

Abstract

The current debate over cloning and germline gene therapy is usually considered in terms of bioethics. The Council of Europe and UNESCO have, however, adopted normative instruments on the human genome, and one that draws heavily on human rights is under consideration at the United Nations. This article suggests the need for more thorough analysis of the underlying assumptions of the references to human rights in these instruments and of the various possible interpretations of the human rights affected by developments in biotechnology. The restrictive approach to genetic manipulation tends to assume the value of protecting the human genome as it is and acknowledges a welfare function of the state. The permissive approach, on the other hand, relies more on a utilitarian calculus of what is good for future generations and a neoliberal political and economic perspective of what the market will bear.

Le débat actuel sur le clonage et la thérapie génique germinale est généralement considéré d'un point de vue bioéthique. Toutefois, des instruments normatifs concernant le génome humain ont été adoptés par le Conseil de l'Europe et l'UNESCO; un nouvel instrument, qui s'applique au clonage reproductif humain, est actuellement à l'étude à l'échelon des Nations Unies. Cet article suggère la nécessité d'une analyse approfondie des hypothèses sur lesquelles reposent les références aux droits de l'homme mentionnée par ces instruments ainsi que les différentes interprétations possibles des droits humains concernés par les développements de la biotechnologie. L'approche restrictive de la manipulation génétique semble accepter la valeur de la protection du génome humain en l'état et reconnaît à l'État une fonction d'aide sociale. L'approche permissive, en revanche, s'appuie plutôt sur un calcul utilitaire des avantages pour les générations futures ainsi que sur une perspective politique et économique néo-libérale de ce que sera le marché.

El debate actual sobre la clonación y la terapia génica germinal es normalmente considerado en el campo de la bioética. Sin embargo instrumentos normativos sobre el genoma han sido adoptados por el Consejo Europeo y la UNESCO, y uno más sobre clonación reproductiva humana basado en derechos humanos está bajo consideración en las Naciones Unidas. Este artículo sugiere la necesidad de un análisis más profundo de las suposiciones subyacentes en las referencias a derechos humanos en estos instrumentos y de las varias interpretaciones posibles de los derechos humanos impactados por desarrollos en la biotecnología. Un enfoque limitado de la manipulación genética tiende a dar por sentado el valor de proteger el genoma humano en su estado actual y reconoce el papel protector del gobierno. De otra parte, un enfoque más permisivo se justifica en un cálculo utilitario de lo que es mejor para generaciones futuras y en una perspectiva neo-liberal económica y política de lo que el mercado podrá soportar.

HUMAN RIGHTS ASSUMPTIONS OF RESTRICTIVE AND PERMISSIVE APPROACHES TO HUMAN REPRODUCTIVE CLONING

Stephen P. Marks

As the United Nations (UN) General Assembly prepares to consider an International Convention against Reproductive Cloning of Human Beings, the scholarly debate over human rights issues raised by the prospect of this technology is growing in intensity.¹ The Human Genome Project (HGP) has fueled the disparate perceptions that genetic manipulation can either improve human lives or create uncontrollable mutation and economic exploitation.² Claims by certain research labs that they are proceeding with cloning of humans, along with the more credible advances made by the biotechnology industry, have stimulated the intergovernmental and scholarly debate.^{3,4}

George Brand anticipated the human rights implications of human genetic manipulation at least 30 years ago when he drew attention to the human rights problems of "artificial in ovulation; in vitro fertilization [IVF]; parthenogenesis; choice of sex of offspring; creation of human beings by an asexual process called cloning; manipulation of the DNA molecule so as to interfere with the processes of heredity ('genetic surgery'); the improvement, by procedures

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adopted before birth, of the future intelligence of a child; and the creation of part-human chimeras."⁵ "It is easy," he warned, "but dangerous, to dismiss all of these possibilities as science fiction."⁶ In fact, the issue of the impact that developments in science and technology will have on human rights has been on the agendas of international organizations at least since 1968.⁷

Today, human rights concerns range from the narrow question addressed by the draft UN convention on human reproductive cloning to germline gene therapy, embryonic stem cell therapy, somatic gene therapy, all questions that arise in relation to genomics, and biotechnology.⁸⁻¹² This article, however, is limited to the human rights issues raised by the first two applications.

The ethical and human rights issues involved are speculative since no human clone has been produced, and, according to a World Health Organization (WHO) study, only one attempt at germline gene therapy has been reported.¹³ However, a National Institutes of Health (NIH) study has stated, "With one notable exception [a French study in which a therapeutic transgene was introduced into the bone marrow cells of children], no therapeutic effects have been achieved in gene therapy trials to date."¹⁴ Somatic gene therapy has been studied intensively, with a few successful outcomes.¹⁵

The potential danger of this type of genetic engineering—and even the inheritability of transgenes—is highly speculative, though "it is not outside the expertise of existing IVF clinics."¹⁶ A partner in a biotech investment firm has said, "I suspect there are more groups than we know who are actually working on therapeutic cloning."¹⁷

