

# Bioethics, Constitutions, and Human Rights

Noëlle Lenoir

## Introduction

Who would have thought twenty-five years ago that the term “bioethics,” a neologism coined by an American biologist, would have met with such success, becoming one of the cornerstones of philosophical and juridical reflection at the end of the twentieth century? For it was in 1970 that the biologist and oncologist Van Rensselaer Potter published his book, *Bioethics, Science of Survival*.

The reference to the question of survival, and therefore to the idea of a potential end to humanity, gave from the outset a sense of what was and still is at stake in bioethics. But what in fact is bioethics? Bioethics, which is a contraction formed from the words “biology” (one of the life sciences) and “ethos” (behavior, customs), is frequently defined as a set of rules intended “to guide human actions” when confronted with choices created by advances in biology and genetics.<sup>1</sup>

The scope of bioethics varies depending on whether we are considering questions related to biology or human genetics alone, or of research in the life sciences as a whole and the applications that result from it. The terms of bioethical law and the law of life forms are sometimes used synonymously by those who wish to remind contemporary society of its duties and responsibilities as regards the preservation of the natural balances on which the continuance of biological life itself depends. This is the ecological and cosmological understanding of bioethics.<sup>2</sup>

For our purposes, we will take up bioethics in its more narrow and usual definition, that is, as biomedical ethics concerned with the law of the living individual in relation to the protection of human rights in general.

### 1. *The Origins of Bioethics*

The phenomenal rise of ethical reflection on the life sciences can not be explained apart from the widespread questioning of the idea of progress.

On the one hand, our techno-scientific society has generated an unprecedented infatuation with technology, which has become the object of all our desires; on the other, it has produced its own challenge to itself. This challenge, moreover, did not originate solely from those “left behind by progress.” On the contrary, it was in the industrialized countries themselves that the critique of the consumer society, of “consumption for consumption’s sake,” and of material progress originated, perceived as a factor of inequality and dehumanization.

Nevertheless, even now scientific and technical progress is usually viewed as a neutral factor from the social and human point of view. It can be a catalyst for good as easily as it can serve evil. To quote an eminent philosopher of science, Georges Canguilhem, science “establishes truths without finality.” It does not provide any lessons on what should be the appropriate behavioral response to the potential results of a scientific discovery. Yet, the effects of progress are present in every moment of our daily lives.

The awareness of this state of affairs gave rise to the conviction that law, as an embodiment of the choices a society makes, was necessary in order to return meaning to progress. Laws could do so by prescribing the positive uses of science while condemning those applications that are likely to be harmful to humanity.

Such is the purpose of bioethical law. Indeed, by having conferred on human beings unprecedented powers to transform their own species, biology and genetics have at the same time burdened humanity with new responsibilities. These responsibilities pose the question of the meaning of history in a new way.

“We, of civilizations, now know that we are mortal,” declared Paul Valéry. This statement could be translated into the language of bioethics by saying: “We, of the human species, now know that we could disappear because of our own deeds.”

According to the philosopher Hans Jonas, bioethics is a response to “the new threat” presented by new biotechnological tools. In his book, *The Imperative of Responsibility*, Jonas goes so far as to argue

for the total renunciation of their use. "Prometheus," he has written, "has been definitively unbound, conferring on science powers that have never before been known and to the economy a frantic energy. These developments require an ethic which, through freely chosen limits, will prevent the power of Humanity from becoming a malediction for it."<sup>3</sup> Although bioethics does not share this kind of profoundly catastrophic view of science and of humanity, it is nevertheless conscious of the need to limit the power of these new scientific and economic forces. "Not everything is permitted" when it comes to the future of humanity.

The judgment rendered by the Nuremberg Tribunal on 19 August 1947 is the key illustration of this point of view. For it is in this text that the initial historical legitimation of bioethics, in the sense of biomedical ethics, is to be found. The catalyst for this development was the shock caused by the revelation that doctors and researchers had actively participated in the atrocities visited upon those interned in the Nazi prison camps. The Nuremberg Tribunal made a formal condemnation of the "experiments" – the shameless torture and sacrifice – carried out on these human guinea pigs. In particular, the Tribunal made explicit mention of the autonomy of each human being, thereby implying the need for free and informed consent prior to any experimentation. "Before an individual agrees to participate in an experiment," the Tribunal wrote, "the person must be informed of its nature, of its duration and purpose, of the means and methods to be employed, of all the inconveniences and risks that might be reasonably foreseen, and of the long-term effects that the experiment might have on the subject's health and person." The principle of informed consent was reaffirmed in a number of later international forums, such as the World Medical Association that developed "The Nuremberg Code" in 1947, followed by other declarations: Helsinki (June, 1964), and Tokyo (1975). This principle figures equally in the Manila Declaration (1988), which was jointly promulgated by the World Health Organization and the Council of International Organizations of Medical Sciences. Lastly, it is becoming part of national legislation and of various international legal instruments either in force or in the process of adoption.

The reference to the judgment of the Nuremberg Tribunal is essential here. It is clear confirmation of the close ties between

bioethics, at its inception, and human rights since jurists usually relate the origin of the protection of the individual in international law to the condemnation of the Nazi leaders and their organizations.<sup>4</sup> How then can it be claimed that bioethical concerns were not sufficiently taken into account as an element in the protection of human rights, when the issue of human rights was directly linked to the birth of bioethics itself?

