rights, and about the items to which such proprietary rights can be applied, are to be answered by reference to what is commonly accepted and recognised — that is, by reference to prevailing conventions. However, if we rely exclusively on prevailing conventions, we will beg our question: in some places, conventions will favour a property analysis, in other places they will not — but, as with all convention-dependent methodologies, ultimately, so what? For this reason, we must try at least to go deeper than our surface conventions.

The first thing to say is that, whatever the substantive entitlements that go with property rights, as rights they are distinctively “exclusionary” and, more controversially, as *property* rights they function in a “preclusionary” manner. Dealing with the exclusionary aspect of property rights, I take it that in any context in which A has proprietary rights over x, then this signifies that A is entitled to exert “control” over x, in the sense that A is entitled to regulate access to, as well as the use and disposition of, x. Here, if B purports to exercise control over x without A’s consent, then B’s unauthorised taking, or use, or disposition of x violates A’s prima facie rights in relation to x. At two levels, it is clear that proprietary rights are “exclusionary.” At one level, property rights *qua rights* are exclusionary in the sense that they override lower-ranking practical reasons; and, at another level, property rights *qua property* are exclusionary in the sense that the substance of the entitlement is such that the rights-holder is able to exclude others (from having access). Yet, this does not fully capture the distinctive nature of *proprietary* rights. What we are missing is the preclusionary element of A’s entitlement.

Let us suppose that A has no need of, or use for, x. Let us suppose, in other words, that x is surplus to A’s requirements. Thus, although B’s unauthorised exertion of control over x will harm A in the sense that it will diminish or subtract from A’s property holdings, such diminution or subtraction does not otherwise harm A — there is, so to speak, no consequential practical detriment to A. Nevertheless, our deep sense of a property right suggests that the fact that x is surplus to A’s requirements is irrelevant to A having proprietary rights over x and to their prima facie violation (recall, indeed, that trespass is actionable without proof of damage). But, what if, whilst A has no need of, or use for, x, B has a pressing need to have x? Is this material to whether A has property in x and to whether B’s unauthorised taking constitutes a violation of A’s prima facie property right over x? Again, it seems that it is not. To be blunt, if A has proprietary rights

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over more food than he requires, and if B is a starving man, B will violate A's prima facie rights by taking a loaf of bread from A without A's consent.

The import of all this is that those who have proprietary rights, such as A, can assert their prima facie entitlements without having to justify their actions by reference to the avoidance of harm in relation to either their own requirements or the requirements of others. Property rights, that is to say, are "preclusionary" in the sense that prima facie property entitlements can be claimed without the rights-holder having to assert his own requirements and without consideration having to be given to the requirements of others. It is enough for the property holder to say, "This is mine": preclusion signifies that no further reason need be given. This does not mean that the respective requirements of the rights-holder and of others may not eventually have to be arbitrated where conflicting rights are at issue; however, so far as the prima facie proprietary entitlement is concerned, the right is distinctively preclusionary.

If this idea that preclusion is fundamental to our conceptual understanding of property is accurate, then such entitlements belong most appropriately in situations where it is enough for the rights-holder A to say simply: "x is my property; I do not give my consent; and whether or not I, or anybody else, requires x is beside the point." If we accept that A can say this to the starving man who needs one of A's surplus loaves, is there any reason why we should not also accept that A can say this to B who needs some part of A's body? In other words, once we have picked out the distinctively preclusionary nature of proprietary rights, it seems singularly inappropriate to deny property in our own body parts.

The second point to make is that any conventional view of property will need a general justifying theory to support the institution of private property. Theoretical support of this kind might be sought in a variety of moral traditions. However, as I have said already, I am treating Alan Gewirth's moral theory<sup>152</sup> as the best justifying (normative) theory available.<sup>153</sup> This means that the justification for the institution of private property in general, as well as any defence of its specific features, must be compatible with the Principle of Generic Consistency (PGC), the supreme moral principle within Gewirth's theory. It follows that any adequate justification of property and property-related entitlements must accord with the PGC's demand that each agent's generic rights to freedom and basic well-being are respected. What, though, might such a justification look like? We can

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152. See ALAN GEWIRTH, *REASON AND MORALITY* (1978).

153. See, e.g., BEYLEVELD & BROWNSWORD, *supra* notes 25, 28.

take our lead from Gewirth's own PGC-based general justification of private property.<sup>154</sup>

Gewirth's general justification for private property involves a combination of what he calls "consequentialist" and "antecedentalist" considerations. Thus:

One kind of PGC-based justification of property rights is *consequentialist*; it bears on the consequences, for persons as prospective purposive agents, of their having such legal rights; or, in Aristotelian terms, it concerns the final cause, the end or purpose served by persons' having property rights. A second kind of justification is *antecedentalist*; it bears on the antecedents, the prior conditions and work activities that determine who has property rights to what; or, in Aristotelian terms, it concerns the efficient cause, the generating process of work that leads to the acquisition of property rights.

Although the two justifications have complex contents and backgrounds, they can be correlated in a general way with the two kinds of necessary goods that are the objects of the human rights. The consequentialist justification derives from the well-being that is the substantive generic feature of action and generally successful action, and that focuses on the purposiveness, the purportedly good consequences or results aimed at by action. The antecedentalist justification derives from the freedom that is the procedural generic feature of action and that focuses on the voluntariness of action, the agent's initiation and control of her behavior. Both freedom and well-being, however, enter into the contents or objects of each kind of justification. And each kind serves both to raise questions for the other and to limit the other, so that neither justification taken by itself establishes conclusive rights to private property.<sup>155</sup>

The gist of the consequentialist justification is that "property rights serve the final cause of providing the conditions for generally successful action and indeed, to an important degree, for purposive action as such."<sup>156</sup> Standing alone, however, the consequentialist justification is compatible with PGC-violating economic inequality; it is also "compatible with complete passivity on the part of persons whose needs are fulfilled"<sup>157</sup> (breaching ideas of productive agency and mutuality that are central to Gewirth's idea of ethical individualism); and, an appeal to generally beneficial consequences (in relation to the generic conditions) does not assist with justifying the particular property holdings that particular agents have. In response to these deficiencies in the consequentialist justification, Gewirth relies on an antecedentalist justification, at the core of which is what he calls "the purposive-labor thesis of property."<sup>158</sup> Gewirth introduces this thesis in the following terms:

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154. See ALAN GEWIRTH, *THE COMMUNITY OF RIGHTS* 166-213 (1996).

155. *Id.* at 169.

156. *Id.* at 171.

157. *Id.* at 201.

158. *Id.* at 184 (emphasis omitted).