Those who would ban human experimentation in cloning and germline gene therapy—applying a *restrictive* approach—fear that such technology threatens human existence as we know it because the genome of future generations will undergo unpredictable mutations and thus alter human nature itself. The more *permissive* approach favors improving human well-being by eliminating life-threatening diseases and enhancing the quality of life and the capacities of human beings. The tension between hope for and

fear of advances in biotechnology and genetics has profound philosophical, political, and economic ramifications. This tension is fueled by divergent and partial responses offered by international trade and intellectual property law, human rights law, and specific instruments on biomedicine.¹⁸⁻²⁰ The interpretation of the human rights implications of cloning and germline therapy is colored by those assumptions, with the consequence that reference to existing instruments of human rights law results at best in ambiguous applications of these standards and more commonly in radically contradictory interpretations.

I have proposed a framework for assessing the human rights implications of this technology elsewhere.²¹ For the purposes of this discussion, I will therefore focus on the ways philosophical and economic assumptions of the restrictive and permissive positions affect the interpretation of human rights standards, using the examples of the human rights to dignity, to found a family, and to health.

The Restrictive Approach

The Economist has described the proponents of the restrictive approach as “a ragbag of unlikely allies: a few academic political theorists, the Roman Catholic church, some anti-abortion zealots, the antiglobalisation brigade and a few mavericks.”²² The concerns of the “ragbag” are, however, serious ones that involve preservation of the human genome, protection of citizens from economic exploitation, and prudence in the face of uncertain risks.

Essentialist Assumptions

The Council of Europe, UNESCO, and draft UN texts represent the restrictive approach. They are supported and expanded on by civil society organizations that have campaigned for a “Genetic Bill of Rights,” and “a minimal core of a regime addressing the development and use of the new human genetic technologies.”^{23,24} This movement came together at a conference in Boston, Massachusetts, which was premised on the “need for policies to prevent the alteration of the human species through genetic engineering.”²⁵ Nongovernmental initiatives in this “species protection”

camp have recently proposed at least three international treaties that support their position. One, which grew out of the Boston conference, resulted in the draft of a Convention on the Preservation of the Human Species.²⁶ The second is a "Treaty to Protect the Genetic Common" that Jeremy Rifkin has reportedly been working on.²⁷ Third is a proposal to draft an international convention on the human genome under a common heritage of humankind regime.²⁸ The proponents of restricting the development and use of potentially harmful manipulation of the human genome tend to share a philosophical—what I call "essentialist"—assumption and a political-economic assumption of the welfare state. They tend to conflate the biological and moral essence of what it is to be a human being and to assume a protective function of the state, leading to certain preferred human rights invoked to support the restrictive position. The essentialist position holds that the human genetic makeup is sacred and must be preserved. It is somewhat allied with the deep ecological perspective that the "natural order" should not be tampered with. Environmentalists tend to regard biodiversity and the genetic complexity of species, as they have evolved over millennia, as worth preserving, and this attitude pervades the normative texts on the human genome.

The concept of the welfare state refers to state policies of intervention that would limit or modify the consequences of the free operation of the market where the social contingencies, such as unemployment and preventable mortality and morbidity, are largely beyond the control of the affected individuals. It includes a concept of positive rights, according to which the state should provide access to certain benefits, and the equality principle, according to which the state has duty to equalize opportunity and ensure basic needs. Welfare-state policies include measures to protect citizens against exploitation by private business where the citizen is easily exploited out of ignorance or unfavorable power relations.

Of course, politically conservative elements of the "rag-bag" mentioned above are not comfortable with the anti-free-enterprise implications of the welfare-state approach but can accept government limitation of freedom for the greater

cause of what is seen as the embryo's right to life. Current normative instruments in biomedicine extend this attitude to the negative value attributed to financial gain from biotechnology. Thus, the European Biomedicine Convention affirms that "The human body and its parts shall not, as such, give rise to financial gain," and the UNESCO Declaration similarly states that "The human genome in its natural state shall not give rise to financial gain."^{29,30}

The Human Right to Dignity

The essentialist and welfare-state perspective is often accompanied by references to the rights to dignity, identity, nondiscrimination, and life, as well as protection against torture, genocide, and other international crimes. These rights are presumed to provide a moral and legal foundation for the restrictive position on cloning and related technologies and are also concerned with the presumed nature, preservation, and integrity of humans, as distinguished from their liberty of action. The implications of genetic manipulation for each of these rights raise complex theoretical and practical issues that have not been sufficiently explored. To illustrate this complexity, I will comment on one right, namely, the right to dignity.