## *2. The Specific Characteristics of Bioethics*

Throughout the world, societies are based on two organizing principles whose application varies from country to country and culture to culture. The first is the principle of hierarchy. This principle leaves little place for freedom, even though it does guarantee a certain amount of security. The second is the democratic principle, with its emphasis on the rights and freedoms of the individual. This principle, which is based on the right to vote and on free elections, entrusts the elected majority with the responsibility to make laws and to impose these laws on all members of the society. However, in some respects majority rule, the very basis of political democracy, has proven to be inadequate in the context of our contemporary pluralistic societies with their extreme sensitivity to contributions from the outside, even if they come only by way of the various media. More and more, this inadequacy requires recourse to monitoring procedures as well as the creation of new institutions and forums for free expression and reflection.

The bioethical approach, which is becoming increasingly common because it responds to a felt need in contemporary society, is related to these procedures. Bioethics Committees, another signal phenomenon of our time, are representative of these fields of interactive and open discussion.<sup>5</sup>

Their status and role vary considerably.<sup>6</sup> These committees were first formed in the 1960s to carry out peer review of articles submitted for publication to various Anglo-American scientific journals: the purpose of the committees was thus to guarantee the professional caliber of the materials accepted. Later, at the request of doctors, ethics committees were formed inside hospitals to help resolve situations that required delicate, sometimes painful, decisions regarding patient care. Other committees were formed to

determine the appropriateness of potential medical experiments on human subjects and, in such cases, to supervise their monitoring. Finally, committees of “generalists” were formed, whose purpose was to offer reflection, discussion, and recommendation.

The French National Committee, which was created in 1983 and was the first of its kind, offered a pattern for such committees: multidisciplinary, multicultural, and independent of party, it is strictly a consultative body. Its charge is to engage in an autonomous discourse beyond various political, philosophical, and religious agendas.<sup>7</sup>

The work of this kind of committee can only be welcomed by the politicians, with whom the final decisions rest. This is because the norms to be established are by definition uncertain, related as they are to the rapidly changing and broad field of biomedicine, a field that is concerned not only with the most intimate aspects of individual life but with the overall future of humanity as well. This latter concern has been met through the creation of a series of international committees. The framework of these committees may be regional (such as the European Union’s Group of Advisers on the Ethical Implications of Biotechnology [GAEIB] to the European Commission<sup>8</sup>) or international (UNESCO’s International Bioethics Committee,<sup>9</sup> which is the only committee on ethics within the United Nations system).

As diverse as these ethics committees are, a valid general observation can be made about the way they function: originally simple forums for discussion, the committees have become organizations that play a significant role in decision-making. Through their analyses, their identification of problems and the kinds of solutions they recommend, the ethics committees are helping legislators “embrace uncertainty,” in the words of Philippe Séguin, President of the French National Assembly. Opening UNESCO’s third session of the International Bioethics Committee in September 1995, Séguin said: “The legislator’s responsibility ... in spite of uncertainties of a technical or moral nature, is to make choices, even though knowing that the future may prove him wrong.” Thus one of the major contributions of bioethics is to present political choices without making the claim that these choices embody absolute, immutable truths.

Bioethics is, in fact, an expression of values. From the point of view of bioethics, the bioethical norms that are enacted into law embody a necessarily provisional balance. As a philosophical exercise, bioethics thus takes its place among those approaches that inquire into the meaning of humanity's evolution. This is why bioethical law can be seen, in a certain sense, as one of the fundamental elements of the general development of civilization in this era of science and technology.

In this way, it can be said that beyond the diversity of laws enacted by national legislatures (see below, part I) stand general guiding principles that the internationalization of bioethical law only strengthens (see below, part II).

## I. The Diversity of National Legislation

### *1. Socio-Cultural Factors That Influence Bioethical Laws*

Apart from Switzerland, which amended its national constitution after a "popular vote" held on 17 May 1992, national governments have limited themselves to the adoption of ordinary laws. The first nations to enact laws in regard to bioethics were those of Western Europe. Now, however, all countries of Europe and nations on all continents are involved. For example, in 1995 Brazil became one of the latest countries to pass bioethical laws.

Differences between legislation mainly reflect various traditions, although the political situation in each country also plays a certain role. This is why the issues dealt with differ from country to country.

In some places, bioethical laws have primarily been concerned with regulating the new ways in which "life is created" through the technologies associated with artificial procreation.<sup>10</sup> In others we have seen the legitimation, through the creation of positive law, of medical intervention to terminate life. For example, in the Netherlands a law was passed in 1994 that rescinded, under certain conditions, the formal sanctions faced by doctors who practice euthanasia on their patients.

In countries where research is less advanced and biomedical practices are less sophisticated, bioethical laws have for the most

part been concerned with regulating the uses of the human body, in particular the regulation of organ removal for the purpose of transplantation.