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The labor justification [theory] of property rights through the generic rights of agency has its deeper basis in the nature of purposive action itself. The reference to purpose serves to connect, at an elemental level, the efficient-cause justification of property rights with the final-cause justification. Since it is by A's own efforts that X is produced or made available in ways that do not harm any other persons, and since A's direct purpose in so producing is to have X as her own thing either as a use value or an exchange value, to say that A does not have a property right in X would be to say that A's purpose in so acting may rightly be frustrated. But this, when generalized, would be an attack on the whole purposiveness of human action and hence on human agency itself. For all human action is performed with a view to achieving the respective agents' purposes; and such action is morally permissible insofar as it does not violate the generic rights of other persons. It follows that persons have property rights in things they have produced for the purpose of having such rights.<sup>159</sup>

As for the antecedentalist justification and mere passivity, Gewirth says:

To be one's own productive agent, so far as possible, rather than being the passive recipient of the agency of other persons, is required by the PGC as the principle that aims to secure the effective rights of purposive agency and autonomy for all persons, and with them *the ethical goods of dignity and self-respect*.<sup>160</sup>

Combining the two lines of justification, Gewirth outlines what he calls "a minimally ideal property situation," in which agents are both the efficient and final causes of their property rights.<sup>161</sup> In such a situation:

Each person is the productive agent of the goods that fulfill his agency-needs, so that each person is self-reliant and economically autonomous. No one needs assistance from others except to help maintain a stable, legally ordered system. We have here an instantiation of an essential part of the PGC's requirements: Each person, both as efficient cause and as final cause, acts in accord with his own rights to freedom and well-being without violating any other persons' rights.<sup>162</sup>

So much for the beginnings of a general justifying conception of property, but what would such a conception dictate with regard to the question of whether an agent can have property in his own body and body parts?

Gewirth touches on this question obliquely when considering the Lockean argument that agents must have property in the fruits of

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159. *Id.* at 183-84.

160. *Id.* at 201 (emphasis added). "So rights, far from being antithetical to community, supply the contents that the community uses to enable all persons to mutually help one another to meet their respective needs of agency and thereby to live lives of dignity as purposive autonomous agents." *Id.* at 213.

161. *Id.* at 202.

162. *Id.*

their labour because persons own, or have property in, themselves.<sup>163</sup> Rejecting this argument, and preferring instead his own purposive-labor thesis, Gewirth's principal reservation is that we should be slow to put property in our own bodies on a par with property in the things that we produce. For, there is an argument that "if it is permissible to remove, by taxation, part of what one has produced, so that one's ownership of this part ceases (even without one's explicit consent), then it would also be permissible to remove part of one's self, such as, for example, one's eyes or kidneys, without one's consent, if these can be used to help persons who lack these organs."<sup>164</sup> However, as Gewirth points out, this argument

ignores the vital difference between one's self with its bodily parts and one's holdings in external things. If some of the former are removed this may drastically decrease or even endanger one's overall well-being. But this need not be the case if some of one's external goods are removed by taxation, especially where one retains sizable amounts of such goods. More generally, one's bodily parts are literally parts of oneself and parts of one's personhood as an actual or prospective agent, in a way that is far more intimate and direct than is the case with any external things.<sup>165</sup>

How far do these remarks take us if we apply them directly to the proposition that, in principle, agents can have proprietary rights in their own bodies and body parts?

First, the taxation argument has no weight against recognising property in the body or its parts. Gewirthian morality puts agents under a duty to assist others where the latter are unable to achieve the generic conditions of agency and where the particular acts of assistance are at no comparable cost to the assisting agent. Taxation to finance welfare benefits is a case in point; but, in principle, the duty to assist covers donating parts of the body (most easily discharged, perhaps, by donating blood).

Second, and related to the first point, the fact that removal of some of one's bodily parts may endanger one's well-being, does not entail that there can be no property in one's own body. It simply highlights that the "at no comparable cost" proviso can come into play quite quickly where removal or donation of body parts is concerned.

Third, it is true, as Gewirth puts it, that "one's bodily parts are literally parts of oneself and part of one's personhood as an actual or prospective agent, in a way that is far more intimate and direct than is the case with any external things."<sup>166</sup> From this, it might be tempting to argue that property presupposes some "distance" between person

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163. *Id.* at 186-94.

164. *Id.* at 187.

165. *Id.* at 187-88.

166. *Id.*

and thing. But, there are too many counter-arguments to overcome. For example, as we have suggested already, the preclusionary aspect of property rights points to our own bodies as the most natural object of such rights; the “distance” argument does not apply to *removed* body parts; and, if we recognise various forms of intellectual property (property in our ideas), is it not arbitrary to insist upon “distance” when it comes to property in body parts? Again, if the argument is that “the more intimate something is the less suited it is to be the subject of a property right,” then, as Stephen Munzer has argued, this hardly tallies with the recognition that we can transfer our blood or semen by way of gift or sale.<sup>167</sup> More importantly, quite apart from existing conventions, there is nothing in the PGC that suggests that property rights presuppose any such distance or lack of intimacy.

Fourth, if we recur to Gewirth’s general justification for the institution of private property, we should be considering whether consequentialist or antecedentalist arguments work in relation to property in body parts. So far as consequentialist arguments are concerned, we need to ask whether recognising a particular set of property rights in body parts would damage the conditions in which agents would enjoy respect for their freedom and well-being. We should not leap to the conclusion, of course, that property in body parts would entail commerce in body parts which, in turn, would lead to the exploitation of the vulnerable. Property rights, as we have said, imply a number of entitlements; commercial exploitation is just one of the standard entitlements, and we can conceive of property in the body absent a right to alienate for financial gain.<sup>168</sup> For the moment, suffice it to say that the consequentialist argument needs further consideration.

What, then, of antecedentalist arguments? At first blush, we might think that there is a fundamental difficulty with such an approach: for, in the ordinary way of things, an agent will not have set about developing its own body parts in a particular way, and thus the productive labour thesis will make little sense here. But, consider again a situation such as that in the John Moore case. Suppose that the doctors, realising that they could develop a commercially profitable cell-line if Moore would let them have his spleen, or other samples of his tissue, then approached Moore with their business plan (just like they might approach a finance house with their plan). Let us suppose that Moore, even though he did not need treatment, agreed to the doctors’ proposal. Why should this not be regarded, so to speak, as a joint venture, with Moore contributing his spleen (just like a financier might contribute the venture capital)? And, if Moore did need

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167. MUNZER, *supra* note 149, at 53.

