BIOLOGICAL DIVERSITY AND POLITICAL EQUALITY: THE SOCIAL IMPACT OF GENETIC TESTS

Jose Luis Lujan and Luis Moreno, Spanish National Research Council

In the present work we deal with the political and social dimensions of modern technologies of genetic diagnosis. In the first place we review the literature on the subject, using the usual distinction between genetic diagnosis in clinical and non-clinical contexts. Then we show the way in which the interaction between these diagnosis techniques and their social context can lead to a redefinition of the concept of illness. Then we examine the political implications that these redefinitions cause. The paper ends with a reflection on the possibility that the use of genetic diagnosis may lead to questioning how the solidarity that is characteristic of advanced industrial societies is organized.

INTRODUCTION

Broadly speaking, political values indicate those objectives which are considered desirable, and technology shows us how to reach such objectives. This is the conventional image of the relationship between the sphere of science and technology and that of politics. Although it is now being questioned, for many years its applicability has determined the parameters of the relations between governments and experts.[1]

It has often been the case that scientific and technical knowledge has redefined political objectives, showing clearly that certain aims were unattainable and that they led to unscientific or socially inefficient management. This is reflected in the tension generated in the political sphere by emphasizing such values as equal rights and obligations while simultaneously supporting the scientific study of human differences. The development of human genetics, and especially behaviorial genetics, has had a clear political dimension.[2] Social Darwinism and eugenics are socio-political movements which have tried, on the basis of certain specialized scientific knowledge, to redefine some of the most venerable political concepts.[3] But this characteristic is not exclusive to biological

explanations of human behavior. Since the dawning of Skinner's behaviorism, for example, there has also been an attempt to define the bounds of social engineering while simultaneously maintaining those aims which are considered scientifically feasible.[4]

The knowledge which human genetic engineering and new genetics in general may bring could conceivably transform our self-understanding as living beings. This change would affect culturally, politically, and morally significant dichotomies, such as those which contrast the public and the private, the natural and the unnatural, health and sickness, or determinism and free will.[5] In many cases, these distinctions may reflect the influence of science and technology in social, political, and cultural contexts. But it must be borne in mind that the relation is not one-sided. It is also possible to analyze political and social influences on science and technology.

POLITICS AND BIOLOGICAL DIVERSITY

In the analysis of the socio-political aspects of human genetics, reference to biological determinism is inevitable.[6] This current of thought is difficult to characterize. It consists of a mixture of popular culture, scientific results, and normative proposals for political action. An interesting point to note is that the idea of biological determinism came before the appearance of genetic science. Dreyfuss and Nelkin speak of a certain type of essentialism that is related to the social definition of personhood in Western culture.[7] The results of genetics would be interpreted against this cultural background, becoming what the authors call genetic essentialism.

Plato, Seneca, and Campanella were convinced that the characteristics of human beings depended on their family origin. This essentialist and determinist concept is not exclusive to thinkers or philosophers, but is deeply rooted in popular belief. This may be the reason for its persistence throughout history. In the nineteenth century scientific support was sought for this thesis. The appearance of evolutionary biology and genetics was taken to be a real step forward in the history of biological determinism. Social Darwinism and eugenics have been the best-known scientific versions of biological determinism. In these two cases, the normative-political character of biological determinism is apparent. The eugenicists not only believed themselves to be in possession of the keys to

understanding human nature, but were also convinced of how, on the basis of that supposed knowledge, they could solve the majority of the important social problems of the late nineteenth and early twentieth centuries.

Biological determinism not only has the capacity to influence the design of scientific research programs, but is also capable of absorbing the results of other scientific disciplines. Just to name a few cases, we can mention craniometry, criminal anthropology, evolutionary biology, genetics, differential psychology, behavioral genetics, ethology, and human sociobiology. As Dreyfuss and Nelkin point out, society usually appropriates science to support dominant values, often extending it beyond the limits of well-established knowledge. It is therefore important to keep biological determinism in mind when it comes to analyzing the political and social dimensions of human genetic engineering.

HUMAN GENETIC ENGINEERING: A PANORAMIC VIEW

When speaking of human genetic engineering, we will refer to three specific areas: (i) genetic tests, (ii) gene therapy, and (iii) the Human Genome Project. Of these three, the last is the best-known owing to the coverage it has received in the media. The Human Genome Project is an international effort to map and sequence human DNA. This entails identifying the sequence of three billion pairs of nitrogen bases. The mapping involves obtaining an important number of genetic markers which serve as reference points within chromosomes.[8] The markers can serve to locate genes that are related to certain human traits.

