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INFORMATION TECHNOLOGY AND BIOMETRIC DATABASES: EUGENICS AND OTHER THREATS TO DISABILITY RIGHTS

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I. INTRODUCTION

With all the recent interest in disability rights, the proposition that the incapacitated and disabled face worsening problems in institutions, hospitals and nursing homes may appear doubtful. An analysis of the ongoing threat to disability rights will seem gratuitously incommodious amid the general optimism about information technology and globalization. But discomfiture at the conceptual lessons of the twentieth century should not make the discussion taboo. Eugenics, the right to life, access to treatment and care in hospitals, and the subjection of the incapacitated to non-therapeutic research, clinical drug trials and tissue removal are undoubtedly matters of the utmost importance to each one of us. These matters affect the disabled, to be sure, but they affect all people in that every one of us becomes disabled when we lose the capacity to communicate and find ourselves in hospitals or nursing homes.

There is an assumption in Western jurisprudence that widening access to information technology and developing central databases bearing medical, biometric and other personal information can only enhance the autonomy of the disabled, increase efficiency and promote disability rights. This paper challenges those fundamental assumptions. If, as will be argued, the lessons of the twentieth century have been forgotten, and if sensitive, medical and personal information is in the hands of new, unaccountable and unreliable parties, we are destined to repeat, more spectacularly given the efficiency of new technologies, the mistakes of that benighted century. As we shall see, disability rights are selective in the context of overweening financial, medical and research interests. In an age of pervasive eugenics, where the inherent dignity of every human being and the objectivity of ethics is doubted, information technology and colossal medical

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databases are likely to threaten rather than promote disability rights and encourage grave systematic human rights abuse.

II. THE HISTORY OF EUGENICS

The twentieth century has been witness to abuse, mutilation and homicide of the disabled. These enormities have been made possible in part by the power of the state, industry, medical research, financial interests and misused personal information. They have also been assisted by an ideology that is skeptical of the principle that all humans have an inherent dignity regardless of disability and seeks to improve “human stock” for the benefit of future generations via agencies under social control. Since the proponent of eugenics also usually doubts the principle against instrumentalization, that evil should not be done that good may come (or the end does not justify the means), there is considerable scope for human rights violations of the kind witnessed in the twentieth century. Further, because eugenicist ideology is mired both in the race for corporate, institutional and personal profit and in the false supposition that all innovation is progress, its re-emergence on a more systematic and destructive scale cannot be dismissed as mere fantasy.

A satisfactory account of eugenics would involve a comprehensive discussion of Thomas Malthus, Francis Galton, Charles Darwin, Margaret Sanger[2] and the ideas of early members of the Eugenics Society. Galton defined it thus: "Eugenics is the study of agencies under social control that may improve or impair the racial qualities of future generations, whether physically or mentally."[3] Even now a new eugenics appears desirable for the purpose of attaining genetic and other human enhancement via artificial reproduction, genetic manipulation, pre-implantation and pre-natal screening techniques, sterilization, abortion and other systems under social control.[4]

Among the enigmas of the history of ideas is the question of how it is that so many of our Western intellectual elite, commonly thought to be the respectable face of liberalism and progressive ideology, actually sport ideas that are quite inhumane and challenge, in fundamental ways, the principle that all

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[2] Daniel J. Kevles, IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY (1986); Stefan Kuhl, THE NAZI CONNECTION, (1994); RICHARD WEIKART, FROM DARWIN TO HITLER: EVOLUTIONARY ETHICS, EUGENICS AND RACISM IN GERMANY (2004).

[3] Francis Galton, ESSAYS IN EUGENICS 81 (1909).

[4] John Harris, CLONES, GENES AND IMMORTALITY: ETHICS AND THE GENETIC REVOLUTION, (2007); Nicholas Agar, LIBERAL EUGENICS (2000); Julian Savalescu, *Procreative Beneficence: Why We Should Select the Best Children* BIOETHICS (2001) 15(5): 413-426.

people, of whatever race and disability, have an inherent dignity (hereafter, the equal dignity principle or EDP). The novelist H. G. Wells, for example, was a renowned eugenicist and worked with his mentor T. H. Huxley to promote a version of social Darwinism. He argued that:

> "I believe that now and always the conscious selection of the best for reproduction will be impossible; that to propose it is to display a fundamental misunderstanding of what individuality implies. The way of nature has always been to slay the hindmost, and there is still no other way, unless we can prevent those who would become the hindmost being born. It is in the sterilization of failure, and not in the selection of successes for breeding, that the possibility of an improvement of the human stock lies."[5]

Intentional killing, sterilization and birth control were, in Wells' view, a sound way to eliminate what he regarded inferior peoples. He, along with his fellow eugenicists, believed that evolution, operating on its own, was not effective. In his *Anticipations of the Reactions of Mechanical and Scientific Progress Upon Human Life and Thought*[6] he dreams of a New Republic freed of the weak, unfit and unproductive and as well as a great number of "blacks, browns, dirty whites and yellow people." Society needed to be controlled and manipulated by a progressive elite. For this reason, he sought to establish eugenic programs. The goal was death to be achieved by opiate induced mercy killings, and it was expected that the men of the New Republic would have "no pity and less benevolence ...", about inflicting death on the unfit, because those who kill the weak will have a "fuller sense of the possibilities of life than we possess."

Thus, his list of those who would not be permitted to propagate, as well as those who would likely be euthanized when they rebelled, included those with transmissible diseases, mental disorders and alcoholism:

> "[T]he men of the New Republic will hold that the procreation of children who, by the circumstances of their parentage, must be diseased bodily or mentally .... that a certain portion of the population ... afflicted with indisputably transmissible diseases, with transmissible mental disorders, with such hideous incurable habits of mind as the craving for intoxication exists only on sufferance, out of pity and patience, and on the understanding that they do not propagate; and I do not foresee any reason to

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[5] H.G. Wells in Francis Galton (ed), *Eugenics: Its Definition Scope and Aims* 10 AMERICAN JOURNAL OF SOCIOLOGY (1904) 11. These were proceedings held in London [emphasis added].

[6] H.G. WELLS, ANTICIPATIONS OF THE REACTIONS OF MECHANICAL AND SCIENTIFIC PROGRESS UPON HUMAN LIFE AND THOUGHT (1904) Available at: http://www.archive.org/details/anticipationsofr00welluoft (last visited, 09/10/2008)

> suppose that they will hesitate to *kill* when that sufferance is abused. And I imagine also the plea and proof that a grave criminal is also insane will be regarded by them not as a reason for mercy, but as an added reason for death. I do not see how they can think otherwise on the principles they will profess." [7]

The men of the New Republic are not delicate. They would not hesitate to kill these unfit:

> "The men of the New Republic will not be squeamish, either, in facing or inflicting death, because they will have a fuller sense of the possibilities of life than we possess. They will have an ideal that will make killing worth the while; ... They will naturally regard the modest suicide of incurably melancholy, or diseased or helpless persons as a high and courageous act of duty rather than a crime."[8]

Wells' vision is clinical, hygienic and detached. His killings are humane:

> "All such killing will be done with an opiate, for death is too grave a thing to be made painful or dreadful, and used as a deterrent from crime. If deterrent punishments are used at all in the code of the future the deterrent will neither be death, nor mutilation of the body, nor mutilation of the life by imprisonment, nor any horrible things like that, but good scientifically caused pain, that will leave nothing but a memory."[9]

As with most attempts to give a definition of what sort of person is to be regarded as "fit" for the purposes of eugenics, Wells' version simply degenerates into another form of discrimination. After an offensive account of the Jews,[10] he concludes that "those swarms of blacks, and brown, and dirty-white, and yellow people will have to go":[11]

> "And for the rest, those swarms of black, and brown, and dirty-white, and yellow people, who do not come into the new needs of efficiency? Well, the world is a world, not a charitable institution, and I take it they will have to go. The whole tenor and meaning of

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[7] *Id.* p. 299-300

[8] *Id.* p.200

[9] *Id.* p. 300.