The protection of human dignity has been treated as the cornerstone of human rights.³¹ The Universal Declaration of Human Rights (UDHR) refers to "the inherent dignity . . . of all" and affirms that "All human beings are equal in dignity and rights."³² This concept is given prominence in the UNESCO Declaration as well: "Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics. That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity."³³ The UNESCO Declaration characterized human reproductive cloning as one of the "practices which are contrary to human dignity [and which] shall not be permitted."³⁴ The aim of the European Biomedicine Convention is "to safeguard human dignity and the fundamental rights and freedoms of the individual with regard to the application of biology and medicine."³⁵ States parties agree to "protect the dignity and iden-

tity of all human beings."³⁶ The protocol adds that "The deliberate creation of genetically identical human beings is contrary to human dignity and thus constitutes a misuse of biology and medicine."³⁷

Dignity is not well defined as a human right and, in fact, at the time the UDHR was adopted, it was regarded as an explanation of why human beings have rights rather than a right in itself.³⁸ Dignity usually means the state of being worthy of honor or respect and not being subjected to humiliation. But in the context of human rights, it is almost always associated with—and provides the human rights rationale for—other human rights. Thus, torture, substandard living conditions, or discriminatory practices may be a violation of "dignity," but in each case, the violation of dignity occurs concurrently with a violation of some other right, the exception being the few cases in which courts in Europe have applied a concept of "objective dignity."³⁹

Francis Fukuyama tries to identify a universal meaning of dignity as "Factor X" or "the human essence, the most basic meaning of what it is to be human."⁴⁰ After digressing around Nietzsche, Plato, and even Habermas, Rawls, and Dworkin, he is thrown back to the concept of a human soul, which is as mysterious as human conscience, although attempts have been made to study the latter scientifically.^{41,42} He may be correct in grounding dignity in the ontological leap, combining "human reason, human language, human moral choice, and human emotions in ways that are capable of producing human politics, human art, or human religion."⁴³ He concludes that we should not disrupt through biotechnology "either the unity or the continuity of human nature [thus defined], and thereby the human rights that are based on it."⁴⁴ However, these arguments support the position that dignity is a rationale for human rights, not the natural-rights position Fukuyama takes. In other words, the four elements that produce Factor X may help us understand what is meant by being worthy of honor and respect and not being humiliated. But this understanding of dignity applies to all human rights, and does not justify the assumption that cloning is necessarily destructive of any or all the for four elements of Factor X. I would agree that the com-

plex physiological and social consequences of cloning may affect one or more of those elements, but we do not have and may never have evidence that such consequences reach a threshold that either disrupts Fukuyama's idea of human nature or violates the human right to dignity.

The psychological dimensions of humiliation have been studied.⁴⁵ One can only speculate about the potential humiliation a clone might suffer should it be possible to produce a viable, healthy human clone. One might assume that such a clone would receive intense media attention, possibly scorn by neighbors, official stigmatization, and other behavior that could generate feelings of humiliation in the clone. However, those acts of discrimination or stigmatization that reach the level of cruel, inhuman, or degrading treatment would be violations of human rights, not the fact of cloning per se. A person arbitrarily detained, tortured, discriminated against, or denied a minimal standard of living may be presumed to be humiliated, but that humiliation is linked to rights deprivation. The issue then becomes whether the potential humiliation from being a clone is sufficient to justify characterizing cloning as a human rights violation by law or treaty. That possibility, however, is not as well established as the empirically verifiable occurrence of humiliation resulting from arbitrary arrest, torture, discrimination, or poverty.

A "natural" twin of another or one who, prior to gestation, was an embryo in a petri dish that was fertilized "artificially" is not usually subjected to attacks on her or his dignity because of that biological fact. Whether being a clone would result in loss of dignity is a factual question that cannot be answered a priori as can cases of discrimination, arbitrary arrest, torture, and extreme poverty.

Should cloning or germline genetic manipulation result in unwanted outcomes that the general population would perceive as "weird" or "freakish," then such forms of biotechnology could indeed violate human dignity. Proponents of this technology could just as easily posit that no such offspring would be produced unless and until such unwanted outcomes were made extremely improbable.

Certainly children produced by IVF have been the

object of curiosity—and some may have felt humiliation—but there is no evidence that humiliation is a necessary result of their biological status. Similarly, a human clone is not basically different from a twin or “test-tube baby.” Even if one accepts Hans Jonas’s argument that the clone would be a “later twin” and therefore suffer from knowing a predetermined future, that alleged restriction on the clone’s “open future” is not by nature a violation of dignity and probably not as much a threat to the clone’s freedom as Jonas claims.⁴⁶

Dignity was at the center of the reasoning of the President’s Council on Bioethics and even in the title of its first report.⁴⁷ The Council explained why it matters that cloning would allow the selection of the genotype of specifications of children: “It matters because human dignity is at stake. In natural procreation, . . . the uncontrolled beginnings of human procreation endow each new generation and each new individual with the dignity and freedom enjoyed by all who came before.”⁴⁸ However, it did not define the term and tended to use it as a code for a theological commitment to the sanctity of human life.