The expression "genetic tests" refers to a distinct group of technologies, some known for quite some time and others which are not, in the strict sense, the results of recombinant DNA technology. A genetic test may involve either the analysis of a particular tangible substance (proteins by means of biochemical analysis) for the indirect detection of genetic differences, or a direct examination of DNA. A classic example of the first type of genetic test is that for phenylketonuria (PKU, a disease of genetic origin), which consists of measuring the concentration of phenylalanine in the blood. There have also been recent developments in genetics which have made the direct examination of DNA possible. With the proliferation of markers, the use of genetic tests may expand considerably. Around 4,000 monogenic diseases are known, and in 1988 some 70 practical genetic tests were available.

Gene therapy consists of inserting a DNA fragment into a group of cells in which it is absent.[9] In this way, a group of gene-modified cells making up an organ such as the pancreas, for example, can produce substances that could not be produced before the alteration. It is thus possible to cure diseases caused by nothing other than the absence of a given substance. There are two kinds of gene therapy: in somatic cells and within germ lines. Therapy in somatic cells produces a gene correction in a specific individual. Therapy within germ lines (in gametes or pre-embryos), ensures that the specific gene manipulation is not brought about only in the individual but also in the individual's descendants (keeping in mind that in human reproduction, each parent contributes half of the genes). By June, 1992, the U.S. National Institutes of Health had recommended the authorization of seventeen clinical trials of gene therapy in somatic cells.

In the course of the last few years, and due to major technological developments, the very concept of gene therapy in somatic cells is undergoing a large transformation. Thus an intervention can be carried out to introduce a gene whose absence is precisely the cause of the disease (e.g., cystic fibrosis). But it can also be carried out to arm a group of cells with certain therapeutic abilities for combatting diseases not caused by the absence of the gene in question (such as AIDS or certain types of cancer).[10, 11]

THE GENETIC TEST: SPHERES OF SOCIO-POLITICAL CONFLICT

In this section, we will analyze the principal problems of a social and political character which arise with the applications of genetic tests. Most of these problems are related to so-called "genetic discrimination." Following an increasingly widespread usage, genetic discrimination is defined as discrimination carried out against an individual or against the members of a family according to real or perceived differences with respect to the "normal genome" (independently of the fact that it is not possible to give a definition for a normal genome).[12] There is a distinction, therefore, between genetic discrimination and discrimination against the disabled.[13] This is an important point because most countries have legislation against discrimination against the disabled but not against genetic discrimination.[14]

Genetic discrimination does not exhaust the socio-political dimensions of human genetic engineering. Among other questions, some important issues are the

obligatory or voluntary nature of genetic tests, the threat to privacy and personal choice, the redefinition of crimes, access to genetic information, and the redefinition of public policies (chiefly within the areas of health, labor and education).

Genetic tests can be used with four main aims: the identification of carriers, pre-natal diagnosis, pre-symptomatic diagnosis, and genetic identification (DNA profiling). It is possible to differentiate the social impact of these tests depending on whether they are implemented in a clinical or non-clinical context.[15,16,17] The following analysis shows that the practical setting of the test determines what the repercussions and level of social acceptance will be to a considerable degree. This is, thus, a clear illustration of the interaction between technology and its use within a social context.

CLINICAL CONTEXTS: CONFIDENTIALITY AND PRIVACY

In general, Western medicine has satisfactorily resolved the questions concerning confidentiality and privacy. However, information obtained by way of a DNA test is *sui generis* medical information requiring specific treatment. Therefore, if a genetic disease or a genetic propensity to suffer a particular disease (expressed in statistical terms) is detected in an individual, a medical difficulty immediately arises concerning the transmission of such information.[18,18]

Regarding the "diagnosis" of the patient, the first question is whether or not a therapy is available for the cure of the hereditary disease or of a disease in which the genetic component is important (although not decisive). In the first instance, the case of cancer is analogous, in view of the uncertainty surrounding available treatments for the cure of patients. In the second instance, it is much more difficult to determine how much of a role a propensity towards unhealthiness plays in comparison to the role of the specific diseases themselves. In this sense, the information gained by the genetic test may be irrelevant to the future health of the patient, and yet its being made known may result in serious problems for the development of a normal life. Thus, a growing current of specialized opinion exists, prone to the view that only that information which is clinically significant should be communicated, and that it should be accompanied by an appropriate assessment of the affected individual, as well as by the support required to maintain a normal social life.