168. See discussion *infra* section IV(C).

the treatment anyway, why should this make a difference? Would it not, then, be analogous to a contribution from a financier who needed to invest in the project? Further, if we suppose that Moore freely contributed his spleen in order that he should have a share in the proceeds of the venture, then we surely have all the ingredients of the productive labour thesis. Recall, Gewirth's argument on this point:

Since it is by A's own efforts that X is produced or made available in ways that do not harm any other persons, and since A's direct purpose in so producing is to have X as her own thing either as a use value or an exchange value, to say that A does not have a property right in X would be to say that A's purpose in so acting may rightly be frustrated.<sup>169</sup>

Granted, in our hypothetical case, the cell-line is not produced exclusively by any one agent's efforts; but this looks like an argument for fair shares (shares in proportion to contribution or whatever)<sup>170</sup> rather than an argument against property rights. And, it is worth remembering Gewirth's important generalisation of the productive labour argument: if we deny the productive agent's claim we seem to attack the very idea of agency itself.

### *C. How Does Respect for Human Dignity Relate to Property in Body Parts?*

According to Article 21 of the Convention on Human Rights and Biomedicine:

The human body and its parts shall not, as such, give rise to financial gain.

This Convention, it will be recalled, is centred on the principle of respect for human dignity, and Article 21 is thought to be one of the most straightforward applications of this principle. If we accept this prohibition, we can still go a long way with the idea of property in body parts — we can still grant the source the right to exclude others from access, to have exclusive use, to control use, and even to alienate by abandonment or gift. However, the sale of one's own body parts would be prohibited and, to this extent, commodification would not be part of the bundle of proprietary rights.

The conception of dignity as constraint can generate a number of objections to commerce in body parts: agents who engage in such commerce betray their dignity by putting a price on their bodies, they instrumentalise themselves, they treat themselves as mere means, they compromise the community's vision of human dignity (like the French dwarfs), and so on. However, this paper is premised on dignity as empowerment that rejects all such duty-driven reasons. Under the

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169. GEWIRTH, *supra* note 154, at 183.

170. *See id.* at 203-13 (discussing the contribution principle).

conception of human dignity as empowerment, the principal question is whether a failure to recognise property in body parts, including the right to sell, violates an agent's right to be recognised as a source of informed choice, to have his or her choices respected, and to have the conditions in which it is possible to operate as a locus of informed choice. On the face of it, a restriction on the possibility of selling body parts might do precisely this.

The general arguments for and against a market in body parts have been neatly summarised by Neil Duxbury.<sup>171</sup> On the positive side, it is argued that such a market would benefit both vendors and recipients, particularly by increasing the supply of tissues and organs to meet the demand which altruism alone cannot satisfy. On the negative side, there are some very obvious dangers in licensing a market in body parts. As Duxbury says, we must consider "the possibility of the market system being abused, exploiting the poor, displacing need in favour of ability and willingness to pay, discouraging altruism and generating a supply of infected materials."<sup>172</sup> What is more, to the extent that attempts are made to minimise these negative features, the regulatory costs involved must also be counted.<sup>173</sup> To avoid intuitionistic pluralism, however, the stock-taking has to be carried out by reference to a governing principle. If we were to take a Gewirthian vantage point, the various positive and negative considerations would be systematically evaluated and weighed relative to the cardinal principle of respect for the freedom and well-being of agents. On this approach, the balancing exercise involves two fundamental sets of issues, one set bearing on respect for freedom, the other on the promotion of well-being; and both sets potentially involve questions of moral principle as well as empirical questions (about what actually happens if commerce

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171. Neil Duxbury, *Do Markets Degrade?*, 59 MOD. L. REV. 331, 338-40 (1996); see also MICHAEL J. TREBILCOCK, *THE LIMITS OF FREEDOM OF CONTRACT* 33-38 (1993). Trebilcock cites the Manitoba Law Reform Commission's *Human Tissue Report* at page 110, for the view that "[c]ommerce in human tissue would likely encourage blackmail, coercion, or duress; cause deterioration in standards of testing; increase the possibility of donors lying or concealing health defects, thus increasing the danger to recipients, as well as wrongly encourage donations from the poor." TREBILCOCK, *supra*, at 35 (alteration in original).

172. Duxbury, *supra* note 171, at 339.

173. See THE NUFFIELD COUNCIL ON BIOETHICS' HUMAN TISSUE: ETHICAL AND LEGAL ISSUES ¶ 6.35 (1995). The Council inventoried positive and negative considerations, emphasising that the reasons against commerce in human tissue "are strongest where difficult medical decisions are being made at vulnerable times in patients' and donors' lives." *Id.* Specifically, the Council warns that a market for procuring tissue "may obstruct rather than secure genuine consent"; that it "may undermine altruistic desires to give tissue, and may reduce the quality and even the quantity of tissue available under non-commercial systems"; that it "might distort rather than merely encourage supply" (the market being skewed towards the supply of infected or damaged tissue); that it "might encourage criminal or morally reprehensible methods of procuring human tissue, and would certainly have to be hedged with many restrictions to prevent unacceptable use being made of the tissue collected"; and that "it may provide large payments to some whose tissue happens to play a prominent part in profitable scientific or technological advance, while ignoring the contribution of many others whose tissue is also collected and studied." *Id.* at ¶ 6.34.

is permitted — and, for that matter, about what actually happens if commerce is *not* permitted).

The first set of questions concerns the familiar dilemma of the double-bind as follows: on the one hand, if some form of commerce, *x*, is permitted, then there is a risk that some vulnerable agents will engage in *x* without freely consenting to do so;<sup>174</sup> on the other hand, if *x* is prohibited, this will restrict the options that are available to agents who would otherwise freely choose to engage in *x*.<sup>175</sup> The question is whether we prioritise defending the autonomy of vulnerable agents or expanding the autonomy of non-vulnerable agents.<sup>176</sup> Depending on how we answer this fundamental question of general principle, a number of empirical matters concerning the scale and extent of the risk involved to vulnerable agents may then become relevant.

The second set of questions concerns the promotion of the well-being of agents. Whilst it is generally agreed that demand for body parts exceeds supply and that an increase in the supply of suitable parts would improve the well-being of needy agents, it is speculated that commerce in body parts might have a number of undesirable direct and indirect effects, the net outcome of which would be to damage rather than promote well-being. If we were to judge that the net outcome of a market would be to damage the well-being of agents, the argument in favour of commerce would not quite collapse: even so, where the damage to well-being was life-threatening, this could only be countered by a life-saving increment to autonomy. If we were to judge that the net outcome would be to promote the well-being of agents, the argument in favour of commerce would be assisted; and the question then would be whether there were overriding arguments against commerce on the autonomy side of the calculation.