The relationship between the concept of human dignity and human nature makes the “right to dignity” a preferred reference point for those on the ecological left and on the religious right to justify their conclusion that inheritable genetic engineering is a violation of human rights. A more dispassionate assessment of the meaning of dignity in human rights practice suggests that the situation is more complex and that, for the time being, there does not seem to be any evidence or even logical claim that the biological fact of being a clone or genetically altered individual results in humiliation or is otherwise contrary to human dignity.⁴⁹

The Permissive Approach

While the Council of Europe and UNESCO texts, as well as the proposed UN convention, suggest a prevailing restrictive position, the permissive position has its own assumptions and preferred reference to certain human rights, focusing on liberty and autonomy of action, which have considerable support among bioethicists.

Utilitarian Assumptions

The philosophical assumptions of those who would allow, under controlled conditions, reproductive human cloning and germline gene therapy are, for the most part, utilitarian and the political-economic position tends to be neoliberal. The preferred human rights invoked to support this position relate to protecting human activity, such as the right to found a family, the right to benefit from scientific progress, freedom of scientific research, or the right to the moral and material interests in one's scientific invention.

The claim of utilitarianism is that an action is morally right if it produces at least as much good for the people affected as any alternative action. In public health, "good" or "utility" is measured by the greatest pleasure and the least pain, and, more generally, as the greatest happiness for the greatest number.

In *From Chance to Choice. Genetics and Justice*, Allen Buchanan, Dan Brock, Norman Daniels, and Daniel Wikler provide the most systematic articulation of an ethical position using a utilitarian calculus: "If and when safety concerns are satisfied for human cloning, we will have to assess what benefits and harms might come from letting it take place."⁵⁰ While they conclude "at this time we believe human cloning does not seem to promise great benefits or uniquely to meet great human needs," they also develop numerous utilitarian reasons why the technology should not be banned.⁵¹ One of the moral arguments they explore is a version of new eugenics, different from the Nazi version, that uses genetics "to improve the chances of future generations for achieving greater well-being."⁵² They find "something unobjectionable and perhaps even morally required in the part of its motivation that sought to endow future generations with genes that might enable their lives to go better. We need not abandon this motivation if we can pursue it justly."⁵³

Others apply different methods of calculating the utility of cloning. Using a model of genetic endowment of offspring under alternative reproductive regimes, Eric Posner and Richard Posner assess the impact that demand for cloning may have on wealth and genetic advantages.⁵⁴ They assume that "[r]ational parents want to maximize their own

welfare, and thus their children's only to the extent that the children's welfare enters into the parents' utility function."⁵⁵ By their utilitarian calculation, cloning would favor "extreme narcissists and other psychotics and misfits" and may "aggravate inequalities in genetic endowment and in wealth, undermine the already imperiled institutions of marriage, alter the sex ratio and create irresistible pressures for eugenic regulations," along with such positive outcomes as increasing "the wealth and power of women."^{56,57} The various utilitarian approaches to the problem weigh the relative value of overcoming infertility and disease and improving the quality of life against the essentialist claims and tend to support using the technology, if made safe, even though it may not be the optimal solution to the problems it claims to address.

The permissive position's assumption that the market should determine conditions under which companies and individuals can develop, market, or consume the technology necessary for human cloning is closely allied with the neoliberal economic position that the state should refrain from interfering with private activity, unless regulation is necessary to protect the freedom of others. This understanding of the relative role of the state and markets is reflected in the rules governing intellectual property and trade, including technology transfer and commercialization of developments in biotechnology. Efforts in Europe to challenge patenting human DNA, as authorized by a 1998 EU Directive, have claimed that such patents would commodify life itself, a process that turns legal subjects (persons) into legal objects and thus infringes on human dignity.^{58,59} The UNESCO Declaration affirms that the benefits of genetic research "shall be made available to all," whereas the European Biomedicine Convention's prohibition of financial gain does not apply to the patentability of biotechnological inventions.⁶⁰⁻⁶² The EU Directive has acknowledged this concern but does not, in the view of its critics, adequately address it.⁶³

Finally, it should be noted that the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) states that "patents shall be available for any inventions, whether products or processes, in all fields of technology,

provided that they are new, involve an inventive step and are capable of industrial application."⁶⁴ In general, international intellectual-property law tends to favor market forces in deciding whether genetic knowledge and methods of manipulation of the genome can be traded for financial gain. However, international intellectual property law tempers free trade by allowing World Trade Organization members to "adopt measures necessary to protect public health and nutrition, and to promote the public interest in sectors of vital importance to their socioeconomic and technological development, provided that such measures are consistent with the provisions of this Agreement."⁶⁵ Moreover, selling embryos that contain cells with cloned DNA that have been selected according to the traits purchasers want for their offspring is opposed by both those who would ban as well as those who would permit cloning.⁶⁶

The Human Right to Found a Family

Proponents of the permissive approach implicitly and sometimes explicitly rely on certain human rights that protect human agency or activity, which include the rights to found a family, to privacy, to freedom of information, to informed consent to medical experimentation, to benefit from scientific advances, and to moral and material interests in a scientific invention or discovery. The human rights relating to scientific progress and moral and material interests clearly favor the permissive approach, as do rights to privacy and information, each one stressing an aspect of the freedom of individuals to act as they please. The example of the human right to found a family is more complex.