The degree of coercion in these laws varies from country to country, and is linked to the role played by the government in relation to the individual and to the social actors. For example, in the United States, the lack of national bioethical legislation – except in the area of organ transplants – bears witness to the relatively small role played by the government in social life. This same liberal tradition inspired the British law of 1990 on human fertilization and embryology. On the other hand, countries like Germany and France have adopted considerably more coercive legislative provisions: for example, limiting freedom of choice in regard to human reproduction (the German law of 1990 on the protection of the embryo; French bioethical laws passed in July 1994).

In Japan, in spite of the predominant role played by the State, there are no bioethical laws. However, social consensus on this matter is apparently so strong that the establishment of legal norms has been deemed superfluous.<sup>11</sup>

The laws of the different countries reflect the traditions of each individual country.<sup>12</sup> For instance, the laws of countries under Anglo-Saxon cultural influence emphasize the autonomy of the individual. This individual is treated as a potential patient or subject of research whose right to give informed consent for care or experimentation must be guaranteed.

In other countries, particularly those under Roman Catholic cultural influence (for example, France or Latin America), the emphasis is more on safeguarding the dignity of the human being, seen as created in the image of God. This point of view justifies the recourse to ethical prescriptions affecting family and social life. In the case of Germany, for historical reasons (Nazism in particular), bioethics has given rise to the enforcement of numerous prohibitions.

The Asian and African vision of the human being as an integral part of the harmony of nature and as an inseparable element of a human community has had a substantial impact in the countries concerned. As a general rule, the individual is expected to submit to the imperatives of the community. For instance, in China euthanasia is not condemned *a priori* when it concerns an individ-

ual who wishes to spare the community at large of a burden that this individual judges to be too onerous.<sup>13</sup>

## 2. *The Contents of Bioethical Laws*

These differences of a cultural nature are obviously expressed in the laws of each country.

This is especially true in matters relating to the beginnings of human life. Indeed this is the subject that provokes the greatest conflict over values. Is the starting of a family, of having or not having children not one of the most fundamental of all freedoms?

In some cases – such as in the United Kingdom for cultural reasons, or in Spain for reasons related to the post-Franquist political climate – the freedom of the individual or couple is deemed to be the overriding concern. The regulation of technologies of artificial procreation is therefore designed to allow their monitoring and evaluation. These techniques are largely accessible to both men and women. In the same spirit, research on human embryos is allowed without restriction, other than technical, until the fourteenth day of gestation.

Other countries (such as Germany and some of the Scandinavian countries) have a much less liberal attitude. Research on embryos is prohibited. Moreover, the use of artificial means of procreation is strictly limited, principally in order to protect the right of the child to be born. As a general rule, only couples have access to this technology. Moreover, certain techniques are banned altogether in order to prevent the stock-piling of surplus embryos (for instance, in Germany, egg and embryo donation is prohibited).

The French bioethical laws passed in 1994 fall in-between the English and German approaches. Although research on embryos is prohibited, studies “with a medical purpose and presenting no danger to the embryo” are permitted.

Prenatal testing, which until recently was completely unregulated, is now subject to some control. For example, the French and Norwegian laws passed in 1994 stipulate that a genetic diagnosis is justified only in cases in which there are grounds for serious medical concern.<sup>14</sup>

In some countries, prenatal screening has been diverted from its therapeutic purpose. For instance, it is known that in China



and India prenatal screening is used primarily to determine the sex of the expected child: when a female fetus is discovered the pregnancy is often terminated. In all probability the law passed in India in 1994, which prohibits such practices, will not – at least in the short or medium term – succeed in overcoming the ancient sexist prejudices that underlie this attitude. However, the political courage to pass such a law should be welcomed at the very least as a hopeful sign.

Preimplantation diagnosis, which is in its early stages, poses the question of eugenics even more radically, since it presupposes a choice of embryos. This is why various laws have already been adopted; some prohibiting it altogether (the German law of 1990; the Austrian law of 1992), others allowing it only under extraordinary circumstances (the French and Norwegian laws of 1994). As for the new French Penal Code, condemns in a general way “the putting into place of a eugenic practice leading to an organized selection of persons” (article 511-1 of the new Penal Code).

These provisions are far from superfluous. Modern genetics not only makes it possible to know an individual’s genetic characteristics; it also allows for the entirely new possibility of modifying the human genome. Indeed the current debate over gene therapy, in particular the debate over germ-line therapy, seems to suggest the potential for a renewed debate over the power of science. Are we really secure from science’s latest temptation to give itself the mission of helping to “improve the species”?

The staggering statements made by the early twentieth-century French physiologist Charles Richet, to which Mireille Delmas-Marty has called attention,<sup>15</sup> must be taken seriously in the light of the current resurgence of eugenic theories.<sup>16</sup> “To force a deaf-mute, an idiot or rachitic individual to live is a form of barbarism ...”, Charles Richet wrote in 1913: “There is a kind of living matter that deserves none of our respect or compassion. By resolutely eliminating them we are doing them a service, because a miserable existence is the best they could hope for from life.” Unfortunately, this kind of discourse did not remain a dead letter. Indeed it underlay eugenic policies which led, during the period between the two World Wars, to the forced sterilization and even elimination of many mentally retarded people both in the United States

and Europe, even before such practices were adopted on a large scale in Nazi Germany.