Without doubt, these are complex issues and the Gewirthian approach does not promise to eliminate the several controversial aspects of the calculation. Nevertheless, the proposition that we should have the right to sell tissue, the loss of which in no way jeopardises our well-being, but which has value to others, is a very different story from sales of whole organs and, from the perspective of dignity as empowerment, it is surely hard to resist. After a long haul, therefore, it

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174. This leaves open the notoriously difficult question of how the conditions of “free consent” are to be specified. If “unforced choice” is the criterion, how do we draw the line between choice that is “forced” and choice that is “unforced”? See DERYCK BEYLEVELD & ROGER BROWNSWORD, *CONSENT IN THE LAW* (forthcoming 2004).

175. Cf. Joel Feinberg, *Legal Paternalism*, in *RIGHTS, JUSTICE, AND THE BOUNDS OF LIBERTY: ESSAYS IN SOCIAL PHILOSOPHY* 110, 124-25 (1980) (discussing how one might reconcile a prohibition against slavery contracts with respect for autonomy).

176. This question of priorities does not simply concern commerce. See, e.g., *Rodriguez v. Atty Gen. of Can.*, [1993] 3 S.C.R. 519 (Can. 1993) (agonising over the question, which concerned assisted suicide); *Pretty v. Director of Public Prosecutions*, [2002] 1 A.C. 800 (H.L. 2001) (holding there is no right to assisted suicide in the United Kingdom).

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seems that we cannot rule-out the idea of property in our body parts; and, if anything, from the perspective of human dignity as empowerment, this is an idea that we should rule-in. In consequence, a tort system geared to protecting human dignity must take on board the possibility of claims that run from this notion, and claims that seek to utilise property-based torts in order to protect an interest in one's own genetic information should be given serious consideration.

D. *If We Rule-In Property: Genetic Data Bases and Genetic Tests*

In a number of countries, perhaps most famously in Iceland, steps are being taken to build a national gene data bank (operated by a private company, DeCode Genetics) with a view to improving the understanding of how genes and environment interact to generate serious diseases. Icelandic law has adopted an opt-out procedure in relation to participation in this scheme. Arguably, this does not take the consent of participants sufficiently seriously. However, where such a scheme is authorised by legislation, there would be no possibility of any kind of tort claim, property-based or otherwise.

In the United Kingdom, the Wellcome Trust and Medical Research Council are leading an initiative to develop a UK Population Biomedical Collection, the so-called UK Biobank.<sup>177</sup> The proposal is that the data base will be built using DNA samples, lifestyle details, medical information, and so on contributed by as many as 500,000 volunteers (who will be in the forty-five to sixty-nine age range). Because the sources will be volunteers, this might seem to be unproblematic. However, the funders of UK Biobank apparently favour participants being brought in on the basis of giving a general consent to their data being used. If this practice is adopted, it is conceivable that one might volunteer on the understanding that the data will be used exclusively for research purposes and will not be commercially exploited only to find out at a later time that commercial exploitation has, in fact, taken place. If one has a proprietary interest in the material that has been contributed to the data bank, could there be the makings of a tort claim here?

An excellent test case for this question has arisen in *Greenberg v. Miami Children's Hospital Research Institute, Inc.*<sup>178</sup> Briefly, in the late 1980s, the lead claimant, Greenberg, approached one of the defendants, Matalon, who at that time was a research physician in Chicago, to request his involvement in a project designed to locate the gene for Canavan disease. Matalon agreed and, for some seven years

177. See *The UK Biobank*, POSTNOTE (Parliamentary Office of Science and Technology), July 2002.

178. 208 F. Supp. 2d 918 (N.D. Ill. 2002); see also LAURIE, *supra* note 4, at 322-23.

(during which time Matalon moved the research to Miami) Greenberg supplied the project with tissue and blood samples from members of his family, including samples from the brain and other organs of his deceased son who had been afflicted with the disease. More generally, the researchers enjoyed considerable co-operation from families affected by the disease — samples were collected and information was gathered from the disease registers, and so on — and the National Tay-Sachs and Allied Diseases Association supported the research by making financial contributions. However, when the gene was duly identified, the researchers took patent protection, as a result of which access to a test for the disease was available only under licence. The plaintiffs, representing the families, objected strongly to this commercialisation of the research, for they contended that they had participated on the understanding that this was a research project for the public benefit and in the expectation that there would be ready access to any pre-natal tests developed. The plaintiffs felt betrayed and, filing a six-count complaint against the defendants, they sought to restrain the latter from enforcing their patent. One of the causes of action pleaded was conversion (based on alleged property in the samples and the genetic information therein).<sup>179</sup> Unlike John Moore's case, where the objection was not to commercialisation per se, but to commercialisation without the tissue source's consent, the Canavan case raises a subtly different question, namely: should the researchers be permitted to commercialise their work when key participants in the project objected in principle to such steps being taken (and would not have participated had they thought this might happen)?<sup>180</sup> The case having come on before a federal district court in Illinois, it has now been transferred to Miami for a hearing on the merits.<sup>181</sup>

If the court in Miami gets to hear the merits of *Greenberg*, how the case will be decided is anyone's guess. There must be a real possibility that, as in *Moore*, the property-based elements of the claim will be dismissed. For our purposes, however, it suffices to say that, if this claim were to be presented in a tort regime designed around the protection of human dignity as empowerment, the premise that the claimants had property in their own genetic information (or in the genetic information of their close family members) could not be dismissed out

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179. Cf. *supra* note 138.

180. One can readily think of other scenarios of this kind. For example, parents who donate an embryo to a cell bank for stem cell research, on the understanding that the project will be exclusively of a research nature, might object if cell lines derived from the embryo are then made available to pharmaceutical companies for a fee.

181. *Greenberg*, 208 F. Supp. 2d at 920 (holding that Illinois had no jurisdiction to hear the case but that, in the interests of justice, it would be transferred to Florida rather than dismissed); see also LAURIE, *supra* note 4.

of hand. Concomitantly, their property-based tort claims should be seriously considered.