[10] *Id.* p. 315-7.

[11] In fact Wells' understanding of history and his social Darwinism came under fire from the English Catholic Hilaire Belloc entitled MR. BELLOC OBJECTS TO "THE OUTLINE OF HISTORY", (1926) and MR. BELLOC STILL OBJECTS (1927). See also G.K. CHESTERTON, EUGENICS AND OTHER EVILS: AN ARGUMENT AGAINST THE SCIENTIFICALLY ORGANIZED STATE (2000).

> the world, as I see it, is that they have to go. So far as they fail to develop sane, vigorous, and distinctive personalities for the great world of the future, it is their portion to die out and disappear."[12]

It is important to bear in mind that Wells was not alone in his belief that an intellectual elite should be used to usher in a new world freed from disability, disease and a great deal more. His discussion with Joseph Stalin about the good society was published with comments by George Bernard Shaw, John Maynard Keynes and others.[13] In his discussion with Stalin on how best to achieve the scientific re-organization of society, Wells argues that a liberal technocratic elite should be thus engaged:

> "Now there is a superabundance of technical intellectuals, and their mentality has changed very sharply. The skilled man, who would formerly never listen to revolutionary talk, is now greatly interested in it. Recently I was dining with the Royal Society, our great English scientific society. The President's speech was a speech for social planning and scientific control. To-day, the man at the head of the Royal Society holds revolutionary views, and insists on the scientific re-organisation of human society."[14]

An avowed atheist, Wells rejected Christianity as promoting stultifying and anti-progressive social and sexual mores. His affair with the eugenicist and founder of International Planned Parenthood Foundation (IPPF), Margaret Sanger, is well documented and highlights precisely the kind of social agencies these and other eugenicists regarded appropriate for relieving society of its most 'defective' elements.

IPPF, a longtime bastion of modern population control and eugenics is most famous for using its considerable finances to promote and facilitate internationally, sterilization, abortion, contraception and, it has been argued, infanticide (particularly in China).[15] It is funded to the tune of hundreds of millions of dollars per annum by a variety of Western governments and multilateral agencies. The Bill and Melinda Foundation is also a key contributor. The organization and its associated ideology, is thriving. There are, therefore, major contemporary interests in defending Sanger's honor. A cursory

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[12] *Id.* p. 317.

[13] Joseph Stalin & H.G. Wells, MARXISM VS. LIBERALISM: AN INTERVIEW (1937).

[14] *Id.* Even at the beginning of the 20th century Wells was working with Bertrand Russell and others for the technocratic reorganization of society. Wells saw the end of World War I as an opportunity to create a new order for society. See H.G. WELLS, THE OPEN CONSPIRACY (1928).

[15] Steven W. Mosher, CHINA MISPERCEIVED: AMERICAN ILLUSIONS AND CHINESE REALITY, (1992); MOTHER'S ORDEAL: ONE WOMAN'S FIGHT AGAINST CHINA'S ONE-CHILD POLICY (1993).

examination reveals a founder whose views challenge the notion that every one of us has inherent dignity whatever our race, class, color, creed, ability or disability.

In her *Pivot of Civilization*, Sanger outlines a vision of the world that regards certain people as “morons, imbeciles and borderline cases”[16], “defectives, delinquents and dependents,”[17] “biological waste”[18] whose accumulation[19] is cause for social concern. The verbal invective might be regarded good fun, a lively example of intellectual exchange between academic colleagues, were it not also accompanied by suggestions of sterilization and ultimate elimination of those she regards “unfit” in that “cradle competition between the fit and the unfit.”[20]

Her writings betray ample evidence of her contempt for men, women and children on grounds of race, creed, disability, skin color, wealth, social status and religion. In *Pivot of Civilization,* in a chapter entitled “The Fertility of the Feebleminded”, she starts out by holding that “[t]here is but one practical and feasible program in handling the great problem of the feeble-minded… the moron, the mental defective, the imbecile.” These are the sterilization and contraception programs she helped to organize. Indeed these programmes turn out to be the answer to everything from insanity, epilepsy, criminality, prostitution, and poverty to mental disability:

> “Modern studies indicate that insanity, epilepsy, criminality, prostitution, pauperism, and mental defect, are all organically bound up together and that the least intelligent and the thoroughly degenerate classes in every community are the most prolific. Feeble-mindedness in one generation becomes pauperism or insanity in the next.”[21]

Sanger also viewed charity as a symptom of a social disease: “Organized charity is the symptom of a malignant social disease… increasing numbers of defectives, delinquents, and dependents. My criticism, therefore, is not directed at the 'failure' of philanthropy, but rather at its success.”[22] She concludes the chapter by arguing that philanthropy and charity is a “sentimental and paternalistic” strategy “increasing the dead weight of human waste”[23]. She says:

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[16] Margaret Sanger, PIVOT OF CIVILIZATION, 41 (1922)

[17] *Id.* at 49. See also 41, 42, 46, 47 for references to the problem of “defectives.”

[18] *Id.* at 59.

[19] *Id.* at 59.

[20] *Id.* at 47, 74, 76.

[21] *Id.* at 38.

[22] *Id.* at 49.

[23] *Id.* at 53.

> “Instead of decreasing and aiming to eliminate the stocks that are most detrimental to the future of the race and the world, [philanthropy] tends to render them to a menacing degree dominant.”[24]

One cannot fail to be impressed by the standard of her rhetoric, but there can be little doubt, despite protestations to the contrary, that she was also a formidable racist. In fact, she was the guest speaker at a Ku Klux Klan rally in Silverlake, New Jersey in 1926 to foster faith in a plan called the "Negro Project," that was designed to sterilize black Americans. Planned Parenthood denies that their founder was racist but her words betray her time and again. In *What Every Girl Should Know* she has this to say of the Australian Aborigines:

> “It is said that a fish as large as a man has a brain no larger than the kernel of an almond. In all fish and reptiles where there is no great brain development, there is also no conscious sexual control. The lower down in the scale of human development we go the less sexual control we find. It is said that the aboriginal Australian, the lowest known species of the human family, just a step higher than the chimpanzee in brain development, has so little sexual control that police authority alone prevents him from obtaining sexual satisfaction on the streets.”[25]

Her recommendations are practical if nothing else:

> “It now remains for the U.S. government to set a sensible example to the world by offering a bonus or yearly pension to all obviously unfit parents who allow themselves to be sterilized by harmless and scientific means. In this way the moron and the diseased would have no posterity to inherit their unhappy condition. The number of the feeble-minded would decrease and a heavy burden would be lifted from the shoulders of the fit.”[26]

She quotes eugenicist Austin Freeman with approval:

> “"Compared with the African negro," he writes, "the British sub-man is in several respects markedly inferior. He tends to be dull; he is usually quite helpless and unhandy; he has, as a rule, no skill or knowledge of handicraft, or indeed knowledge of any kind...”[27]

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[24] *Id.*

[25] Margaret Sanger, WHAT EVERY GIRL SHOULD KNOW, 47 (1920).