The International Covenant on Civil and Political Rights (ICCPR) recognizes, "the right of men and women of marriageable age to marry and to found a family . . ."⁶⁷ IVF is widely recognized as an acceptable means of implementing this right. Supporters of the permissive position would extend that argument to cloning as a means of realizing the human right to founding a family, though the ICCPR does not stipulate the method by which children are created.

Others, however, could interpret "family" and reproductive rights as requiring male and female chromosomes,

which may be assumed to be the only meaning of founding a family the authors of the UDHR and the ICCPR had in mind. Such a concept of family is also based on an unpredictable mix of genes resulting in what the UNESCO Declaration refers to as "uniqueness" or what Joel Fineberg calls the "right to an open future," or what Hilary Putnam posits as the right of the child "to be a complete surprise to its parents."⁶⁸⁻⁷⁰

The question therefore becomes whether parents can decide freely the extent to which biotechnology will assist them in determining their offspring's gene set or whether some societal standards must be met as a precondition to found a family, such as combining X and Y chromosomes or ensuring the randomness of sexual reproduction. The right to found a family is inseparable from reproductive rights, which include the right "of men and women to decide freely and responsibility on the number and spacing of their children," as well as the right "to have access to safe, effective, affordable and acceptable methods of family planning of their choice."^{71,72}

Proponents of the permissive approach to cloning and gene therapy would underscore the terms "decide freely" and "method of their choice," whereas supporters of the restrictive approach would stress "decide . . . responsibly" and "acceptable methods." On balance, the right to found a family is more likely to favor the permissive approach over the restrictive one.⁷³ However, like the right to dignity, this right does not unambiguously support either side. It does, however, set some normative limits on what is to be protected by restricting access to inheritable genetic engineering, in that, at the one end, it requires that the means of reproduction be socially acceptable and that, at the other, parents to have a wide range of reproductive choice.

Conclusion: The Human Right to Health and Biotechnology

The ambiguity of the examples briefly raised previously illustrates how the appeal to certain human rights may support the restrictive position, while others may be

invoked for the permissive position. This is paralleled by the debate over the ethical issues in which the “ethical pros and cons of human cloning . . . are sufficiently balanced and uncertain that there is not an ethically decisive case either for or against permitting it or doing it.”⁷⁴ Certain types of rights seem to lend themselves to certain sides of the debate. In the most general terms, the restrictive position tends to invoke those human rights that relate to the nature and integrity of human beings, while the permissive position tends to favor those related to free agency. The human right to health is probably the most directly concerned and the most ambiguous. Those who oppose human genetic manipulation believe that it threatens human well-being and therefore violates the right to health (defined as “physical, mental and social well-being”); those who support new eugenics consider such technology as potentially enhancing human well-being and therefore contributing to the realization of the right to health.⁷⁵

All major UN and regional human rights treaties, as well as the European Biomedicine Convention, reaffirm the right to health.^{76,77} In its General Comment, the Committee on Economic, Social and Cultural Rights (CESCR) linked it to “living a life of dignity,” which involves some 14 related rights.^{78,79} Reproductive rights figure prominently in the analysis of the right to health, which the CESCR has defined as “the right to control one’s health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation.”⁸⁰ The CESCR lists four “interrelated and essential elements” of services in relation to the right to health—accessibility, affordability, appropriateness, and quality of care.⁸¹ The permissive position could claim that cloning and germline gene therapy should be accessible and affordable because they contribute to improved health and are appropriate because they do not compromise the belief system of the directly concerned parties. Finally, such advanced methods of selecting genes to avoid disease, overcome infertility, and improve quality of life could be seen as part of quality of care. The

restrictive position would argue that the biological and social consequences of the technology are too grave and therefore should not be accessible. The considerable cost is likely to make the technology available only to the wealthy, and it could not be made affordable to all people who might want to use it. It would not meet the appropriateness criterion either, because it would violate deeply held religious or ethical beliefs of many in society about human nature.

The CESCR's analysis of the right to health also involves three types or levels of obligations of state parties.⁸² A state's obligation to *respect* the right to health could be interpreted as requiring that no government agency participate in or fund dangerous genetic manipulation, or it could prohibit them from doing so. The obligation to *protect* could mean that the state should prevent the biotech industry from offering such services or, conversely, that it should encourage it to do so. The obligation to *fulfill* could mean that steps must be taken through all branches of government and in budgetary allocations to suppress cloning and related technology or, on the other hand, that it must tolerate, promote, and even practice genetic manipulation. National policies and legislation show a wide divergence of laws and practice.⁸³ Clearly, neither current formulations of the right to health nor state practice answers the question of whether genetic manipulation is contrary to human rights.