Confidentiality has always been considered a fundamental pillar of medical practice. This situation is being altered by the growing use of genetic tests, applied not only to "healthy" citizens but also to sick ones. We must also bear in mind the current technological capacity for storing and transferring information about individuals.

In 1983, the U.S. Presidential Commission for the study of Ethical Problems in Medicine recommended that confidentiality only be breached in extremely exceptional circumstances.[20] Taking the situation in Europe as a reference, it might be emphasized that the European Convention on Human Rights considers health protection a possible legitimate limit to the right to privacy and confidentiality.[21]

Physicians who work for businesses or insurance companies may experience serious pressures to divulge information that, as we shall see further on, could be thought to possess an economic value. Employees themselves may feel pressured (even by the simple need to obtain work) to allow access to their genetic information.[22] Therefore it makes good sense to delay passing on medical information to businesses or insurance companies.[23]

Genetic information has wide repercussions in matters relating to human reproduction. An implicit medical convention exists requiring specialists in genetic medicine to avoid pressuring parents, in favor of protecting their freedom of choice. This includes the option of abortion or giving birth to a foetus with deformities or genetic disorders.[24] In accordance with these considerations, genetic information must be restricted to purely clinical aspects, since what is being dealt with is the genetic diagnosis of sicknesses or of parental and prenatal tests.[25] But some authors point out that this is not always the case and that genetic counsellors may end up pressuring parents in one way or another, or not give all of the facts which a fully informed decision would require.[26]

The use of genetic tests in human reproduction is a highly controversial issue.[26,27,28] As we shall see further on, this is an area in which it is difficult to set clear boundaries between the clinical and the non-clinical. In fact, it constitutes an excellent example for analyzing the social character of the distinction between what is and what is not considered an illness.[17]

NON-CLINICAL CONTEXTS: DISCRIMINATION, SOLIDARITY AND EQUAL OPPORTUNITY

The use of genetic tests in non-clinical contexts is a delicate matter and poses a real challenge for the regulation of these practices. At the heart of this debate lies the potential social discrimination which private or public institutions with access to genetic information could exercise.[12,13,15,22,29,30,31]

In the workplace:

One particular area of conflict is in labor relations. The information derived from genetic tests might interest four different groups of people: the worker, other workers, the company, and insurance companies. The question revolves around a group of not always complementary interests which are potential sources of conflict over the possible uses and misuses of the information obtained through genetic tests.[32]

Workers may see their labor expectations conditioned in accordance with their own genetic information. In personnel selection processes, as well as in cases of litigation over work-related accidents or illnesses, corporations and companies would be able to act on the genetic data of their potential employees or salaried personnel. The co-workers of any worker "under observation," would be able, in turn, to demand access to this type of information, claiming as a reason their own protection when faced with possible accidents. In the case of a company's having subscribed to some policy with an insurance agency, the agency would be able to pressure the company in different ways into refusing to hire high-risk workers.

In general, it is worth identifying the two opposing views concerning the use of information facilitated by genetic testing: (1) genetic information is entirely private and can only be transmitted and made use of by strictly personal decision; or (2) genetic information belongs to the community and ought to be used according to what has been "decided" and regulated by the social group.[32] In a way analogous to what has happened after serious debates have been resolved involving the private-public conflict, it makes sense to suppose that future normative regulations will adopt an intermediate position, or, at least, one equidistant between the two extremes. We should not, however, fail to note that

the application of genetic tests could entail opportunities for discrimination and stigmatization in the work environment.

In 1985 the International Labour Organization declared that health examinations of workers could not be used for discriminatory aims, or in any other way that might prove detrimental to their interests. In 1989, the European Parliament advocated the prohibition of the use of genetic tests in labor recruitment. In the United States there is no consensus on whether the ADA (Americans with Disabilities Act, approved in 1990) precludes genetic discrimination in the work environment.[12,13,33] In the United Kingdom, the Nuffield Committee on Bioethics Report recommends that genetic screening be carried out in the workplace if the following conditions are satisfied: that there is clear evidence of a causal relation between the working environment and the development of the condition to be screened for; that a serious risk exists for the worker or for third parties; that the intensity of the condition in question cannot be lessened through corrective measures in the working environment; that the worker's rights are protected, including that of not being subjected to genetic testing or to receive assistance in the case of a new work placement. The committee also recommends that workers' representatives and the relevant health institutions be consulted.[34]