[26] Margaret Sanger, *The Function of Sterilization* in BIRTH CONTROL REVIEW 299 (1926).

[27] *Id.* at 59. Quoting from AUSTIN FREEMAN, SOCIAL DECAY AND REGENERATION (1921).

With population control concerns outlined in her book, *Woman and the New Race*, she asserts that the "most merciful thing that a large family does to one of its infant members is to kill it."[28]

The history of the eugenics movement is an eye-opener for anyone who wishes to undertake an analysis. The Eugenics Society both in the UK and in America is a veritable "Who's Who" of the ruling elite. From Marie Stopes, John Maynard Keynes, Lord Dawson, to Major Leonard Darwin, son of Charles. J. B. S. Haldane in 1922 recommended a future in which eugenic social engineers would control human reproduction in such a way as to improve the stock of mankind. Julian Huxley, the first director of the United Nations Educational and Scientific and Cultural Organization, in *UNESCO its Purpose and Philosophy*, recommending a global evolutionary humanism for UNESCO, wrote immediately after the war in 1946:

> "At the moment, it is probable that the indirect effect of civilisation is dysgenic instead of eugenic; and in any case it seems likely that the dead weight of genetic stupidity, physical weakness, mental instability, and disease-proneness, which already exist in the human species, will prove too great a burden for real progress to be achieved. Thus even though it is quite true that any radical eugenic policy will be for many years politically and psychologically impossible, it will be important for Unesco to see that the eugenic problem is examined with the greatest care, and that the public mind is informed of the issues at stake so that much that now is unthinkable may at least become thinkable."[29]

It is beyond our scope to analyze the eugenics movement historically. To do so would take us away from the issue at hand, namely the danger of central databases and biometric information in the current socio-political climate. My primary aim here is to highlight certain matters: first, that the elimination of the unfit using euthanasia, sterilization and other techniques has its roots in a time-honored intellectual tradition; second, to point out that the ideology bore remarkable fruit in the twentieth century; thirdly, to suggest, as we shall see, that the ideology is far from absent in contemporary socio-political thinking. Given these and other pressures, certain emerging technologies and databases are able to facilitate in new and devastating ways the identification and elimination of those regarded unfit and unproductive, in ways that are so institutional and bureaucratic that they become routine. Since the ideological interest in the

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[28] Margaret Sanger, WOMAN AND THE NEW RACE, (1920). Available at: http://infomotions.com/etexts/gutenberg/dirs/etext05/7wmnr10.htm

[29] Julian Huxley, UNESCO ITS PURPOSE AND PHILOSOPHY, A PREPARATORY COMMISSION OF UNESCO, (1946) at 21. http://unesdoc.unesco.org/images/0006/000681/068197eo.pdf. (last visited, 08/14/2008)

elimination of the unfit has not disappeared and because many proponents of eugenics reject the principle against instrumentalization and the principle of equal dignity, there is good reason to believe these dangers are real rather than imaginary. With information tracking devices, the goal of the elimination of the unfit may be accomplished via insurance companies, government screening policies, advance directives and other disincentives to procreate or continue living. These are ways of implementing eugenicist ideals that are infinitely more sophisticated but no less morally problematic than those adopted in the 20th century in Germany, America, Australia, Scandinavia and elsewhere. While the developments may be regarded progressive by advocates of eugenics, these ends are won by altering attitudes (respect for the vulnerable, the young, the old and the disabled), in ways so fundamental that they are likely to have serious intergenerational implications. It is far from surprising that the liberalism and eugenics of Sanger, Wells and many of the Bloomsbury Group, should have ushered in an age that has so decimated the native population of Western liberal nations that their birth-rate is nowhere near replacement level while replacement is taking place by the very people that certain amongst them regarded as the "unfit", "unwanted" and sub-optimal. I have argued this point elsewhere[30] and leave the self-destructiveness of liberalism for another day. Our principle concern is with the dangers of central medical and biometric databases.

III. INTERNATIONAL LAW AND DISABILITY RIGHTS

A. POST-WAR SENSIBILITIES

The horrors that emerged during the Second World War are well known and need no recounting. Indeed many European conventions and codes may be regarded a direct response to the violations of the innocent demonstrated so spectacularly in the twentieth century. That Julian Huxley felt it necessary to insist that "the eugenic problem" be re-visited so that "much that now is unthinkable may at least become thinkable" is testimony to the shock caused by revelations of the Nazi eugenics atrocities.

It is at least arguable that the *European Convention for the Protection of Human Rights and Fundamental Freedoms* was brought into existence precisely because certain fundamental human rights had been systematically violated in 20th century Europe.[31] The idea behind the convention was to articulate universal

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[30] For an analysis of the self-destructiveness of liberalism Jacqueline Laing, *Law Liberalism and the Common Good* in HUMAN VALUES: NEW ESSAYS ON ETHICS AND NATURAL LAW Edited by David S. Oderberg and T.D.J. Chappell, (2004) at 184-216.

[31] Numerous international documents support a total ban on non-therapeutic research on the mentally incompetent These include the NUREMBERG CODE (1947) at 1 "The voluntary

and timeless principles against which domestic legislatures could be tested. Whether positive international law is able to supply the need for a timeless and universal standard given its status as positive law is a question we leave for another day. What can be asserted with some confidence is that the abuses of the twentieth century gave rise to a new awareness that social convention cannot be the final arbiter of human rights.

The notion of equal dignity informs Article 2 of the *European Convention for the Protection of Human Rights and Fundamental Freedoms* which provides that:

> "Everyone's right to life shall be protected by law. No-one shall be deprived of his life intentionally save in the execution of the sentence of a court following his conviction of a crime for which this penalty is provided by law."[32]

Importantly for the rights of the disabled, Article 3 too states that:

> "No one shall be subjected to... inhuman or degrading treatment or punishment."[33]

Article 8 also states that:

> "Everyone has the right to respect for his private and family life, his home and his correspondence."[34]

Non-discrimination against the disabled is also made explicit in Article 14 which stipulates that:

> "The enjoyment of the rights and freedoms set forth in this Convention shall be secured *without discrimination* on any ground such as sex, race, colour, language, religion, political or

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consent of the human subject is absolutely essential"; WORLD MEDICAL ASSOCIATION, DECLARATION OF HELSINKI: RECOMMENDATIONS GUIDING PHYSICIANS IN BIOMEDICAL RESEARCH INVOLVING HUMAN SUBJECTS, adopted by the 18th World Medical Assembly, Helsinki Finland, June 1964; the International Covenant on Civil and Political Rights G. A. Res. 2200 (XXI), 999 U.N.T.S. 171 (1966), art 7; the World Health Organizations, Guidelines for good clinical practice for trials on pharmaceutical products (1995) WHO Technical Report series No. 850, Annex 3 at 3.3 (f) and (g). Expressing certain reservations on these non-therapeutic invasions see Penney Lewis, *Procedures that are Against the Medical Interests of Incompetent Adults* 2 OXFORD JOURNAL OF LEGAL STUDIES. 575-618 (2002).

[32] European Convention for the Protection of Human Rights and Fundamental Freedoms, Dec. 4, 1950, art. 2 , http://conventions.coe.int/treaty/en/Treaties/Html/005.htm.