The Expert Group on Human Rights and Biotechnology, convened by the UN High Commissioner for Human Rights in January 2002, acknowledged indirectly that a human rights analysis does not lead to automatic answers to the complex issues of human rights and inheritable genetic manipulation. Recommending that the High Commissioner's primary goal should be "to ensure that the human rights aspects of reproductive human cloning be identified and effectively introduced into the debates on the proposed convention and into the wider public debate," the group also recommended that "particular attention be drawn to the definition of the proscribed activity in any ban and to the implementation and monitoring of the obligations parties assume under the treaty." Assuming cloning could be banned, the group urged the High Commissioner to see that any ban focus "on an individual's *intention* to copy genetically another human being rather than on the technique itself."⁸⁴

In sum, human rights provide a normative foundation for those who would ban as well as those who would permit reproductive cloning of human beings. Human rights cannot be expected to resolve basic antinomies of social thought, for they are the product of political and legal processes that require the coexistence of divergent perspectives. They set boundaries of what are the minimal conditions for a life of dignity in society. The fact that human rights texts emerge from compromises and reflect minimal standards does not disqualify them from being important to decision making on biotechnology. On the contrary: At one end of the continuum is human creativity and desire for perfectibility, which must be protected and encouraged through the human rights to freedom of research and to participate in and benefit from scientific invention. At the other end lie the essence of our humanity and the integrity of physical, mental, and spiritual existence of each human being, which are the responsibility of those who play a role in bringing new human beings to viability. Human rights standards do not answer the question, Should cloning and germline gene therapy be allowed or banned? They do, however, provide guidance in setting limits of how far one can go in either direction.

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2. The project, which began in 1990 and is described as the largest scientific research effort ever undertaken in the biological sciences, is a 15-year, \$3 billion (US) international collaboration to trace and identify all human genes. At least 18 countries have established genome research projects, and about 1,000 individuals from 50 countries are members of the Human Genome Organization (HUGO), which helps coordinate information exchange.

3. CNN, interview with Clonaid chief scientist, Brigitte Boisselier, retrieved 18 August 2002 from www.cnn.com/2001/HEALTH/06/29/cloning.lab. CNN, interview with University of Kentucky professor Panayiotis Zavos, retrieved 18 August 2002 from www.cnn.com/2001/WORLD/europe/03/22/human.cloning/index.html. See also R. Mishra, "Clone Research Quietly Builds in World's Labs," *Boston Globe*, 21 June 2002, A1.

4. See J. B. Cibelli, R. P. Lanza, and M. D. West, "The First Human Cloned Embryo," *Scientific American*, January (2002): 45–51.

5. G. Brand, "Human Rights and Scientific and Technological Developments," *Human Rights Journal* 4/2–3, (1971): 351–364, at 354.

6. See note 5.

7. United Nations, Final Act of the International Conference on Human Rights, UN pub. E.68.XIV.2, 1968, p. 3. See also United Nations Action in the Field of Human Rights, UN Pub. E.88.XIV.2, 1988, pp. 302–306.

8. Reproductive human cloning refers to asexual reproduction by means of which the nucleus from a woman's is removed and replaced with deoxyribonucleic acid (DNA, the substance of which genes are made) taken from an adult's cell. The egg is then stimulated to form an embryo that is implanted in a woman's uterus, there to develop into a fetus and eventually a human baby with the same genotype as the adult whose cell provided the DNA. See "Advanced Cell Technology," *Journal of Regenerative Medicine* November 2001; G. Kolata, "Company Says It Produced Human Embryo Clones," *New York Times*, 26 November 2001, retrieved from www.nytimes.com. See also "Working Kidney Built From Embryo Clone," *Genomics & Genetics Weekly* 22 February–1 March 2002, retrieved from www.newsrx.com.

9. Germline therapy or inheritable genetic modification is a process of changing genes in eggs, sperm cells or very early embryos. New segments of DNA are inserted into a germ cell (either sperm or egg) before fertilization; the fertilized cell's altered gene or genes then change trait(s) passed on to future generations, potentially affecting our species' gene pool. Germ, or stem, cells have the ability to divide for indefinite periods in culture and create specialized cells. See M. R. Capecchi, "Human Germline Gene Therapy: How and Why," in G. Stock and J. Campbell

(eds.), *Engineering the Human Germline : An Exploration of the Science and Ethics of Altering the Genes We Pass to Our Children* (New York: Oxford University Press, 2000), pp. 31–42.

10. Embryonic stem cell therapy technique uses embryo-derived stem cells (ESC) to produce difference kinds of tissue that can replace defective or missing tissue or organs for therapeutic purposes. To overcome immune rejection to cell lines derived from different individuals, it is proposed to use clonal embryos derived from the individual to be treated. This technique is often referred to as “therapeutic cloning” and is strenuously opposed by those who fear it would lead to reproductive cloning. Chairman of the President’s Bioethics Council, Leon Kass, for example, has said that “an *effective* ban on reproductive cloning requires a ban on *all* human cloning, including the creation of embryonic clones.” Prepared testimony by Dr. Leon Kass, The Committee on Energy and Commerce, R. 1644, Human Cloning Prohibition Act of 2001, and H.R., Cloning Prohibition Act of 2001, Subcommittee on Health, 20 June 2001, retrieved 19 August 2002 from <http://energycommerce.house.gov/107/hearings/06202001Hearing291/Kass451.htm>. See also, G. Annas, “Cell Division,” *Boston Globe*, 21 April 2002, p. E1. See also National Institutes of Health, *Stem Cells: Scientific Progress and Future Research Directions*, retrieved from www.nih.gov/news/stemcell/scireport.htm.