## V. GENETIC DISCRIMINATION

For some time, there have been concerns that the availability of information about an individual's genome might prompt a new form of discrimination (genetic discrimination). Although such discrimination might operate in a number of contexts, the principal concerns, thus far, have centred on the possible contractual practices of employers and insurers. In principle, such parties might decline to do business with those who are bad genetic risks or, if they do business, they will do so only on terms that are weighted to reflect the genetic risk.<sup>182</sup> For the most part, the fear has been that discrimination of this kind would be a negative response to adverse medical conditions. However, as a recent report from the Nuffield Council on Bioethics suggests, discriminatory practices might also fix on adverse non-medical conditions within the normal range of behaviour.<sup>183</sup> For example, some employers might decline to employ an applicant whose genetic make-up indicates a predisposition towards aggressive behaviour, and insurers might load the premium for applicants whose genetic make-up indicates a predisposition towards risk-taking — although, so long as employers interview and take up references, and so long as insurers check an applicant's claims history, their practice might not be revolutionised by advances in behavioural genetics. Thus far, in the United Kingdom, there is no direct legislative prohibition on the use of genetic information (whether medical or non-medical) in insurance or employment, although sex-linked or race-linked discrimination might be caught indirectly, and discrimination on the basis of an existing disability of genetic origin would be regulated by the Disability Discrimination Act 1995.<sup>184</sup>

Currently, in the United Kingdom, the position is being regulated on a voluntary good practice basis, with the Human Genetics Commission flagging up the possibility of "genetic non-discrimination" legislation being considered some years ahead. With regard to the insurance sector, following the recommendations of the Science and Technology Committee and the Human Genetics Commission, discussions took place between the Government and the Association of

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182. See, e.g., NUFFIELD COUNCIL, *supra* note 31, ch. 15 (for discrimination focusing on non-medical genetically-based conditions); NUFFIELD COUNCIL ON BIOETHICS, *GENETIC SCREENING: ETHICAL ISSUES* chs. 6, 7 (1993); Philippa Gannon & Charlotte Villiers, *Genetic Testing and Employee Protection*, 4 *MED. L. INT'L* 39 (1999); David Partlett, *The Misuse of Genetic Information: The Common Law and Professionals' Liability*, 42 *WASHBURN L.J.* 489 (2003).

183. NUFFIELD COUNCIL, *supra* note 31, at ch. 15.

184. See HUMAN GENETICS COMM'N, *WHOSE HANDS ON YOUR GENES?* 39 (2000); see also LAURIE, *supra* note 4, at 158-64.

British Insurers (ABI). This led to the agreement of a five-year moratorium on the use of genetic test results by insurers.<sup>185</sup> The moratorium will apply to life insurance policies up to £500,000 and critical illness, long-term care insurance, and income-protection up to £300,000 for each type of policy. Over these limits, the insurance industry may use genetic test results, but only where the tests have been approved by the Genetics and Insurance Committee.<sup>186</sup> There will be a review of the financial limits of the moratorium after three years. Although the moratorium is voluntary, the ABI will monitor compliance by its member companies, and the Government has said that it will extend the remit of the Genetics and Insurance Committee to give it an enhanced role in monitoring compliance with the moratorium (including taking up complaints from individuals who believe that an insurance company has failed to comply with the moratorium).

In a number of European countries — for example, in Austria, Norway, and France, where genetic testing for employment purposes is illegal<sup>187</sup> — employers are not permitted to require genetic tests.<sup>188</sup> In the U.S., too, the use of genetic testing in employment is widely regulated. By contrast, employers in the UK are not legally restricted in this way; nevertheless, in practice, they are seemingly backing off the use of genetic testing (although genetic information in a broad sense might impact on employment practice). Following its recent survey, the Human Genetics Commission reports:

There still does not seem to be any evidence that genetic test information is being used in employment, either during recruitment or as part of occupational health programmes. The Ministry of Defence has confirmed that they no longer screen aircrew recruits for sickle cell disease carrier status, although selective testing may be carried out where there is a clinical indication.<sup>189</sup>

One general exception is that police and scenes-of-crime officers are requested to supply DNA samples for elimination-from-inquiry purposes, and some would argue that supplying such a sample should be a condition of entry to the police force.<sup>190</sup> Even the Institute of Directors (on behalf of employers) found relatively low levels of support for

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185. The Nuffield Council on Bioethics recommends that genetic information about behavioural traits should be treated as falling within the terms of the five-year moratorium and, thus, not to be used by insurance companies. NUFFIELD COUNCIL, *supra* note 31, at ¶ 15.37.

186. This is an advisory committee, set up by the Government in 1998, which includes representatives from both the insurance and consumer sides as well as an independent geneticist and actuaries.

187. See HUMAN GENETICS COMM'N, *supra* note 184, at 40. In some other European countries, including the Netherlands, Spain and Denmark, genetic testing is limited to cases "where there is an unambiguous health requirement for the job, or where the protection of the employee's health in the workplace calls for such a test." *Id.*

188. See LAURIE, *supra* note 4, at 158-64 (contrasting between the regulated position in the U.S. and the deregulated position in the UK).

189. INSIDE INFORMATION, *supra* note 15, at ¶ 8.8.

190. *Id.* at ¶ 8.9.

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workplace testing. About half of the respondents supported genetic testing to ascertain whether employees were at risk from occupational exposure to chemicals or the like; and there was some support for testing designed to identify employees who might have sickness problems or who might take early retirement.<sup>191</sup> Whether UK employers would go quite as far as sharing the view, evocatively expressed by Steven Fink, that genetic tests are “radioactive” is unclear.<sup>192</sup> Broadly speaking, though, employers in the UK seem to be acting in compliance with the Commission’s principle of respect for persons, which, as the Commission interprets it, militates against requiring an individual to take a genetic test as a condition of employment.<sup>193</sup>

Let us suppose, however, that the situation changed. Let us suppose that employers began to demand genetic tests as a condition of employment, to the point where one’s tested genetic profile became a required part of one’s curriculum vitae. Or, again, let us suppose that insurance companies were to alter their practice to require that a potential insured took a genetic test and disclosed the results in the application for insurance. As a matter of law, insurers and employers might appeal to the classical principle of freedom of contract in order to defend such requirements. In such a scenario, the Government might well push through dedicated legislation to set a regulatory framework to deal with genetic discrimination in employment and insurance. However, in the absence of such a dedicated response, how would the existing resources of English law fare? We can look at three possibilities: an extension of the Human Rights Act 1998; an innovative response by contract law; and an innovative response by tort law designed to protect an interest in human dignity.

#### A. *The Human Rights Act 1998*

The Human Rights Act 1998, it will be recalled, incorporates the principal provisions of the European Convention on Human Rights into English law. According to Article 14 of the Convention, the Convention rights and freedoms are to be secured without discrimination on any ground, including the standard grounds of sex, race, colour, language, religion, political opinion, or the like. Although the Con-

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191. *Id.* at ¶ 8.14.