[33] *Id.* art. 3.

[34] *Id.* art. 8.

> other opinion, national or social origin, association with a national minority, property, birth or other status."[35]

The fact that a person is disabled, even severely disabled, is no grounds to discriminate against his rights to life and to freedom from inhuman and degrading treatment. This affirms the inherent dignity of every person however disabled he or she might be.

The twentieth century also witnessed non-therapeutic research on the non-consenting in hospitals and institutes across Europe and in the U.S. The experimentation on the vulnerable and disabled is now well-known and needs no repeating. Shortly after the war, various international instruments supported a total ban on non-therapeutic research on the mentally incompetent. These included the Nuremberg Code (1947) at 1 "The voluntary consent of the human subject is absolutely essential."[36] The World Medical Association Declaration of Helsinki: Recommendations Guiding Physicians in Biomedical Research Involving Human Subjects, adopted by the 18th World Medical Assembly, Helsinki Finland, June 1964 required that "[i]n research on man, the interests of science and society *should never* take precedence over the interests of the subject."[37] Other Covenants seeking to prohibit utilitarian invasions on the non-consenting included the International Covenant on Civil and Political Rights article 7 which stated that "No-one shall be subjected without his free consent to medical or scientific experimentation."[38] The World Health Organizations, Guidelines for good clinical practice for trials on pharmaceutical products (1995)[39] also articulate outright prohibitions on non-therapeutic research without express consent. Likewise there is hope for the vulnerable incapacitated in the *Convention on the Rights of Persons with Disabilities* which contains numerous re-statements and clarifications of some of the protections already mentioned: the right to life (article 10), freedom from medical and scientific experimentation

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[35] *Id*. art. 14.

[36] "The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision." Nuremberg Code (1947).

[37] World Medical Association, Declaration of Helsinki: Recommendations Guiding Physicians in Biomedical Research Involving Human Subjects, adopted by the 18th World Medical Assembly, Helsinki Finland, June 1964. Recent alterations to the Declaration merely highlight the novelty of recent moves to permit what was, at one time, regarded as unthinkable.

[38] G. A. Res. 2200 (XXI), 999 U.N.T.S. 171 (1966).

[39] WHO Technical Report series No. 850, Annex 3 at 3.3 (f) and (g)

without consent (article 15), freedom from exploitation and abuse (article 16 (5)), respect for physical and mental integrity on an equal basis with others (article 17), retention of fertility on an equal basis with others (article 23 (1)(c)), freedom from discriminatory denial of health care or food and fluids on the basis of disability (article 25 (f)).

B. CORPORATE INTERESTS AND ALTERING INTERNATIONAL LAW

As hoped by Julian Huxley, memories are short and financial and medical interests powerful. The 2000 Declaration of Helsinki, in contrast with its first incarnation which required that "[i]n research on man, the interests of science and society *should never* take precedence over the interests of the subject"[40] and in contrast with the Declaration of Geneva 1948 which contained the affirmation that "the health of my patient shall be my first concern", outlines the following social utilitarian agenda:

> "2. It is the duty of the physician to promote and safeguard the *health of the people*. The physician's knowledge and conscience are dedicated to the fulfillment of this duty.
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> 3. The Declaration of Geneva of the World Medical Association binds the physician with the words, "The health of my patient will be my first consideration," and the International Code of Medical Ethics declares that, "A physician shall act only in the patient's interest when providing medical care which might have the effect of weakening the physical and mental condition of the patient." (This latter no longer appears in the updated version of the I.C.M.E.)
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> 4. Medical progress is based on research which ultimately must rest in part on experimentation involving human subjects.
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> 5. In medical research on human subjects, *considerations related to the well-being of the human subject* should *take precedence* over the interests of science and society....
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> 26. Research on individuals from whom it is not possible to obtain consent, including proxy or advance consent, should be done only if the physical/mental condition that prevents obtaining informed consent is a necessary characteristic of the research population. The specific reasons for involving research subjects with a condition that renders them unable to give informed consent should be stated in the experimental protocol for consideration and approval of the review committee. The

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[40] *Id.*

> protocol should state that consent to remain in the research should be obtained as soon as possible from the individual or a legally authorized surrogate."[41]

The absolute prohibitions on non-therapeutic research performed upon the non-consenting have been removed. The duties of the doctor relate in part to "the health of the people" not that of his "patient". The International Code of Medical Ethics articulates an incoherent duty of physicians. The demands of medical progress alone[42] are outlined in unmistakable terms.

Perhaps unsurprisingly given the current intellectual climate, there is growing pressure from drug companies and their lobby-groups for non-therapeutic research conducted without prior consent. This view is reflected not only in Article 26 of the 2000 version of the Helsinki Declaration and the European Convention on Human Rights and Biomedicine (the *Biomedicine Convention*), interpreted by reference to its Additional Protocol concerning Biomedical Research (see Council of Europe 1997 and 2005). It is observable too in paragraph 4.8.14 of the 1996 guidelines of the self-styled International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use. In short, Article 17(2) of the Biomedicine Convention permits research that *will not benefit the participant*, as long as it is intended to benefit those with the participant's condition or of the same age and entails only minimal risk and minimal burden for the participant. Since risk and burden are regarded as minor in severely mentally disabled patients, virtually any kind of invasive research is envisaged as permissible.

Research without consent in emergency situations is also addressed by the Additional Protocol concerning Biomedical Research. Article 19 of the Protocol states that where the urgency of the situation renders it impossible to obtain prior consent from the participant or even a legal proxy, research may still take place as long as certain conditions are satisfied.[43] These require that research of comparable effectiveness cannot be carried out in non-emergency situations, the result is approved by the competent body, that the participant's previously

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[41] World Medical Association, Declaration of Helsinki: Recommendations Guiding Physicians in Biomedical Research Involving Human Subjects, Edinburgh, October, 2000.

[42] In this new environment, the strategy of tarring critics as a new class of "know-nothings" whose ignorance hampers science and corporate, government and academic income-generation schemes, highlights a new era of demonization of intellectual opponents: MORTON HUNT, THE NEW KNOW-NOTHINGS: POLITICAL FOES OF THE SCIENTIFIC STUDY OF HUMAN NATURE, (1998).

[43] Council of Europe, Additional Protocol to the Convention on Human Rights and Biomedicine Concerning Biomedical Research, 25 Jan. 2005. Additional Protocol, art. 19.

expressed objections are respected, and research that is *not intended to produce a benefit* to the participant must seek to benefit persons in the same population and entail only *minimal risk and burden* (Art. 19(2)).

Of course, it is possible that some of the research and intervention contemplated is indeed minor and justifiable on grounds that they are likely to be in the best clinical interests of the patient. However, given the utilitarian thrust of contemporary positive international law and domestic law of the kind we shall soon examine, it cannot safely be supposed that the interests of science and society would not take precedence over the interests of those regarded as having no meaningful life and no interests of any kind. If a patient has no best interests of any kind, then logically speaking, virtually anything may be done to him, so long, perhaps, as it does not distress onlookers.

Conceptually speaking, the combined rejection of the EDP and commitment to the idea of living people with "no best interests", "grotesque lives" and "lives unworthy of life" have significant implications for the disabled. They constitute the mechanism by which assault, experimentation, mutilation and homicide become possible and desirable. In what follows, an analysis of recent UK law reform is used to highlight threats to disability rights once jealously guarded by post-war sensibilities and legislation.