Labor discrimination based on genetic information includes unfavorable treatment in the drawing up of contracts in professional work conditions. There are two principal kinds of case. First, workers might not be hired because of the possibility that they may develop an illness of genetic origin (or which depends to a great extent on genetic factors), adducing a potentially high level of absenteeism, a lower rate of production than their peers, or that they might require a higher level of medical attention. Secondly, a worker may not be hired, or may not perform determined jobs, because there is the possibility that he or she may be exposed to certain products which are toxic for those who are known to possess a certain susceptibility of genetic origin. While the first case is motivated only by economic interests, the second can be justified as a protective measure for the health of the worker. But in this last assumption it also makes sense to consider reforms in the productive processes employing products which, in the last analysis, are not healthy for the workers as a whole.[35]

Insurance:

Prenatal testing raises a wide range of questions for health insurance, extending to any sort of genetic testing for life and disability insurance. These prenatal tests can detect malformations in the later development of the child. This raises the problem of the delimitation of responsibilities concerning who ought to pay for the costs of the possible illnesses known to be probable or certain before birth. In Europe it is assumed that, once parents' freedom of choice is safeguarded, other insured parties, whether in public or private health systems, will indirectly help to cover the costs of the affected persons. In the United States, parents currently feel pressured to abort, given the unlikelihood of finding insurance for the child.[36]

Where genetic testing in general is concerned, there is no doubt that insurers will be in a better position to calculate their risks if they have access to the genetic information of the insured. In such a situation it would be no exaggeration to suppose that not only individuals, but entire families would have immense difficulties subscribing to insurance policies for life, sickness, or disability because of their genetic constitution.[12,31] The normative options would fluctuate between a general obligation to subscribe to insurance, which would entail undesired collateral effects, and a restriction on insurance companies' ability to obtain certain genetic information. These problems worsen notably in those countries in which a universal public health system has not been developed, such as the United States. Moreover, all of these considerations will have to be kept in mind in future reforms of national health systems, and in the maintenance of welfare state benefits generally. It might be argued as well, as several authors do argue, that the development of human genetic engineering makes it even more necessary to eliminate obstacles to universal access to health services.[12,13,37]

In both cases genetic testing in the workplace, and genetic testing for insurance, one of the underlying questions is volition. Most bioethicists agree that the most adequate way to confront the problems described above is to guarantee the voluntary character of the test. Some, however, argue that individual autonomy ends where a situation arises in which a newborn child has an illness for which there is a known effective treatment.[24] Others, however, warn of the risk entailed by the obligatory nature of genetic tests, which may be carried out inappropriately or prematurely.[38]

The European Parliament in 1989, and the Council of Europe in 1992,

made declarations against insurance companies' right to demand genetic information as a condition for a contract. In the Netherlands insurance companies and the government came to a provisional agreement with a peculiarity worth noting: the use of genetic tests is not completely prohibited but restricted. Companies cannot demand genetic information when covering "real needs" (such as access to health) of individuals or their families. Beyond this threshold, and subject to the social and financial circumstances of the individual, the prohibition disappears.[37] In the United Kingdom, the Nuffield Committee recommends a temporary prohibition on insurance companies' demands for genetic data, with two exceptions: first, whenever there is a well-documented family history of genetic illness, and second, whenever insurance policies for large sums of money are drawn up.

Other Contexts:

There are other contexts in which genetic testing becomes problematic. In the field of justice questions can arise relative to privacy, intimacy, willingness, or the presumption of innocence in relation to genetic tests used to identify criminals.[39]

Since the turn of the century, all types of instruments used to measure the "mental characteristics" of students have been used in schools and education centers: personality tests, I.Q. tests, or brain activity tests. The social discrimination which results from the use of these tests is extensively documented.

Currently genetic tests can be used to determine a very limited group of human characteristics. But some scientists believe that with the success of the Human Genome Project the genes associated with specific behaviors and personality traits can also be found.[40] If this possibility becomes a reality, schools would certainly become one of the most contentious settings for the use of genetic tests.[41]

GENETIC TECHNOLOGIES AND SOCIAL CONTEXT: THE CONCEPT OF ILLNESS

Up to this point we have considered some of the social conflicts which the employment of genetic tests can lead to in certain circumstances. But we ought to

bear in mind that human genetic engineering (tests and therapy) can be utilized with respect to human conditions which are not currently taken to be illnesses. The polemical character of these possible applications is greater than that examined in the previous section. It is precisely in this context that biological determinism can play a notable role. In what follows, we will attempt to show how the interaction between genetic-test technologies and the social context can lead to a redefinition of the concept of illness. We think that such a redefinition would possess important social, moral, and political dimensions. The argument will concentrate on the possible applications of genetic engineering to human reproduction.