Such social eugenics would be the long-term risk of gene therapy if it were to be used for “improving” non-pathological genetic characteristics.<sup>17</sup> As for germ-line therapy, the aim of which is to transfer to humans transgenetic technology that is currently only practiced on plants and animals, there is a real question as to whether it should be envisaged at all. Indeed should it not be banned by law the world over, as has already been done by most European legislatures?

The potential social impact of the extension of predictive genetic tests is also an issues of particular concern. Now that it is possible for individuals to know the risk factor their genetic heritage presents, they will be able to adapt their behavior, for preventive measures, by changing their life styles and by accepting regular medical examinations. But at the same time this predictive form of health care could result in new forms of social exclusion and discrimination.

The risks of such discriminatory practices where employment and insurance are concerned are becoming better and better assessed. Ethics committees and legislative bodies have expressed legitimate concerns on this score, as voiced by the media.<sup>18</sup> However, the forces favoring the expansion of preventive medicine, which include important economic and financial interests, may very well carry the day, given that health costs have become an ever more onerous economic burden.

The definition of what constitutes the end of life is itself in question.

The international context, with its combination of accelerated population growth and general economic instability, lends itself to this kind of discussion. The debate over euthanasia is an example; the concept of “brain death,” although it conflicts with certain religious taboos (in Asia and in Islam), has become increasingly accepted under the dual pressures from the medical establishment and the need for donor organs. For example in Tunisia a law was passed in 1991, contrary to religious law, authorizing organ removal from dead bodies. In Israel, in spite of philosophical and religious doubts, the concept of brain death has finally been

accepted. Even in Japan, where death is traditionally acknowledged only after the completion of the funeral rites, a proposed law on organ transplantation was presented to the Diet in 1994. These legislative developments reveal the constantly changing relations between science and society, with science appearing more and more as a vector for the transformation of mentalities, customs, and habits.

## **II. The General Foundations of Bioethical Law**

### *1. The Guiding Principles of Bioethics*

Through a comparative study of bioethical laws, as well as an analysis of the directives of existing ethics committees, it can be seen that there is a unity of contemporary thinking on ethics that transcends the diversity of national legal prescriptions and recommendations.<sup>19</sup> Of course, the ways in which medical research and biomedical practice are framed in law vary according to the mentalities, the level of economic and technological development, and the social structure of each country. Nevertheless, there is a remarkable similarity in the way that bioethical questions are posed almost everywhere in the world; that is, they are raised in relation to the protection of the rights of the human person in all his or her social and individual complexity.

By giving primacy to the human person, bioethics is thus concerned with the fate of humanity itself. To quote the words of Professor Jean Bernard, the primary goal of bioethics is to maintain "the sense of the human," so that the technologies related to life forms do not reduce the human being to his or her biological substratum.

The rights of the human person, which it is the mission of ethics to promote, are multifarious. This is so because of the various guises in which the human person appears: as an individual, "endowed with reason and conscience," as the Universal Declaration of Human Rights puts it; but also as part of the human species in the sense of being a member of the "human family" as defined by the life sciences; finally, as a man or woman "situated" in a community that assigns specific rights and responsibilities to its citizens. In all these cases the common denominator is the view of the

human person as possessing an inherent value. Living, as we do, in a period of divisive, even hostile particularisms rooted in concepts of ethnicity, language, historical past and culture, bioethics has the virtue of establishing bridges between cultures. Its aim is to foster an indispensable dialogue between cultures on the place of the human person and of his or her future in the face of the progress of science. This dialogue is especially pertinent because of the crucial need to ensure a minimum of solidarity among the world's nations in order to guarantee human control of science.

The juridical and political affirmation of the rights of the human person is at the heart of bioethics. The primacy given to the individual in regard to advances in biology and genetics is recognized in the principle of the dignity of the human person. This principle, which is mentioned in the preamble to the United Nations Charter of 26 June 1945, and reaffirmed in the preamble to the Universal Declaration of Human Rights of 10 December 1948 – where “the inherently equal dignity of all members of the human family” is proclaimed – finds its full expression in the bioethical view of human rights. The first of these rights is based on the acknowledgment of the existence of the human being as such, that is as a subject who can not be treated as an object by science. As a corollary, the concept of human dignity presupposes respect for the other in his or her singularity and identity, both cultural and genetic. This respect, which goes beyond mere tolerance of the other, is based on the right of the other to his or her dignity both because he is different from me and because he is part of me. “Any human being is all humanity”: this famous phrase of Jean-Paul Sartre summarizes the philosophical and juridical scope of the principle of dignity that is different from all other principles of law and right.

It is, in the first instance, on this principle of dignity that the distinction between civilization and barbarism rests. This is clear from the text of the Universal Declaration of Human Rights, in whose preamble acts of barbarism that revolt the conscience of mankind are explicitly condemned. By making dignity a fundamental principle of civilization, the Universal Declaration provides the human being with a defense against the resurgence or persistence of barbaric practices, such as slavery or servitude (article 4), torture, cruel, inhuman, or degrading treatment (article 5).

The principle of dignity prohibits all inhuman acts, such as the experiments carried out on detainees in Nazi concentration camps or on prisoners of war in Japan. Today it should also prohibit the kinds of exclusion and discrimination that the advances of genetic research might promote.