C. THE DISABILITY CONVENTION: FOOD AND WATER, NON-THERAPEUTIC RESEARCH AND FERTILITY.

The threats presented to disability rights by such interests are borne out by the recently adopted Disability Convention and are outlined and discussed below. The *Convention on the Rights of Persons with Disabilities* with its *Optional Protocol* was adopted on 13 December 2006 at the United Nations Headquarters in New York, and was opened for signature on 30 March 2007. This document is one of the few remaining defenses of the EDP in international law. In the face of the fluctuating Biomedicine Conventions, and Helsinki and Geneva Declarations adapted to the demands of science, commerce and cash-strapped governments, the Disability Convention brings hope to the vulnerable that we all become when we are in hospitals and institutions around the world. Among the affirmations of the intrinsic human dignity of the disabled presented in this document are Articles 10, 15, 16, 17, 23, and 25. These provisions explicitly recognize the temptation there is to deny the disabled food and fluids, use them in experiments, sterilize them, abuse, mutilate and kill them.

> "ARTICLE 10 - RIGHT TO LIFE
>
> States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others...

> ARTICLE 15 - FREEDOM FROM TORTURE OR CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT
>
> 1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation...
>
> ARTICLE 16 – FREEDOM FROM EXPLOITATION, VIOLENCE AND ABUSE
>
> 5. States Parties shall put in place effective legislation and policies, including women and child focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted...
>
> ARTICLE 17 – PROTECTING THE INTEGRITY OF THE PERSON
>
> Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others...
>
> ARTICLE 23 – RESPECT FOR HOME AND THE FAMILY
>
> (c) Persons with disabilities, including children, shall *retain their fertility* on an equal basis with others....
>
> ARTICLE 25 – HEALTH
>
> In particular, States Parties shall:
>
> (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance ...
>
> (f) Prevent discriminatory denial of health care or health services or *food and fluids* on the basis of disability..."

Although it has 129 signatories, the Convention is in the process of being ratified. There are currently 71 signatories to the Optional Protocol, 27 ratifications of the Convention and 16 ratifications of the Optional Protocol. Those representing corporate and research interests continue to lobby governments to prevent ratification. The resulting document, however, remains a remarkable defense of the disabled.

The *Disability Convention* suggests that the EDP is most fully acknowledged by the disabled and their advocates themselves. Wisdom is most often gained through suffering. The lessons of history suggest that there would be a substantial temptation to eradicate suffering by eradicating sufferers by those with commercial, financial, research and ideological eugenics-style interests.

IV. EUGENICS, SOCIAL UTILITY, AND HUMAN DIGNITY

Part of the problem with eugenics, in a climate in which corporate, institutional and other interests are permitted free reign, is precisely its focus on productivity and social utility instead of human dignity and the just treatment of individuals, both here and now and in an inter-generational context. This in part explains the utilitarian anxiety about those regarded unfit or unproductive. But how does this tie in with the information revolution, biometric data and central databases? There is, after all, much optimism about information and communication technology and the increased efficiency offered by centralized databases. The answer to this question is best summed up with an analysis of the direction of contemporary law reform and its implications for the disabled.

A. LAW REFORM: WHICH TECHNOLOGIES? WHAT THREAT?

In recent times there have been numerous significant alterations to domestic British law. Between 1997 and 2001, it has been pointed out, over 3000 new crimes were created and many laws passed that have important implications for civil liberties, human rights and the rule of law.[44] In 2003 I highlighted some of these important alterations of law in the British national press arguing that much English law was being turned on its head.[45] It outlined the far-reaching law reform then being undertaken by government.[46]

Those same moves continue apace. At that time I spoke of the collection and use of DNA data from people who had not been convicted of any offence. I pointed out that the reason this was objectionable was the long-held principle in English law that an individual is presumed innocent until proven guilty. Since then one of the hundred or so Criminal Justice Acts introduced by the current government has made the practice of State officers taking and using the DNA of those not convicted of any offence, quite legal.

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[44] Nick Clegg, Liberal Democrat Home Affairs spokesman: "Since Tony Blair came to power, Labour has created more than 3,000 new criminal offences. That's almost one a day." Liberal Democrat party conference, 18 September 2001; Kirsty Walker, *3,000 new criminal offences created since Tony Blair came to power* DAILY MAIL 16 August 2006.

[45] Jacqueline Laing, *Welcome to Big Brother Britain*, DAILY MAIL 28 March, 2003, at 12.

[46] This paper considers only certain of the alterations to the domestic law of the United Kingdom that have a bearing on civil liberties, parliamentary sovereignty and the rule of law. These will undoubtedly have counterparts in the United States and other jurisdictions. This paper concentrates on the legal position in the United Kingdom for the purposes of simplicity.

Since then there has been a veritable explosion of legislation undermining the principle of the presumption of innocence, individual liberty and the rule of law. Thousands of new crimes have been created since 1997. I spoke then of moves to extend detention beyond the 24 hour limit to 36 hours. The government has now accepted 42 day detention without charge.[47] We have seen: abolition of the double jeopardy rule, the erosion of the right to silence, now a conditional right from which adverse inferences may be drawn,[48] confiscation of assets thought to be derived from crime without any need for a criminal trial and without all the protections afforded by the criminal law.[49]

The "Snoopers Charter" is well and truly entrenched now with at least 23 Statutory Instruments made under the Regulation of Investigatory Powers Act 2000. These laws permit a vast number of officials, insurance companies, and bureaucrats, access to private information relating to personal telephone calls, emails, purchases and much more.[50]

Ongoing revelations that the United States intelligence agencies are to be given access to much private data belonging to British individuals merely confirms the proposition that confidential information is now in the hands of hidden and unaccountable parties whose interests are not the same as those to whom the information properly belongs nor indeed with their own governments.[51] These developments are worrying enough in themselves but there are significant implications for disability rights.

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[47] David Davies, the Shadow Home Secretary recently resigned from his post because of the threat that he perceived to the rule of law and genuine political freedom as a result of this law reform: http://news.bbc.co.uk/1/hi/uk_politics/7450627.stm

[48] Criminal Justice and Public Order Act 1994 as later amended by numerous statutory instruments.

[49] Proceeds of Crime Act 2002.

[50] At the same time proposals are in place to satellite track every car in Britain with a view to introducing a pay as you go road-user scheme, ostensibly in order to relieve congestion. Residents of and visitors to London in particular will know about the vast number of surveillance cameras on every street, pavement and public place with Britain possessing one fifth of the world's surveillance cameras, whose justification is said to be deterrence of traffic and criminal offences. This may be regarded a matter tangential to the question of medical and biometric databases. But in a climate in which dissent is no longer tolerated this kind of tracking is likely to be a matter of some importance also.

[51] Daniel Martin, *US to get access to your personal files - bank details, visited websites, salaries* DAILY MAIL, 29 June, 2008.

B. ID CARDS, DNA DATA AND MEDICAL RECORDS

The government plans to upload millions of confidential medical records, in many cases without patients' consent, to a central national database from where information can be made available to numerous unaccountable third parties. Details of genetic illnesses, mental and physical, may also be included, and there are no laws to prevent the addition of DNA profiles. The government has a £12 billion scheme to computerize the health service, which is currently underway. The National Health Service initiative is said to be "the world's biggest civilian IT project" in which each person's cradle-to-grave medical records no longer remain in the confidential custody of their GP practice. Instead, it is planned that 50 million medical summaries will be loaded on the Spine[52] and subject to the scrutiny of numerous bureaucrats, busybodies and also, ominously for all of us, insurance companies.