Genetic tests work to identify some of the characteristics of an individual. In accordance with certain health parameters, one group of such characteristics can be qualified as "illnesses," "retardations," or "deficiencies," and others as possessing "health," "well-being," or "superiority." In general, it can be said that some genetic conditions are regarded as positive and others as negative. However, which ones are thought to be positive or negative, or which imply advantages and which disadvantages, does not remain static over time. In analyzing the interaction between the new genetic-test technologies and their social context, we should mention two factors that influence the extension of such concepts as "health" and "disease,""advantage" and "disadvantage": (i) technological capacity for diagnosis and therapeutic intervention, and (ii) the group of characteristics that at a given moment might be socially prevalent. All of those which cannot be positively valued will eventually be considered to be disadvantages.

The new genetic-test technologies contribute to the redefinition of the parameters of perfection, of deviation, or of what actually constitutes a defect. Currently there are certain characteristics which, if not considered advantageous to their carriers, are socially classified neither as disadvantages nor as problematic. But if at the moment of making decisions about reproduction, some test technologies allow the identification of "doubtful" characteristics, and other technologies make their elimination or substitution possible, it seems logical to think that couples would choose to have children only when all possible uncertainty had been eliminated. Thus, will responsible parents of the future be able to accept the possibility that their son or daughter might have a defect? Should they not go to every length to avoid all possible disadvantage?[12]

Technological advances in human genetic engineering may change the concept of illness or of others such as responsible parenthood. This latter concept is currently applied with respect to born children, but the possibilities made available by technology may also extend their significance to reproductive options.[38] The genetic testing of embryos (pre-implantation tests) make the *in vitro* fertilization of fertile women possible. A woman who refuses the application of these technologies may appear irresponsible in allowing herself to have a child with some deformity of known genetic origin.[26,28]

Technology, however, does not function in a vacuum, but in certain social contexts. Future parents may feel obliged to make certain reproductive decisions if some traits are socially encouraged while others are discouraged. The use of genetic tests in non-clinical contexts, for example in the workplace or in schools, may in fact fulfil this function. This would then result in an interactive process that would blur the boundaries of concepts such as illness, and traits judged to have social value could be included. At the same time the boundary between clinical and non-clinical use would become increasingly hazy. As we have previously pointed out with respect to genetic tests, this boundary also acts to provide a dividing line along the spectrum from the least contentious uses to the most problematic.

We can examine an illustration of this argument. In early 1994 the media reported the case of a sterile black woman who resorted to *in vitro* fertilization. This woman, married to a white man, decided to request an ovum from a white woman. Given the need to resort to fertilization and the fact that she could "choose," the mother decided that her child would be white, with a view to avoiding the problems of racial discrimination. This case exemplifies how a wide group of human traits could become, in the fairly near future, the object of intervention by way of assisted reproduction technologies. In this context, for example, genetic tests could be used to identify conditions in an embryo or fetus not currently considered illnesses. This suggests a eugenic use of these technologies.

The social context may also be influential in a different though related way. Most of the socially encouraged traits are polygenic, that is, several genes are involved in their determination. In these cases, there is substantial interaction between genotype and environment. Given that the data supplied by genetics tests

can only be statistical, various kinds of interpretation are conceivable. The nature-nurture debate about explaining human behavior is paradigmatic of the ambiguity that statistical data produce. Social context, ideologies, and professional or social interests would all condition interpretations of the statistical data.

In deciding between possible lines of research in human genetics, social context is considered the most influential factor. This is especially true when the question is one of establishing which human traits are to be the object of study. On the other hand, in the case of characteristics that are products of the interaction between genes and the environment, it is possible to emphasize either. To concentrate on only one of these factors is a decision, in our view, of a moral and political nature. If genetic factors are chosen, as proponents of biological determinism have done throughout this century, it should not be alleged that it is a choice dictated by some natural law. It is in fact choice which precludes the possibility of putting any other type of political or social alternative into practice (for instance labor, education, or health).

TRANSPARENT INDIVIDUALS

In the previous sections we have examined how genetic information can affect the way in which certain private contracts have traditionally been established, in particular in relation to work and insurance. This circumstance gives us cause to reflect on the implications of human genetic engineering on a wider scale, that of the so-called "social contract."