192. Steven Fink, EEOC v. BNSF: *The Risks and Rewards of Genetic Exceptionalism*, 42 WASHBURN L.J. 525 (2003).

193. The view taken by the Nuffield Council on Bioethics is that employers should discharge their responsibility to provide a safe working environment by removing hazards, not employees, from the workplace. Concomitantly, the Council recommends that employers should not require applicants to take a genetic test as a condition of employment; rather they should “monitor employees for early warning signs of behaviour (such as violence) that would make them incapable of performing the job satisfactorily.” NUFFIELD COUNCIL, *supra* note 31 at ¶ 15.21.

vention does not specifically identify genetic discrimination as a prohibited ground, it is eminently arguable that such a ground could be read as within the ambit of Article 14. For instance, one might cite in support of this view, Article 2 of the Universal Declaration of Human Rights, which articulates a broad principle of non-discrimination. This might then be tied to Article 2 of the UNESCO Universal Declaration on the Human Genome and Human Rights, according to which: “a) Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics. b) That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.”<sup>194</sup>

Commenting on this last-mentioned Article, Hectór Gros Espiell, the Chairman of the Legal Commission of UNESCO’s International Bioethics Committee, has said:

Article 2 of the Declaration asserts that the genetic characteristics of the person can in no way justify limits on the recognition of his or her dignity or the exercise of his or her rights. This is a fundamental principle whose corollary is the prohibition of all discrimination based on genetic characteristics as set forth in Article 6 [which prohibits “discrimination based on genetic characteristics” such as would infringe human dignity]. This article is derived from Article 2 of the Universal Declaration of Human Rights . . . and adds the genetic criterion to it.

Many other instruments adopted by UNESCO also refer to this principle of non-discrimination . . . . In taking the dignity of the human person as its reference, the Declaration seeks above all to condemn any attempt to draw political or social inferences from a purported distinction between ‘good’ genes and ‘bad’ genes.<sup>195</sup>

At the very least, then, it is arguable that a principle of non-discrimination (including genetic discrimination) protects the implementation of the Convention rights.

So far so good and, if one of the (primary) Convention rights provided that there was a right to insist upon a contract of employment or a contract of insurance, or essential contracts (or something of that kind), it would be open to argue that such a primary right should be secured without any genetic discrimination. However, the Convention does not so provide. In the absence of such straightforward provision, we must try to get to first base by identifying a primary Convention right (say, against degrading treatment or in support of privacy or family life) through which a prohibition on genetic discrimination might flow.<sup>196</sup> This would require some interpretive ingenuity;

194. Universal Declaration, *supra* note 13. This Declaration was adopted in November 1997 and, on December 9, 1998, the United Nations General Assembly adopted Resolution A/RES/53/152 endorsing the Declaration. *Id.*

195. H. G. Espiell, *Introduction, in BIRTH OF THE UNIVERSAL DECLARATION ON THE HUMAN GENOME AND HUMAN RIGHTS 3* (1999).

196. *Cf.* Beale & Pittam, *supra* note 7, at 156.

but, if citizens were being excluded from the employment or insurance markets on genetic grounds, this would be a serious complaint inviting an imaginative judicial response. If such a claim were to be brought successfully against the State (States having positive as well as negative responsibilities under the ECHR), corrective legislative action would be required. If, however, the claim was made against a *private* employer or insurer and, if it relied entirely on Convention rights, this would run into the objection that, even if the Convention rights have some degree of horizontal applicability, they do not have full-blooded horizontal effect of the kind presupposed by such a claim.<sup>197</sup>

### B. *Contract*

In England, as in most other legal systems, the classical principle of freedom of contract has been progressively cut back.<sup>198</sup> Most obviously, in the area of consumer contracts, standard forms and exclusion clauses have been heavily regulated, limiting the parties' freedom to set their own terms.<sup>199</sup> It is also the case in England that dedicated legislation has been introduced to limit the freedom to choose one's contractual partners, at any rate where free choice involves an unacceptable form of discrimination — witness, in particular, the constraints on this aspect of freedom of contract introduced by the Sex Discrimination Act 1975<sup>200</sup> and the Race Relations Act 1976.<sup>201</sup> Of course, even before these legislative inroads into party freedom, the common law had long restricted the freedom of some tradespersons — common carriers and innkeepers are the standard examples — to choose their customers.<sup>202</sup>

So, in the notorious modern case of *Constantine v. Imperial Hotels, Ltd.*,<sup>203</sup> the Imperial Hotel in London was held to be in breach of its common law duty when, without sufficient excuse, it refused to honour a booking by declining to accommodate a well-known West

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197. See *supra* note 7.

198. See ROGER BROWNSWORD, *Freedom of Contract*, in COMMON LAW COMMON VALUES COMMON RIGHTS: ESSAYS ON OUR COMMON HERITAGE BY DISTINGUISHED BRITISH AND AMERICAN AUTHORS 135 (2000).

199. See, e.g., ROGER BROWNSWORD, *CONTRACT LAW: THEMES FOR THE TWENTY-FIRST CENTURY* (2000).

200. Sex Discrimination Act 1975, pts. II, III, & VII, § 29 (dealing with discrimination in the provision of goods, facilities, or services).

201. Race Relations Act 1976, pts. II, III, & VIII, § 20 (dealing with discrimination in the provisions of goods, facilities, or services).

202. See 24 HALSBURY'S LAWS OF ENGLAND ¶ 402 (4th ed. 1991) (restating the standard for common carriers); 5(1) HALSBURY'S LAWS OF ENGLAND ¶ 1113 (restating the standard for innkeepers). There is also a suggestion that, at one time, blacksmiths might have been similarly restricted. See 5(1) HALSBURY'S LAWS OF ENGLAND ¶ 1116 n.2 (citing *Johnson v. Midland Ry Co.*, 4 Ex. 367, 372-73 (1849)).

203. [1944] K.B. 693 (1944). In fact, the plaintiff had a contract with the defendants for the reception of his wife, his daughter, and himself at the hotel. However, the action was brought in tort (on the case) rather than in contract.

Indian cricket player and his family. Following the example of *Constantine*, the legislation of the 1970s renders it unlawful to discriminate on the grounds of sex or race in the provision (or non-provision) of accommodation.<sup>204</sup> However, this is just one instance of the many applications of the legislation, the scope of which extends well beyond the common law principles in confining the opportunities for contractors to deal on the basis of their prejudices. In the result, there is now a considerable jurisprudence relating to racial and sexual discrimination (and, more recently, recognition and regulation of disability discrimination).<sup>205</sup> In this setting, might an innovative court find a way of reworking contractual principles in order to protect persons from unacceptable forms of genetic discrimination? In particular, how might contract law be utilised to protect a party against the unfair genetic loading of a contract, or against the improper denial of a contract for genetic reasons? And, would contract law assist a claimant who had refused to accept a non-negotiable offer for precisely the reason that it was tainted with genetic bias?