The British government has plans to require citizens to hold an identity card.[53] Many want the cards to hold much more than identifying information: social security information, tax details and even medical records and a genetic profile. All of this would be electronically encrypted and not verifiable by the card holder. What this all spells is massive new scope for social control in implementing new programmes. It also invites new parties power over the costly, those with inheritable diseases, the disabled, the historically reviled (people of certain races, classes, creeds and sexual orientation) and many others. It also allows new parties the power over individuals and classes of people regarded politically undesirable. For disability rights, the implications are profound. It is sometimes difficult to envisage how novel programmes could operate to undermine disability rights.

As observed in previous sections, social structures that enable the identification of those with inheritable diseases, giving them incentives to undergo sterilization, abortion and long-term contraception, are bound to be of eugenic value. Whilst in hospital, the denial of treatment to those deemed to have "worthless lives" has historical precedent and need not be regarded as unreal in the current utilitarian environment. Those regarded a cost to the state have more than one reason to fear for their very lives and safety. The goals of eugenicists like Sanger, Wells and Huxley are doubtless better achieved by efficient management targets and institutional inducements as well as penalties. The speed with which the identification of whole classes of unfit and unproductive individuals (and their progeny) can take place will doubtless increase the efficiency of the process.

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[52] David Leigh and Rob Evans, *Warning over privacy of 50 million patient files*, THE GUARDIAN, 1 November 2006.

[53] Identity Cards Bill 2004.

As we have seen in previous sections there is greater scope than ever for eugenic intervention via "agencies under social control." It is important to realize that concerns to improve the stock of humanity are undoubtedly inter-generational. These targets affect not merely this person here and now, but also his descendants. These interventions already exist at the beginning of life by screening for disability and selective abortion (for those unborn regarded unfit or progeny of the unfit). For those regarded as "superior stock", there are long-established reproductive programmes involving their "genes," in the context of artificial reproduction, (often irrespective of whether these allegedly optimal individuals are available to nurture the child they biologically parent).[54] There is continuing scope for eugenic intervention, as Sanger outlined, by way of sterilization and other contraceptive services offered to the "unfit" and "undesirable" so that their "stock" is minimized.

Finally there is, as Wells and others pointed out, the possibility of eugenic intervention by way of induced death, the euthanasia of the "unfit and unproductive." Whilst refusal of treatment and care can be construed as a useful cost-saving device where eugenically designated sub-optimal subjects are concerned, organ transplantation, research and clinical trials remain lucrative ends to which the "worthless" living body can be put. In a context in which eugenicist ideals combine with the demands of efficiency, inter-generational cost-saving and profit maximization, biometric data and information databases undoubtedly offer considerable possibilities.

Improved means of identifying those most vulnerable and best suited to socially useful tasks remains vital to the efficiency of such programmes. Central medical and DNA databases speed up the business of identifying perfect match organs, costly individuals, and inter-generationally undesirable stock. Bearing in mind that this sensitive information is available to government and business administrators, insurance companies and sundry others the dangers of information misuse are all too real.

It will be objected that these scenarios are alarmist and implausible and that discrimination against the disabled (and others traditionally regarded undesirable) has been stamped out thanks to new human rights awareness following the war. In what follows, it is argued that these developments are more than mere possibilities. On the contrary there is reason to believe that recent law reform allows the interests of science, efficiency and eugenics to take precedence over the rights and dignity of the disabled.

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[54] Jacqueline Laing, *Artificial Reproduction, Blood Relatedness and Human Identity* 89 MONIST: INTERNATIONAL JOURNAL OF GENERAL PHILOSOPHICAL ENQUIRY 548-567(2006); Jacqueline A. Laing and David S. Oderberg, *Artificial Reproduction, the 'Welfare Principle', and the Common Good* MED. L. REV., 13 (2005) 328-356.

Recent changes to UK law governing the incapacitated illustrate the radical nature of contemporary law reform. There is every reason to believe the altered law is at odds with post-war prohibitions and human rights law properly understood. Legislation is now in place to permit novel third parties (often ignorant of the implications of what they are authorizing) to remove life-sustaining treatment (which includes food and fluids), to authorize non-therapeutic research, removal of tissue including organs as well as non-consensual sterilization. Radical new impetus has recently been given to the doctrine of substituted consent. This permits third party representatives to authorize what was once outlawed both at international law and domestically. Given that what is envisaged is not merely induced death, but *non-consensual* sterilization, non-therapeutic research and removal of organs, the threat to disability rights presented by information databases, cannot be dismissed as imaginary.

C. ALTERING POSITIVE LAW: RIGHTS OF THE INCAPACITATED

The positive domestic law surrounding incapacity and disability has seen dramatic alteration in Britain in recent times. The *Mental Capacity Act 2005*[55] has significant implications for mentally incapacitated patients in the UK. Most notably they give a catalogue of new actors the power to withhold and withdraw "treatment" including nutrition and hydration from patients who, it should be highlighted, may not be dying.

These new decision-makers include donees under lasting powers of attorney[56] (attorneys or representatives) and those purporting to bear the advance decisions[57] (which may be verbal) of mentally incapacitated patients. In addition, wide-ranging powers are established in respect of a virtually unrecognizable Court of Protection now empowered to make life and death decisions governing removal of "treatment" as well as decisions to perform research on, remove tissue from, sterilize and abort the young of mentally incapacitated patients. I have argued elsewhere that the Act breaches

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[55] Mental Capacity Act 2005.

[56] The Act extends the ambit of existing powers of attorney to include medical and indeed life-and-death decision-making. Section 11(8) of the Act states that a lasting power of attorney extends to refusing consent to the carrying out or continuation of *life-sustaining treatment* (which includes food and fluids after *Airedale NHS Trust v. Bland* [1993] AC 789, where the lasting power of attorney contains express provision to that effect. Section 11(7)(c) extends to consent to "treatment" which includes non-voluntary sterilization and abortion.

[57] Section 26(3) "A person does not incur liability for the consequences of withholding or withdrawing a treatment from P, if at the time, he reasonably believes that advance decision exists which is valid and applicable to the treatment."

fundamental human rights and inverts good medical practice by criminalizing staff intervening to save the lives of their patients by using very simple treatments (like antibiotics and insulin) as well as basic care like food and fluids. At the same time, for a financially overburdened National Health Service, it also places the legal responsibility for these decisions, on unaccountable substitute decision-makers. Whereas, prior to the Act bad clinical treatment could be the subject of a tort action, disciplinary proceedings or even criminal proceedings, such is not the case with bad clinical treatment authorized by a substitute decision maker. Needless to say, these substitute decision-makers cannot be sued for bad medical treatment in the way that the NHS and doctors once could be.

The legislative basis for this recent law reform is to be found in the *Mental Capacity Act 2005* which in turn needs to be read in conjunction with other legislation that has appeared recently. The *Human Tissue Act 2004* (which came into force in 2006) permits *inter alia* use of tissue from non-consenting patients and the *Medicines for Human Use (Clinical Trials) Regulations 2004* (S.I. 2004/1031) allows for clinical drug trials on non-consenting patients on the authority of novel representatives. The *Mental Capacity Act 2005* also expressly permits non-therapeutic research on non-consenting subjects on the authority of novel third parties.