The principle of dignity presents a second unique feature absent in other individual rights: it is absolute. Unlike other principles, such as those on which individual freedoms are based, the right to dignity can not be restricted in any way.

As a general rule, individual freedoms come up against two types of limitations, both of which express the constraints inherent in community living. The first of these, as article 4 of the "Declaration of the Rights of Man and Citizen" of 1789 expresses it, is the view that "freedom consists in being able to do anything that causes no harm to another person." The basis of the second kind of constraint can be seen in the judicial pronouncements emanating from the jurisprudence of Constitutional Courts, which assert that freedom is "neither general, nor absolute." It must be reconciled with other principles and rules of a constitutional nature.

To take just one example from the biomedical field: The right to carry out research freely must be aligned with the right to safety and health for the person who takes part in a medical experiment. The balance of these two imperatives is currently expressed in various regulations concerning biomedical research on human beings.

This is not the place to take up the controversy concerning the putative existence of a "supra-Constitutionality," in whose name it is argued that some principles are to be placed at the top of the hierarchy of rights; nor will we inquire here into the validity of the concept of "natural right" which is sometimes attributed to the principle of the dignity of the human person. Rather we will simply point out that the very concept of the dignity of the human person, viewed as the foundation of bioethical law, considerably strengthens the concept of the human person as a subject of law. It endows this human being with an inherent *value* prior to identifying him or her as an individual or a member of a community.<sup>20</sup> The decision of the French Constitutional Council, dated 27 July 1994 – and which remains to date the only decision on a matter of bioethics by any constitutional court – is instructive in this regard.<sup>21</sup>

Although the French Constitution of 1958 does not mention the principle of human dignity, as it is in other European constitutions, - nor does it appear in the Declaration of 1789 – the Constitutional Council was able to derive this principle from a phrase in the introduction to the preamble of the French Constitution of 1946. Indeed, France expressed in that text its will to make a radical break with “the regimes that attempted to subjugate and debase the human person.” In the decision of 27 July 1994 the Constitutional Council stated: “It follows from these terms that the safeguarding of the dignity of the human person against all forms of subjugation and debasement is a principle that has constitutional force.” This deductive reasoning confers on the concept of human dignity its full historical significance. The acknowledgment of this principle in domestic French and international law after World War II was a direct result of the realization that humanity could be the instrument of its own destruction. Indeed, the very logic of safeguards proposed by bioethics is to prevent humans from doing harm to each other.

With this in mind, how can it be seriously affirmed that there exists a conflict between the principle of the dignity of the human person and the rights and freedoms of individual persons? Certainly not insofar as the principle of dignity transcends that of rights and freedoms. Of course, it is true that the principle of human dignity has been abused in the past; for instance, as a pretext for the censorship of books. Even more dramatically, it was used at the beginning of this century as an argument to justify state-sponsored eugenics. Still later, it became a fundamental element of the Nazi doctrine that “the life of some persons is not worth being lived.”

However, the misuse of the principle of dignity in no way invalidates it altogether. Indeed, the principle is crucial for justifying the setting of limits on the life sciences.

To give but one example from French legislation: it is the principle of human dignity that is the reason behind the restrictions on individual liberty over one’s own body. These restrictions refer mainly to the assertion of the non-patrimonial character of the elements and products of the human body, in particular organs, tissue, cells, or genes. Moreover, it justifies limitations on research activities, in particular the prohibition of research on human embryos.

As Professor of Law Bertrand Mathieu has pointed out, “the right to dignity is the matrix of a series of guarantees that are formally recognized in law but which must be protected in order to ensure the respect of the principle itself.” According to a French law of 1994 on bioethics, these guarantees are “the primacy of the human person, respect for the human being from the very beginning of life, the inviolability, integrity and non-patrimonial character of the human body,<sup>22</sup> and the integrity of the human species.”

As a source of new specific rights, and as a general principle of absolute character, human dignity thus becomes *the* inalienable right par excellence. It is a principle that applies in all circumstances, even in times of war or of “public emergency which threatens the life of the nation” (article 4 of the United Nations Covenant on Civil and Political Rights of 1966, and article 15 of the European Convention on Human Rights). Moreover, it can never be subject to any limitation or variation.

Although bioethics may appear as a source of constraints, it also affords an opportunity for the creation of new areas of freedom. This is because human liberty, which Kant defined as “a unique and inherent right that belongs to each man by virtue of his humanity,” is the other guiding principle of bioethics and an integral part of human dignity. Two essential guarantees of individual freedom are affirmed in bioethical law, both on the national and international level.

The first concerns the free and informed consent of an individual. We are talking here about consent to receive care, to submit to experimentation, to donate organs, tissue, and cells, as well as to the disclosure of individual medical data for purposes of research.