A bold approach would be to redefine the public policy limits on freedom of contract. As a starting point, it is surely plausible to suggest that English law is committed to a general principle of non-discrimination. This general principle is already specifically recognised and articulated in relation to racial, sexual, and disability discrimination; and there is ongoing discussion about further provision for religious, age, and sexual preference discrimination, and the like. Should we not include genetic discrimination in this list? After all, the UNESCO Universal Declaration on the Human Genome and Human Rights explicitly provides that respect for human dignity condemns any attempt to discriminate on genetic grounds; and, as we have suggested, a similar provision might be implicit in the Human Rights Act. Moreover, for those who think the Rawlsian<sup>206</sup> thought that racial or sexual discrimination is unjust, genetic discrimination will seem to be a similar case. For, behind a Rawlsian veil of ignorance, contractors will have no more knowledge of their actual genetic profile than of their race or sex. In consequence, their risk-averse approach will dictate that the basic principles of fair dealing in society should not allow for one's genetic characteristics to be used against one.

Despite the support offered by ideas of this kind, some courts might feel uncertain about using a redefined public policy category as a free-standing reason to interfere with the options exercised by contractors, especially where we are dealing with the option *not* to con-

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204. See Sex Discrimination Act 1975, § 29(2)(b); Race Relations Act 1976 § 20(2)(b).

205. See Disability Discrimination Act 1995.

206. JOHN RAWLS, A THEORY OF JUSTICE (1971).

tract at all.<sup>207</sup> They might be assisted, however, by regulatory doctrines that are more focused. For example, the doctrine of unconscionability might be used to challenge a term that is weighted in such a way that it reflects a genetic reason;<sup>208</sup> and, although good faith in negotiations is not yet recognised as a general principle of English contract law,<sup>209</sup> it does have a foothold in consumer contracts and, equally significantly, in insurance contracts (via the principle of utmost good faith), on which basis the non-selection of a particular contractor for genetic reasons might be open to challenge.<sup>210</sup> Good faith, too, might be the opening for the claimant who has walked away from a genetically biased non-negotiable offer.

Having said that it might be difficult to draw directly on the non-discrimination clause of the Human Rights Act 1998, nevertheless the Act might add weight and direction to a claim that is driven by recognised contractual doctrinal resources (for example, where public policy is invoked, or with regard to the implied term as to mutual trust and confidence in an employment relationship);<sup>211</sup> and, certainly, the experience of other European legal systems is that background constitutional rights can feed into private law through general doctrinal gateways (such as good faith in contract law).<sup>212</sup> Moreover, where Convention rights are being prayed in aid in a support role of this kind, the question of whether the Act applies horizontally in private law disputes is much less likely to be raised.<sup>213</sup>

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207. It is one thing to invite a court *not* to enforce a contract as contrary to public policy. *See, e.g.*, *Horwood v. Millar's Timber & Trading Co.*, [1917] 1 K.B. 305 (C.A. 1916). It is another matter, though, to invite a court to reverse a refusal to contract as contrary to public policy.

208. *See, e.g.*, *Credit Lyonnais Bank Nederland v. Burch*, [1997] 1 All E.R. 144, 151 (C.A. 1996) (emphasising that the jurisdiction to relieve against unconscionable bargains, "although more rarely exercised in modern times, is at least as venerable as its jurisdiction to relieve against those procured by undue influence"). Moreover, the court said that "the jurisdiction is in good heart and capable of adaptation to different transactions entered into in changing circumstances." *Id.*

209. As Lord Ackner famously asserted in *Walford v. Miles*, the adoption of a requirement of good faith would be incompatible with the adversarial ethic underpinning English contract law. Thus:

[T]he concept of a duty to carry on negotiations in good faith is inherently repugnant to the adversarial [sic] position of the parties when involved in negotiations. Each party to the negotiations is entitled to pursue his (or her) own interest, so long as he avoids making misrepresentations. . . . A duty to negotiate in good faith is as unworkable in practice as it is inherently inconsistent with the position of a negotiating party.

[1992] 2 A.C. 128, 138 (H.L. 1991-92).

210. *See generally* GOOD FAITH IN CONTRACT: CONCEPT AND CONTEXT (Roger Brownsword et al. eds., 1999). For some signs that the tide of opinion in the United Kingdom (especially in England) might be turning in favour of a general principle of good faith in contracts, see several of the papers in GOOD FAITH IN CONTRACT AND PROPERTY (A. D. M. Forte ed., 1999).

211. For recent discussion of this evolving implied term, see The Hon. Mr. Justice Lindsay, *The Implied Term of Trust and Confidence*, 30 *INDUS. L.J.* 1 (2001).

212. *See, e.g.*, Andreas Heldrich & Gebhard M. Rehm, *Importing Constitutional Values Through Blanket Clauses*, in *HUMAN RIGHTS IN PRIVATE LAW*, *supra* note 7, at 113.

213. In fact, in *Wilson v. First County Trust Ltd.*, [2002] Q.B. 74 (C.A. 2001), the leading case on the application of the Human Rights Act in the field of contracts, the Court of Appeal has taken an extraordinarily robust approach. According to section 6 of the Act, public authorities have an obligation to act in a way that is compatible with the Convention rights; so much is

Finally, it is worth noting that, failing all else, where the boundary between the public and private is hazy, there might be opportunities to plead abuse of contractual right by way of judicial review.<sup>214</sup> But, this is literally, where all else fails. There is a more direct and broader-ranging approach to the matter, and Tort signposts the direction in which we should be looking.

### C. Tort

Let us suppose that tort law set out to protect an interest in human dignity. As we have seen already in the *Constantine* case,<sup>215</sup> even before dedicated (non-) discrimination legislation, there was a common law capacity to respond to blatant affronts to a person's dignity. Granted, *Constantine* arose in the context of a common calling and concerned racial discrimination; nevertheless, the thought that a dignity-protecting tort system might be capable of responding more widely to acts of genetic discrimination is surely quite plausible. Let us suppose then that the tort system takes on this challenge. If it is guided by the conception of human dignity as empowerment, how might the land lie?

From the perspective of human dignity as empowerment, it is true that the tide runs strongly in favour of individual choice — the right to say yes but equally the right to say no — but only so long as this is compatible with respecting others as choosing agents who need a supportive context for their own autonomous existence.<sup>216</sup> If discrimination on genetic grounds involves regarding bad risk humans as incapable of exercising choice, or as inferior, or something of that kind, then this is certainly something to be targeted. Similarly, if genetic discrimination has the effect of excluding persons from having access to important public goods, or from the enjoyment of conditions in which one can maintain a sense of one's own value, or if it consigns persons to circumstances that are demeaning or degrading, then respect for human dignity is also violated.<sup>217</sup>

It should not be forgotten, of course, that there are a number of possible reasons for selection (and non-selection). For example, dis-

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uncontroversial. However, section 6 explicitly provides that the courts are themselves included as public authorities. Taking this at face value, the Court of Appeal in *Wilson* has said that, as a public authority, it has a statutory obligation to act in a way that is compatible with the Convention rights and that this obligation applies even where the dispute is between two private parties. *Wilson*, [2002] Q.B. at ¶ 31. There is recent support for this view, which effectively by-passes the horizontality debate, in *Mendoza v. Ghaidan*, [2002] 4 All E.R. 1162 (C.A. 2002). However, the House of Lords has given leave to appeal in *Wilson* and has yet to pronounce.