As we shall see, these proposals exist against an intellectual backdrop that can be described as sympathetic to utilitarian concerns. In successive volumes of *The Lancet* senior medico-legal figures representing the International Forum for Transplant Ethics, make the case for removal of organs from non-consenting living patients in a permanent non-responsive state for use in transplantation. They also recommend societal opt-out organ retention as a way of increasing the stock of organs available for transplant.[58] For non-utilitarian bio-ethicists these suggestions might highlight the aims, driving interests and moral limits of the legislation.[59]

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[58] R. Hoffenberg, M. Lock, N. Tilney, C. Casabona, A.S. Daar, R.D. Guttmann, I. Kennedy, S. Nundy, J. Radcliffe-Richards and R.A. Sells, Should organs from patients in permanent vegetative state be used for transplantation? 350 THE LANCET, 1320-1321 (1997); I. Kennedy, R.A. Sells, A.S. Daar, R.D. Guttmann, R. Hoffenberg, M. Lock, J. Radcliffe-Richards and N. Tilney, The case for "presumed consent" in organ donation 351 THE LANCET 1650-1652 (1998).

[59] It is also worth remembering too that some twenty years earlier in 1984, at the 5th Biennial Conference of the World Federation of Right to Die Societies held in Nice, Australian bioethicist Dr. Helga Kuhse suggested a strategy for the implementation of euthanasia by lethal injection: “If we can get people to accept the removal of all treatment and care—especially the removal of food and fluids—they will see what a painful way this is to die and then, in the patient's best interest, they will accept the lethal injection”, RITA MARKER, DEADLY COMPASSION, at 94, 267 (1993). Arguing for voluntary euthanasia by lethal injection, see PENNEY LEWIS, ASSISTED DYING AND LEGAL CHANGE, (2007).

There was considerable opposition to the *Mental Capacity Act 2005* during its passage through Parliament not merely to the worrying dehydration questions raised but also to other matters. Controversial procedures like non-voluntary sterilization and non-voluntary abortion (then questionably permitted but only on a High Court order[60]) are now in the hands of these newly empowered agents. A profoundly different Court of Protection has emerged, one that no longer merely deals with the financial welfare of the incompetent but one that oversees his very right to food and water, and bodily integrity. Importantly, the Act allows non-therapeutic research (section 30) to be performed on certain mentally incapacitated patients *without their consent*. It abolishes the High Court's jurisdiction to hear applications on the above-mentioned matters with the substitution of (and even then only in certain cases) the Court of Protection, an institution that affords very little of the transparency, requirement of representation, ordinary appeal and procedural form demanded by other English courts.

Indeed the *2004 23rd Report of the Joint Committee on Human Rights* confirmed these and a number of other fears. At the time the Mental Capacity Bill ("the Bill") was being debated in Parliament, it was argued by this author[61] and others that the Mental Capacity Act would also raise the prospects of violations in respect of the right to life (art. 2 ECHR), freedom from inhuman and degrading treatment (art. 3), or respect for family and private life (art. 8)[62] and involve discrimination against the disabled (art. 14). It would also involve arbitrary deprivations of liberty occasioned by insufficient procedural safeguards as outlined in *Winterwerp v Netherlands*[63] and *HL v United Kingdom*[64] and use of easily alterable *Codes of Practice* to specify matters that affect the law of homicide and assault. It was argued that this involved an absence of procedural safeguards against abuse of fundamental human rights.

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[60] On non-voluntary sterilization of a disabled person: *Re F (Mental Patient: Sterilization)* [1990] 2 AC 1; on compulsory abortion *Re SG* [1991] 2 FLR 329 respectively.

[61] For a fuller discussion of the human rights abuses invited by this legislation see: Jacqueline Laing, *Food and Fluids: Human Law, Human Rights and Human Interests* in ARTIFICIAL NUTRITION AND HYDRATION (Christopher Tollefsen, ed.), (2008) at 77-100; *The Mental Capacity Bill 2004: Human Rights Concerns* FAM. L. J. 35 137-143 (2005); *Mental Capacity Bill - A threat to the vulnerable* 154 NEW L. J. 1165 (2004); *Disabled Need Our Protection* 101 LAW SOC. GAZ. 12 (2004); *The Right to Live: Reply to the Chief Executive of the Law Society* 102 LAW SOC. GAZ. 11 (2005). *"Vegetative" State – The Untold Story* 152 NEW L. J. 1272 (2002).

[62] See also *Glass v UK* (Application No 61827/00) [2004] 1FCR 553.

[63] (1979) 2 E.H.R.R. 387.

[64] (Application No. 45508/99) 5 October 2004.

Perhaps the most disquieting aspect of contemporary developments that flies in the face of the post-war prohibitions, particularly the *Nuremberg Code*, is found in the permission to conduct non-therapeutic research on the non-consenting. Section 30 of the Act permits intrusive research to be carried out on... a person who lacks capacity to consent if it is carried out— "(a) as part of a research project which is for the time being approved by the appropriate body..." Section 31 (4) (b) permits non-therapeutic research that has no potential to benefit P without P's consent provided that the research is "intended to provide knowledge of the *causes or treatment of, or of the care of persons affected by the same or a similar condition*." (The emphasis is mine.)

At the same time, the *Medicines for Human Use (Clinical Trials) Regulations 2004* [65] Schedule 1 Part 5 Regulation 12 makes express provision for clinical trials on non-consenting mentally incapacitated patients upon the consent of a "legal representative". In such a case: "[i]nformed consent given by a legal representative to an incapacitated adult in a clinical trial shall represent that adult's presumed will."[66] Attorneys, advance decisions and court appointed deputies are all mechanisms by which research on the non-consenting might be achieved. The Regulations do however require that: "[t]here are grounds for expecting that administering the medicinal product to be tested in the trial will produce a benefit to the subject outweighing the risks or produce no risk at all."[67] This requirement of "benefit to the subject" is only stated in the alternative in the Mental Capacity Act 2005. So the 2005 Act goes much further on this point than do the Clinical Trials Regulations.

There are, however, concerns about the way the regulations define the legal representative of an adult lacking capacity. If no satisfactory personal representative is available then either the doctor, if not involved in the clinical trial, responsible for the patient's care may be the legal representative, or indeed anyone nominated by the health service body providing care for the patient. The potential for conflicts of interest and the risks to the patient presented by this possibility have been commented upon.[68] Further the *Medicines for Human Use (Clinical Trials) Amendment (No. 2) Regulations* 2006/2984 came into force on 12 December 2006. These Regulations amend the *Clinical Trials Regulations (2004/1031)* to allow an incapacitated adult to be included in a clinical trial met

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[65] (S.I. 2004/1031).

[66] Medicines for Human Use (Clinical Trials) Regulations 2004 Schedule 1 Part 5 Regulation 12.

[67] Schedule 1 Part 5 Regulation 9.

[68] Richard Nicholson, *Another Threat to research in the United Kingdom* 328 BRIT. MED. J 1212-1213 at 1212(2004).

notwithstanding the fact that his legal representative has not given informed consent (paragraph. 4). Reg. 2 applies where: (i) treatment is required urgently; (ii) the nature of the trial requires urgent action; (iii) it is not reasonably practicable to meet the conditions specified; and (iv) the procedure adopted has been approved by an ethics committee. The Amendment Regulations therefore allow clinical trials in emergency situations on incapacitated adults *without consent*.