11. Somatic-cell gene therapy involves the modification of the genes of cells of specific organs or tissues that are inserted into a patients and survive only for the lifetime of that individual.

12. Advisory Committee on Health Research, *Genomics and World Health* (Geneva: World Health Organization, 2002).

13. See note 12, p. 63.

14. National Institutes of Health, *Stem Cells: Scientific Progress and Future Research Directions* (Washington, DC: Author, 2001), p. 102.

15. See note 12, pp. 63–65

16. See note 14, p. 33.

17. R. Mishra, “Clone Research Quietly Builds in World’s Labs,” *Boston Globe* 21 June 2002, A1, quoting Jean-François Formela, of Atlas Ventures.

18. The principal trade and intellectual property instruments are the General Agreement on Tariffs and Trade (GATT) 15 April 1994; Agreement on the Application of Sanitary and Phytosanitary Measures (SPS Agreement); the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS), Article 27.1, Marrakesh Agreement Establishing the World Trade Organization, Annex 1C; Directive 98/44/EC of the European Parliament and of the Council of 6 July 1998 on the legal protection of biotechnological inventions Article 5(2), 1998 OJ (L 213) 13 (EU Directive); and the General Agreement on Trade in Services (GATS).

19. The principal human rights instruments are the International Covenant on Economic, Social and Cultural Rights (ICESCR), 16 December 1966, 993 U.N.T.S. 3; and the International Covenant on Civil and Political Rights (ICCPR), 16 December 1966, 993 U.N.T.S. 171.

20. The principle biomedicine instruments are the Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine:

Convention on Human Rights and Biomedicine, Article 21 (1997); the Council of Europe, Additional Protocol to the Convention for the Protection of Human Rights and the Dignity of the Human Being with Regard to the Application of Biology and Medicine; and the Universal Declaration on the Human Genome and Human Rights (UDHGHR), UNESCO, 29th Sess., 29 C/Resolution 19 (1997), reprinted in *Records of the General Conference*, UNESCO, 29th Sess., 29 C/Resolution 19, at 1 (1997).

21. S. P. Marks, "Tying Prometheus Down: The International Law of Human Genetic Manipulation," *Chicago Journal of International Law* 3 (2002): 121–136.

22. *The Economist*, 14 April 2001, 21.

23. Genetic Bill of Rights of the Council for Responsible Genetics (CRG), Article 2, "All people have the right to a world in which living organisms cannot be patented, including human being . . . and all their parts." *Gene Watch. A Bulletin of the Council for Responsible Genetics* 13/3 (2000): 3. Retrieved from www.gene-watch.org/petition/index.html.

24. Center for Genetics and Society, San Francisco, CA, retrieved 28 June 2002 from www.genetics-and-society.org/policies/minimal.html.

25. Beyond Cloning: Protecting Humanity from Species-Altering Experiments, 21 and 22 September 2001, retrieved 18 August 2002, from www.bumc.bu.edu/www/sph/lw/website/index1.htm.

26. G. Annas, L. B. Andrews, and R. M. Isasi, "Protecting the Endangered Human Species: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations," *American Journal of Law and Medicine* 28 (2002): 151–178.

27. See note 22.

28. J. M. Spectar, "The Fruit of the Human Genome Tree: Cautionary Tales about Technology, Investment, and the Heritage of Humankind," *Loyola of Los Angeles International and Comparative Law Journal* 23/1 (2001): 37–40.

29. See note 20, Council of Europe, Convention on Human Rights and Biomedicine, Article 21.

30. See note 20, UDHGHR, Article 4. See also N. Lenoir, "Universal Declaration on the Human Genome and Human Rights: The First Legal and Ethical Framework at the Global Level," *Columbia Human Rights Law Review* 30: 557–558.

31. See A. Verdross, *Die Würde des Menschen als Grundlage der Menschenrechte*, René Cassin *Amicorum Disciplulorumque Liber*, vol. 1. *Problèmes de Protection Internationale des Droits de l'Homme* (Paris:1969), Pédone, p. 417–423 (focusing on Ancient Greece and the Western tradition).