214. See ROGER BROWNSWORD ET AL., *THE LAW OF CONTRACT* 137-45 (Michael Furmston ed., 1999).

215. See *supra* note 203.

216. See Gannon & Villiers, *supra* note 182 (commenting on the significance of autonomy where genetic tests are proposed for employees who are already in employment).

217. Cf. NUFFIELD COUNCIL, *supra* note 31, at ¶ 15.31.

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criminatory decisions might be designed to protect the party discriminated against, or to protect third parties, or to economise. What purported justification, if any, counts as a good reason in this context? Before we could articulate even the broad parameters of a dignity-based tort claim against wrongful genetic discrimination, we would need to reflect on both the scope of the protected interest and the kinds of justifying defences that would be available.

Having eschewed human dignity as constraint, we should not now turn to it in support of a claim against genetic discrimination. Nevertheless, it is worth commenting that such a conception of human dignity invites a community to pin its colours to the mast. To allow for discrimination on genetic grounds is to make a certain sort of statement about the kind of community that this is. If this is not the community vision that we share, if this is not our idea of a civilised society, then a limit must be placed on selection (or non-selection) for genetic reasons. If we have a clear sense of what constitutes improper or abusive reliance on genetic information, then the community's vision can be translated into its regulatory position. This might mean that only certain specific discriminatory reasons or attitudes are controlled. On the other hand, a more robust view might be taken, prohibiting all forms of genetic discrimination (in other words, there would be a prohibition on the use of genetic information for the purposes of selection or non-selection, irrespective of the particular reason for which that information would be used). Such a precautionary approach might make very good sense where the protection of the culture is judged to be more important than the preservation of the maximum amount of freedom and choice. However, it would be ironic, indeed, if human dignity as constraint proved the more effective and straightforward basis for developing a tort against genetic discrimination in a freedom-loving society.

## VI. CONCLUSION

New genetic (and information) technologies promise to enhance and extend the boundaries of our knowledge — we are likely to know more about others as they are likely to know more about us — and, with that, our power to choose and control one another. Such a changing social context may generate new kinds of grievance which might then be articulated as novel claims in the tort system. If the claims are so novel that they fit no recognised cause of action, they are liable to be filtered out at an early stage without any serious argument. One of the attractions, therefore, of a general principle, or of a broad cause of action, such as that designed to protect human dignity, is that it offers a real prospect of novel claims at least being brought

forward and given serious consideration. Moreover, the flexibility of such a cause of action gives it some chance of staying connected to rapid technological development. Thus, if what essentially concerns us about the new genetics is that it threatens our interest in human dignity, we need to instate a generalised principle in the tort system protecting our interest in human dignity as the regulating idea for the development of more specific genomic torts (such as, perhaps, the tort relating to over-information or violation of the right not to know). But, crucially, the generalised principle (and its underlying tort) would always be in the background to be relied on where specific genomic torts did not quite cover the case.

The obvious problem with such a generalised principle or open-ended cause of action, however, is that it leaves too much to interpretation. Lest we should forget this downside, in *Wainwright v. Home Office*,<sup>218</sup> Mummery L.J. has recently spelled out precisely this reservation in relation to recognising a generalised tort action for violation of privacy:

As to the future I foresee serious definitional difficulties and conceptual problems in the judicial development of a “blockbuster” tort vaguely embracing such a potentially wide range of situations. I am not even sure that anybody — the public, Parliament, the press — really wants the creation of a new tort, which could give rise to as many problems as it is sought to solve. A more promising and well trod path is that of incremental evolution, both at common law and by statute . . . of traditional nominate torts pragmatically crafted as to conditions of liability, specific defences and appropriate remedies, and tailored to suit significantly different privacy interests and infringement situations.<sup>219</sup>

How does this stand relative to the purpose of this paper, which has been to explore (a) how far incremental development might take us and (b) how much difference a “blockbuster” dignity-based tort might make in relation to genomic grievances? Because the developments that I have been considering, whether incremental or blockbuster in nature, are based on the conception of human dignity as empowerment (which, in turn, is very closely related to existing notions of human rights and the importance of individual autonomy), we can say that they would not represent major changes of direction for either English or American tort law. Nevertheless, let me repeat that, whether or not, all things considered, the recognition of a new dignity-based tort would be the right way to respond to legitimate grievances arising from modern human genetics requires further discussion. Bearing in mind this caveat, our question is whether the development

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218. [2002] Q.B. 1334 (C.A. 2001).

219. *Id.* at ¶ 60.

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of such a tort would significantly assist claimants in the short, medium, or longer term.

In the time that has passed since I started work on this paper, I have become less confident about the time-frame in which it is meaningful to think of short, medium, or longer term. Genetics seems to be an accelerating science, but it is still, relatively speaking, in its infancy. However, in the short term, it seems to me that claimants in the United Kingdom who are aggrieved by genetic discrimination might be assisted by a more explicit protection of human dignity in the tort system.<sup>220</sup> In all probability, though, such transitional assistance will be overtaken by dedicated legislative provision addressing this new form of regulated prejudice. In the short term, regard to considerations of human dignity might also strengthen the demand for confidentiality to be respected (so that a precautionary approach is required in relation to the circulation and onward-transmission of genetic information). In the mid-term, the adoption of human dignity in the tort regime could be important for the protection of the right not to know and, possibly, for the extension of property-based tort claims. Certainly, the circulation of genetic information and the construction of data bases and the like will have reached a point where litigation looks like an option for the airing of some grievances. Finally, in the longer term, genetic testing and embryonic (and gamete) manipulation of various kinds is likely to become much more commonplace in reproductive circles; occasionally things will go badly wrong; and, when this happens, claims for dashed hopes might be recognised if human dignity as empowerment has impressed itself on the tort system.

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220. As always, of course, the interaction between the contract and tort regimes will affect the point at which the pressure to respond is felt. For instance, if the contract regime develops a rapid response to grievances concerning genetic discrimination in transactional settings, this may reduce the demands made on the tort regime; and vice versa.