The second guarantee concerns the right to respect for private life. This principle is affirmed in constitutional jurisprudence and in many texts. The endorsement of this principle has become necessary because of the considerable increase in the storage and dissemination of genetic data, particularly computerized, and of the difficulty of preserving their confidentiality. Moreover, genetic data yield information not only about an individual but also about his or her family. Some form of balance must be achieved among these competing interests. Finally, genetic data contain social and economic information useful to third parties – Social Security,

insurance companies, employers, etc. – who directly or indirectly bear the costs associated with health care delivery. Has the time not come for these third parties to be denied access to such individual medical information?<sup>23</sup>

The principle of the dignity of the human person leads to a recognition of rights inherent in the idea of humanity understood as a collective value. Claude Lévi-Strauss, during a conference held at UNESCO in 1952 on “Race and History,” pointed out that this idea, which encompasses all forms of human culture and race without distinction, appeared rather recently in human history.<sup>24</sup> For millennia, when humans lived in symbiosis with their immediate environment (both animal and natural), the concept of humanity did not extend beyond the boundaries of one’s own village or tribe. The feeling of compassion for all humanity and the urge to relieve the sufferings of human beings on a planetary scale did not emerge until the nineteenth century. It was only then that humanitarian action took on an international character and acquired its institutional framework. Still, it was not until the rise of Nazism, with its insane theories and genocidal practices, that the concept of humanity, endowed with inherent rights, received explicit legal expression. The concept of “crime against humanity,” of an imprescriptible nature, recognized by the statute of the Nuremberg Tribunal in 1945 established, for the first time, humanity as being an autonomous subject.<sup>25</sup>

The legal protection of this universal humanity, understood as “the human species,” endowed with an inherent right to “integrity” (according to the term used in the French bioethical law of 29 July 1994), has been strengthened. However, the acknowledgment of the integrity of the human species does not imply the inviolability of the genetic heritage. Although this principle figures in some European instruments, such as in the Recommendation on genetic engineering adopted in 1992 by the Parliamentary Assembly of the Council of Europe, it did not appear in later instruments. Actually, such a principle would have little practical bearing insofar as the human genome is subject to constant mutations. On the other hand, the principle of the integrity of the human species is at the origin of the condemnation of all eugenic practices based on genetics.



This notion of integrity also poses the question of the possible legal scope of the concept of "human biodiversity," a diversity that reflects the richness of differences among human beings. As the philosopher Alain Finkielkraut has written, "mixing [*métissage*] is no longer a risky and marvellous possibility; it is the very definition of being human."<sup>26</sup>

## *2. The Rise of International Bioethical Law*

The issues associated with bioethics have been framed not only within a national socio-juridical context; they have also given rise to increasing legal activity at the international level. Over the past twenty years, independent of basic texts related to human rights, a series of declarations that proclaimed principles of bioethics have been drawn up. These statements have been made public either on the occasion of scientific conferences and congresses, or in the context of the activities of various scientific organizations, some of them governmental, some not. For instance, the Inuyama Declaration, made public by the Council of International Organizations of Medical Sciences in 1990, defined the ethical standards expected of scientific researchers and pointed to the necessity for a responsible application of knowledge in the field of genetics.

International governmental organizations have also become involved in the field of bioethics. Among them, the European organizations (the European Union and the Council of Europe) have been especially active. By the same token, within UNESCO itself, the International Bioethics Committee has made a study preliminary to a universal declaration on bioethical issues.

The approach of these organizations varies according to their attributions, areas of competence, and mode of operation. Thus the European Union, whose goals are primarily economic, has led the European Commission to be especially attentive to the distrustful attitude of the European public toward the development of biotechnologies. The Commission has also taken up the question of the impact of the application of biotechnologies on the fundamental rights of European citizens as explicitly laid out in the Maastricht Treaty (article 3F) of 1992. As a result, the Commission created, in 1992, "The Group of Advisers on the Ethical Implications of Biotechnology," which operates along the lines of an

ethics committee. Composed of nine members from nine different nations, the committee is multidisciplinary, pluralistic, and autonomous. It deals with questions that are submitted to it by the European Commission on a case by case basis or can decide to address questions *ex officio*. It can also comment on European bioethical legislation that is either pending or in force. It has, in this regard, offered its opinion on a number of bioethical issues: the 14 June 1989 law on the safety of blood transfusions; the proposed directive regarding biotechnology patents; the proposed regulation concerning labeling of genetically-engineered foodstuffs; and on gene therapy in the perspective of the creation of a European-wide health policy. Its concrete recommendations nevertheless reflect the guiding principles of bioethics: *inter alia*, the protection of the dignity of the human person; respect for the principle of free and informed consent of patients; and the safeguarding of the confidentiality of individual genetic data.

The Council of Europe has taken a different approach. Based on the European Convention for the Defence of Human Rights and Fundamental Freedoms of 1950, the Council is in the process of drawing up a framework Convention on Bioethics. Its preliminary report, which was released in 1994, has not been approved by the Parliamentary Assembly of the Council of Europe. Two types of provisions are especially controversial: those that allow member States to authorize, under certain conditions, embryo research; and those that envisage the possibility of allowing experimentation on vulnerable patients who are unable to give their free and informed consent. As for the rest of the preliminary draft convention, it merely restates the international consensus on what constitutes the two fundamental principles of bioethics: respect for the dignity of the human person, and the protection of human rights and freedoms.<sup>27</sup>

UNESCO, which has been involved in the bioethical debate since the 1970s, has taken a different tack. According to a resolution of the General Conference of its Member States, dated 15 November 1993, UNESCO is involved in the drafting of an "International Instrument on the Protection of the Human Genome." The originality of UNESCO's approach is of course a function of its being part of the United Nations system, which aims to inte-

grate universalism and pluralism. This innovative character is also due to the vision of its Director General, Federico Mayor, who created the International Bioethics Committee (IBC) in 1992. With its fifty members hailing from forty countries and representing a variety of disciplines, the Committee is an independent force, at the heart of UNESCO, dedicated to the exchange of ideas among all cultures of the world.