Further, the 2005 Act implies that a patient's very organs are at risk given the new moral and legal climate. After all, influential English-speaking philosophers have endorsed the idea of organ removal without explicit consent.[69] In 1995 there was public outcry to the draft Mental Incapacity Bill, as it was then called, because it envisaged the removal of tissue - and thus organs from - the non-consenting vulnerable (Clause 10 *Mental Incapacity Bill 1995*). The defense of this non-therapeutic intervention on the non-consenting mentally incapacitated may be regarded a broadly utilitarian one.

On this view, the mentally incapacitated patient, perhaps in a persistent non-responsive state, is regarded as a potential source of benefit to third parties and a "non-person"[70], having "no meaningful life" and therefore "no best interests" morally speaking. Once the patient is regarded in this way, there can be little reason to object to use of his body for the benefit of others. R. Hoffenberg, M. Lock, N. Tilney, C. Casabona, A.S. Daar, R.D. Guttmann, I. Kennedy, S. Nundy, J. Radcliffe-Richards and R.A. Sells suggested this in *The Lancet*[71] in an article entitled "Should organs from patients in permanent vegetative state be used for transplantation?" back in 1997. The authors argue that the only reason against removing organs from patients who are persistently non-responsive without their consent was that there was then no consensus to support the activity. Accordingly, it was concluded that: "For religious, cultural and other traditional reasons, it is likely that the proposal would be rejected, nevertheless, the arguments in favour are sufficiently compelling to justify serious debate."[72]

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[69] JOHN HARRIS, WONDERWOMAN AND SUPERMAN: THE ETHICS OF HUMAN BIOTECHNOLOGY 104-7 (1992); PETER SINGER, RETHINKING LIFE AND DEATH, (1994).

[70] Op cit. see PETER SINGER PRACTICAL ETHICS (1979) cf. Jacqueline Laing *Innocence and Consequentialism: Inconsistency, Equivocation and Contradiction in the Philosophy of Peter Singer* in HUMAN LIVES: CRITICAL ESSAYS ON CONSEQUENTIALIST BIOETHICS, (David S. Oderberg And Jacqueline A. Laing eds.) 196-225 (1997).

[71] R. Hoffenberg, M. Lock, N. Tilney, C. Casabona, A.S. Daar, R.D. Guttmann, I. Kennedy, S. Nundy, J. Radcliffe-Richards and R.A. *Sells, Should organs from patients in permanent vegetative state be used for transplantation?* 350 THE LANCET, 1320-1321 (1997).

[72] *Id.* p. 1321.

These authors will be pleased with the progress made by way of recent legislation. They facilitate precisely the state of affairs they recommended in the *Lancet*. But there are good reasons to think the use of the non-consenting severely disabled for organ transplantation is at odds with the principle that every human being has an inherent dignity however disabled (as embodied in the Universal Declaration and the European Convention), with the principle of autonomy, with the Nuremberg Code, with the First Declaration of Helsinki, the Geneva Convention, and with the Hippocratic Oath to name but a few authoritative sources. There is reason to think too that even the most liberal understanding of the teachings of the great sacred traditions of the world would lead one to reject this utilitarian programme. Far from promoting progress, these legislative developments appear to invite human rights abuse. If such is the case, there is good reason also to suppose that these proposals will ultimately undermine confidence in the medical profession and medical research.

D. ALTERED INTERESTS AND SUBSTITUTE DECISION-MAKING

Whatever one may think of the controversial cases of *Bland* [73] (and in the US, *Schiavo*)[74], legislation that opens the door to substitute decision-making creates new hazards for the vulnerable. Given the multiple interests involved, the gravity of the outcomes envisaged (nothing short of mutilation and homicide) and the natural limitations of a vulnerable person's ability to successfully challenge the decisions involved, one might have expected an invocation of a precautionary principle. In reality the precautionary principle is now set out in terms that unambiguously allow scientific research, efficiency and social utility to take precedence over the interests of the vulnerable.[75]

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[73] *Airedale NHS Trust v. Bland* [1993] AC 789.

[74] Greer, George W., Circuit Judge. *In Re: The Guardianship Of Theresa Marie Schiavo, Incapacitated*, File No. 90-2908GD-003, Fla. 6th Judicial Circuit, February 11, 2000; *In re Guardianship Of Theresa Marie Schiavo, Incapacitated. Robert Schindler and Mary Schindler, Appellants, v. Michael Schiavo, as Guardian of the person of Theresa Marie Schiavo, Appellee*, Case Number: 2D00-1269, Florida Second District Court of Appeal, January 24, 2001*; In Re: Guardianship Of: Theresa Marie Schiavo, Incapacitated. Robert Schindler And Mary Schindler, Appellants, v. Michael Schiavo, as Guardian of the person of Theresa Marie Schiavo, Appellee*, Case Number: 2D01-3626, Florida Second District Court of Appeal, October 17, 2001.

[75] Government Response to the Report from the House of Commons Science and Technology Committee: Human Reproductive Technologies and the Law Annual Report, Department of Health, 21 September 2005, pp. 175 to 189. "Recommendation 3: We do not see why the area of human reproductive technologies should do anything other than proceed under a precautionary principle currently prevalent in scientific, research and clinical practice. This means - as specified in paragraph 46 above - that *alleged harms to society or to patients need to*

A target-setting culture that prioritizes information sharing, fewer insurance claims, cost-cutting initiatives, organs for transplant, live bodies for research, and responsibility shifting, can only serve to worsen the already precarious position of the disabled and incapacitated. The ignorance of substitute decision-makers who rely on interested medical opinion in an institutional context for their information, and the existing mix of interests are bound to be both dangerous and lethal. As we have seen, a new eugenics in which social utility trumps the inherent dignity of the human being under-girds much contemporary bioethics.

Given the socio-historical context in which these legislative reforms are taking place, central databases replete with medical and biometric information are far from unproblematic. They supply the wherewithal with which to identify those most vulnerable - those regarded unfit, unproductive and undesirable – as well as their assets, beliefs, and progeny. Not only is individual abuse of data possible on a one-off basis, institutions, both governmental and corporate, now have well-established and elaborate systems to make the elimination of the undesirable, in the words of Wells, "worth the while". Far from safeguarding the vulnerable against abuse and homicide, recent legislation invites the same. With new industries and interests in the human body, its parts and its offspring, information databases of the kind discussed present a novel threat to human dignity.

V. CONCLUSION – BEST PRACTICES

At institutions and conferences around the globe, much time and effort is expended on discussing the rights of the disabled. The critical issues, however, are often left unaddressed. E-inclusion and monolithic central databases alike are hailed as presenting humanity with undeniable scientific progress. Debates focus on quality-of-life matters, on access to information technology and on other pragmatic issues. These very concerns highlight a certain utilitarian attitude to disability for they fail to analyze latent and more fundamental questions about attitudes to the disabled and the implications of new technologies for the future given the history of the twentieth century.

Corporate, institutional and research interests should not obscure the very real risk of human rights violations so evident in Europe's recent past. When the principle affirming the inherent dignity of each person, however disabled, is comprehensively overtaken by the demands of efficiency, progress and maximal

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be demonstrated before forward progress is unduly impeded. (Paragraph 47)." [Emphasis added].

social utility, and when a new eugenics, indifferent to the justice of the means used to achieve ends is pervasive, we are likely to see systematized abuse not merely of private information but of whole classes of people. In this environment, the risks associated with vast central medical databases are likely to far outweigh their undoubted value.