32. United Nations, Universal Declaration of Human Rights, Preamble and Article 1.

33. See note 20, UDHGHR, Article 2.

34. See note 20, UDHGHR, Article 11.

35. See note 20, Council of Europe, Preamble to the Convention on Human Rights and Biomedicine.

36. See note 35, Article 1, and Explanatory Report to the Convention for the Protection of Human Rights and Dignity of the Human Being with

- Regard to the Application of Biology and Medicine, Para. 9.
37. See note 35, Preamble to the Additional Protocol to the Convention on Human Rights and Biomedicine on the Prohibition of Cloning Human Beings.
38. See M. A. Glendon, *A World Made New. Eleanor Roosevelt and the Universal Declaration of Human Rights* (New York: Random House, 2001), p. 146.
39. See S. J. Malby, "Human Dignity and Human Reproductive Cloning", *Health and Human Rights*, 6/1 (2002): 112, this issue.
40. F. Fukuyama, *Our Posthuman Future. Consequences of the Biotechnology Revolution* (New York: Farrar, Straus and Giroux, 2002), p. 150.
41. See note 40, pp. 161–162.
42. See note 40, p. 166.
43. See note 40, p. 170.
44. See note 40, p. 172.
45. The psychological dimensions of humiliation have been extensively studied by Evelin Gerda Lindner, M.D., of the Institute of Psychology, University of Oslo. See E. G. Lindner, "Humiliation and the Human Condition: Mapping a Minefield," *Human Rights Review* 2/2 (2001): 46–63; E. G. Lindner, "Humiliation—Trauma That Has Been Overlooked: An Analysis Based on Fieldwork in Germany, Rwanda/Burundi, and Somalia," *Traumatology* 7/1 (2001): 43–68.
46. A. Buchanan, D. Brock, N. Daniels, and D. Wikler, *From Chance to Choice: Genetics and Justice* (Cambridge: Cambridge University Press, 2000), p. 198.
47. President's Council on Bioethics, *Human Cloning and Human Dignity: An Ethical Inquiry* (Washington, DC: Author, July 2002), pre-publication version retrieved 11 August 2002 from www.bioethics.gov/cloningreport/fullreport.html.
48. See note 47.
49. See note 46, p. 201.
50. See note 46, pp. 199–200.
51. See note 46, pp. 200–201.
52. D. Wikler, "Eugenic Values," *Science in Context* 11/3–4v (1998): 468.
53. See note 46, p. 60.
54. E. A. Posner and R. A. Posner, "The Demand for Human Cloning," in M. Nussbaum and C. R. Sunstein (eds.), *Clones and Clones: Facts and Fantasies about Human Cloning* (New York: Norton, 1998), pp. 233–261.
55. See note 54, p. 251.
56. See note 54, p. 257.
57. See note 54, p. 258.
58. See note 18, European Communities, Council Directive 98/44/EC on the legal protection of biotechnological inventions (EU Directive), Article 5.2.
59. See note 58, Articles 5(1), 6(1), and 6(2)(a)(b)(c).
60. See note 20, UNESCO Declaration, Article 12.
61. See note 20, European Biomedicine Convention, Article 3.
62. See note 20, Explanatory Report, 36 ILM 817, Para. 134.

63. See note 20, EU Directive, Preamble, Paras. 11 and 18.
64. See note 18, TRIPS, Article 27.1.
65. See note 18, TRIPS, Part I, Article 8.1. The Doha ministerial meeting in 2001 reinforced this principle. See World Trade Organization, Declaration on the TRIPS agreement and public health, adopted on 14 November 2001, WTO doc. WT/MIN(01)/DEC/2, 20 November 2001.
66. D. W. Brock, "Cloning Human Beings: An Assessment of the Ethical Issues Pro and Con," in M. Nussbaum and C. R. Sunstein (eds.), *Clones and Clones: Facts and Fantasies about Human Cloning* (New York: Norton, 1998), p. 160.
67. See note 19, ICCPR, Article 23 (2).
68. See note 20, UNESCO Declaration, Article 2(b).
69. J. Feinberg, "The Child's Right to an Open Future," in W. Aiken and H. LaFollette (eds.), *Whose Child? Children's Rights, Parental Authority, and State Power* (Totowa, NJ: Towman and Littlefield, 1980).
70. H. Putnam, "Cloning People," in Justine Burely (ed.), *The Genetic Revolution and Human Rights* (New York: Oxford University Press, 1999), pp. 12, 13.
71. Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), Article 16(1)(e).
72. Programme of Action of the International Conference on Population and Development (Cairo, 5–13 September 1994), A/ CONF.171/13, Para. 7.2 (18 October 1994).
73. See note 66, p. 84.
74. See note 66, p. 162.
75. The quoted definition of the right to health as "physical, mental and social well-being" comes from the WHO Constitution.
76. See note 20, Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, 19 November 1996, Article 3.
77. See note 19, ICESCR, Article 12, which refers to the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health."
78. See note 19, ICESCR, General Comment 14, 4 July 2000, Para. 1, E/C.12/2000/4.
79. See note 78, Para. 3.
80. See note 78, Para. 8.
81. See note 78, Para. 12.
82. See note 78, Para. 33.
83. As a project of Global Lawyers and Physicians for Human Rights, Rosario Isasi has developed, a systematic compilation of national and international references on both human cloning and germline engineering, www.glphr.org/genetic/genetic.htm. See also Annas, note 26, pp. 174–178, for a summary of legislation relating to human species protection.
84. Editor's note: see also "Expert Group on Human Rights and Biotechnology Convened by the UN High Commissioner for Human Rights: Conclusions on Human Reproductive Cloning," this issue.