It was the IBC that initiated the discussion on a future "Declaration on the Protection of the Human Genome." This period of discussion proved to be a catalyst for a broad intercultural dialogue. Not only was the text discussed and submitted for public debate during the annual meetings of the IBC held at UNESCO headquarters, it was also disseminated internationally to university and academic circles, as well as to ethics committees, in order to generate comments and observations from all around the world. The resulting synthesis of remarks addressed to the IBC constitutes a document of paramount importance, since it gives an unprecedented vision of the world's cultural and national sensitivities to matters of bioethics. Above all, it allows us to reject the idea that no international consensus is possible on basic bioethical principles. More especially, as such a consensus exists and corresponds to the objectives of UNESCO; and in particular to "the democratic principles of the dignity, equality, and mutual respect of men," as proclaimed by the Preamble to UNESCO's Constitution of 1946. The final form of such a declaration would not merely be a simple restatement or extension on an international level of ideas already expressed in national constitutions and laws; rather this document would embody a new concept, by connecting the human genome to the idea of the common heritage of humanity.<sup>28</sup>

This idea of the common heritage of humanity, which was originally formulated in the nineteenth century, was revived in the 1960s. It is an idea that surfaces at certain historical moments, when human beings become acutely aware of the fact that they are fated to live together and must therefore cooperate to defend their common interests. The idea of a common heritage of humanity first arose in regard to certain resources and material goods, the management of which required international cooperation. Whether it be the high sea beds, outer space, or even celestial bod-

ies; none of these fall under the territorial sovereignty of States. However, this idea soon grew to encompass cultural goods of worldwide significance which were made part of the world's heritage while remaining under the legal jurisdiction of the local government in which they were found. The protection of these goods, monuments of civilization and culture, is in great measure due to UNESCO, in particular the UNESCO Convention on "The World's Cultural and Natural Heritage" of 16 November 1972.

Today, by including the human genome as one element in the common heritage of humanity, it can be hoped that the following aims will be achieved: To begin with, this principle underscores the notion that humanity's genetic heritage, although encompassing neither the human personality nor its individuality, must be protected from potential exploitation and modification by contemporary science, which can alter human genes regardless of any therapeutic purpose. This heritage, as the word indicates, represents more than itself. As Paul Auster has written in his novel, *The Invention of Solitude*, "each person carries in his genes the heritage of all humanity that preceded him." This is why the human genome, as a collection of data, represents a massive source of basic knowledge that must be made available to humanity and be put at its service. It should be viewed like human rights, and the governing principles of bioethics as being themselves part of the cultural heritage of the human community.<sup>29</sup>

As the philosopher and biologist Henri Atlan has underlined, the real subject of bioethics is not the human genome, since this simple DNA molecule does not even in itself represent life.<sup>30</sup> The essential subject of bioethics is the human person in all his or her multiplicity. Thus the rejection of all forms of reductionism is a crucial element in the declaration prepared by the IBC. The human being cannot be reduced solely to his or her genetic capital. The myth of a pure race should not give way to the myth of the purity of genes.

The proliferation of bioethical norms, witnessed at national and henceforth at international level, is not a product of chance. Rather this development embodies the search for new landmarks in the face of the failure of holistic ideologies and the realization that 'economistic' thinking is inherently limited. In this sense, bioethics can be the yeast to give rise to a new way of thinking that will

lead our societies to find the necessary balance between the powers of science and the dignity of the human person.

## Notes

1. J.-P. Changeux, "Penser la bioéthique, un débat philosophique," in: F. Mayor, *Amicorum Liber*, vol. II, Brussels, 1995.
2. P.-A. Taguieff, "L'espace de la Bioéthique," in: *Discours sur la Bioéthique* (Mots/Les langues du politique), No. 44 (September 1995).
3. H. Jonas, *The Imperative of Responsibility*, Chicago, 1984.
4. Y. Madiot, "La protection internationale de la personne," in: *La Personne Humaine sujet de Droit* (Publications de la faculté de droit et des sciences sociales de Poitiers), Paris, 1994.
5. See the survey carried out by the UNESCO Bioethics Unit under the direction of G. Kutukdjian in: *The UNESCO Courier*, No. 11 (November 1994).
6. C. Ambroselli, *Les Comités d'éthique*, published in the series "Que sais-je?," Paris, 1990. See also S. Lebris, *Etude pour le Conseil de l'Europe sur les Comités d'éthique*, Strasbourg, 1994.
7. J.-P. Changeux (note 1).
8. See the brochure on the GCEB, available through the General Secretariat (I. Arnal, European Commission, 200 rue de la Loi, 1040 Brussels).
9. Proceedings of the IBC, available from the Secretary General (G. Kutukdjian, UNESCO Bioethics Unit, 1 rue Miollis, 75015 Paris).
10. J.-L. Baudouin and C. Labrusse-Riou, *Produire l'Homme, de quel droit?*, Paris, 1987.
11. H. Yoichi and C. Sautter (eds.), *L'Etat et l'individu au Japon*, Paris, 1990.
12. N. Lenoir, "Bioéthique et politiques de santé publique," in: M. Berthod-Wurmser (ed.), *La Santé en Europe*, Paris, 1994.
13. See the report by R.Z. Qui, "Ethical Issues in Genetic Screening and Testing in a Multicultural Context," presented to UNESCO's International Bioethics Committee in September 1995 (*Proceedings*, vol. II). Qui Ren Zong is the director of the Program on Bioethics at the Chinese Academy of Social Sciences.
14. N. Lenoir, "Aspects juridiques et éthiques du diagnostic prénatal: le droit et les pratiques en vigueur en France et dans divers autres pays," in: *Publications de l'Institut suisse de droit comparé. Actes du Colloque International sur 'l'Analyse génétique humaine et la protection de la personnalité'*, Lausanne, April 1994. See also D. Shapiro, "Genetic Testing and Screening," Report to the IBC, *Proceedings*, 1995.
15. M. Delmas-Marty, "Le crime contre l'humanité, les Droits de l'homme et l'irréductible humain," in: *Revue de Science Criminelle*, No. 3 (July-September 1994).
16. J.-P. Thomas, "La courbe en cloche ou éternel retour de l'eugénisme," in: *La Revue des Deux Mondes*, No. 2 (1995).
17. H. Edgar, *La Thérapie génique*, Report to IBC, *Proceedings*, 1995; P. Lehn, *La Thérapie génique* (Report to GCEB, 1994).

18. See the opinion of the Comité consultatif national d'éthique pour les sciences de la vie et de la santé, entitled "Génétique et médecine: de la prédiction à la prévention," No. 46 (30 October 1995).
19. J. Russ, *La Pensée éthique contemporaine*, published in the series "Que sais-je?," Paris, 1994.
20. N. Lenoir, "Les Etats et le droit de la bioéthique," in: *Revue de Droit Sanitaire et Social*, No. 2 (April-June 1995).
21. B. Mathieu, "Un juge constitutionnel réservé face aux défis de la science," in: *Revue Française de Droit Administratif*, No. 1018 (1994). Along the same lines: the report "Pour une reconnaissance de principes matriciels en matière de protection constitutionnelle des droits de l'homme," in: *Revue Dalloz*, No. 27 (1995). See also the commentary on the decision of the French Constitutional Council in: L. Favoreu and L. Philip, "Les grandes décisions du Conseil constitutionnel," Dalloz, 8th edition (1995), p. 847.
22. The principle of the non-patrimonial and non-commercial character of the human body is deeply rooted in the French juridical tradition, in particular since the first blood donation law of 1952. But such a principle is not generally accepted in all countries. Thus in the United States the debate on whether the individual has a patrimonial right to elements and products of his or her body remains intense, following a 1988 decision of the California Supreme Court in connection with the John Moore Case. The plaintiff had his claim for damages from a group of scientists dismissed who had used his blood cells because of their rare and highly interesting properties. However, the Court dismissed the plaintiff's case on the grounds of the way in which the cells had been exploited and not on the basis of any general principle associated with the non-patrimonial character of the elements or products of the human body.
23. The question of the confidentiality of medical data is complex, and the more crucially so because economic and social agents, whether public or private, are increasingly reluctant to assume the burden of the health risks associated with certain individuals. The right protects against such a trend which is contrary to social solidarity. Thus the European Court of Justice, in a decision of 5 October 1994, has taken the view that the right to privacy, contained in Article 8 of the European Human Rights Convention, covers a person's right not to have to disclose information on his or her state of health. In this particular case, a job applicant who knew that he was infected with the HIV virus was allowed to refuse an HIV test. Nevertheless, in the view of the European Court, the employer could be justified to make the recruitment of an employee subject to the results of medical tests as part of the hiring process, on the condition that his legitimate interest warrants it. See *L'Idée d'humanité* (Actes du Colloque des Intellectuels Juifs), Paris, 1995.
24. A. Finkielkraut, "Le fardeau de notre temps," in: *ibid.*
25. M. Delmas-Marty (note 15).
26. *Ibid.*
27. The text of the draft convention is to be found in: *Dictionnaire permanent, ou bioéthique et biotechnologies*, Paris, 1994.
28. M. Bedjaoui, "Le génome humain comme Patrimoine commun de l'Humanité, ou la Génétique, de la peur à l'espérance," in: F. Mayor (note 1). See also H. Gros Espiell, "Le génome humain, Patrimoine commun de l'humanité," (in press). It should be noted that, according to a decision of the French Constitu-

tional Court of 27 July 1994, the notion of a common genetic heritage of humanity has no constitutional foundation.

29. We find here an idea similar to the one enshrined in the Preamble of the Council of Europe Statutes of 1949, proclaiming adherence of the signatory states "to the spiritual and moral values that are the common heritage of their peoples."
30. H. Atlan and C. Bousquet, *Questions de Vie. Entre le savoir et l'opinion*, Paris, 1994.