In the last third of the century there has been a major revival of so-called neo-contractual political theory, in which the work of John Rawls is considered central. We shall refer to the work of this author in order to discuss and analyze some social aspects of the use of genetic information.

Laying the foundation for his conception of justice, Rawls sets up a hypothetical situation which he calls the "original position," a contemporary version of the classic "natural state." Individuals who find themselves in the "original position" are covered by a "veil of ignorance." This veil only permits knowledge of "the general facts of human nature" and practically obscures any other information: status, social class, abilities and intelligence, cultural level or life plans. Rawls thinks that a group of individuals who find themselves in this

situation will reach an agreement with regard to the principles of justice that should govern social life. The first is that "each person is to have an equal right to the most extensive basic liberty compatible with a similar liberty for others." The second specifies two conditions under which social and economic inequalities could theoretically be justified: "Social and economic equalities are to be arranged so that they are both (a) to the greatest benefit of the least advantaged and (b) attached to offices and positions open to all under conditions of fair equality of opportunity."[43,44]

Rawls's argument is interesting for our discussion. The possibility of establishing a social contract would depend, among other factors, on not knowing about the lives of the interested parties. In other words, opting for the principles of social justice mentioned above would be dependent on each person being able to imagine him or herself in the social position of any other person. This point is essential for the existence of a public agreement, explicit or otherwise, which makes possible the systems of solidarity that are characteristic of advanced industrial societies.

Let us assume that genetic tests can eventually offer us highly reliable information regarding people's lives, their possible diseases, their longevity, their aptitudes and personality traits. The problem would remain as to whether the use of this genetic information could lead to individuals no longer considering it reasonable to imagine themselves in the situation of any other. If such a thing occurred, the prevailing systems of solidarity could lose a great deal of their legitimacy.

When the agreement between insurance companies and the government (see above) was reached in the Netherlands, some of its critics argued that an injustice was being committed against those individuals who were "free from defects."[37] For many years individuals with genetic "defects" which were then impossible to identify had been insured. Thus new genetic-test technologies made it possible to question the terms under which these types of contract were traditionally established. Therefore, private insurers could lose the mutuality of risk which characterizes them and cease to satisfy some of their social functions. The problem that arises has to do with the social scope of genetic technologies and whether their implementation would question wider forms of civil solidarity.

It has been thought that the systematic and indiscriminate use of genetic information could lead to individuals' being placed in "professional niches," or "insurance niches," ultimately in their own "social niche."[45] This is obviously a hypothetical and improbable situation. But if we assume that it could occur, this has the advantage of making us reflect on the social impact of some of the possible uses of human genetic engineering. As we implied above, there have been, and already are, certain social actors interested in the complete divulging of personal genetic information. The determination of "social niches" could lead, among other things, to the denaturalization or redefinition of private contracts such as those related to work, or to the mutuality of risk, or of social contracts such as those concerning health and education. Genetic tests would make individuals transparent; they would lift the Rawlsian veil and reopen debates about the classic forms of solidarity in Western democracies.[46]

There is a very broad tendency to contrast a defense of equality and solidarity with that of the private sphere of rights and freedoms. The analysis that we have undertaken here offers a different image. Maintaining the inviolability of privacy and the right to intimacy (in this case concerning genes) seems to be a necessary condition for attaining a social solidarity agreement. Democratic culture urges us to seek the greatest possible transparency in the functioning of public institutions. Transparency and public participation must be extended to the formulation of scientific policies and to technological assessment processes. This is a political transparency which should not be seen as being incompatible with a certain opaqueness in the private personal sphere.[47]

CONCLUSIONS: SCIENCE, TECHNOLOGY, AND POLITICS

The current and future uses of human genetic engineering raise new social and political problems, but they also reopen the debate over old issues which have persisted over time. That is, technological change obliges Western democracies to maintain a continuous debate about certain basic political responsibilities. More specifically, human genetic engineering sets up a wide array of alternatives about which it is necessary to make decisions. And, in fact, it brings new life to the old problem of the relationship between descriptive concepts such as human biological diversity and normative concepts such as political equality.

Political equality (equal rights, opportunity, and access to certain basic goods) is an agreement among citizens. It is a fiction or a construct in that it does not have its foundation in some tangible equality among persons. However, for centuries, this normative concept has served to govern human relations and to establish bonds of solidarity. It is in this sense that it must be valued, and the verification of biological inequality among humans is not a reason to question political equality. The regulation of science and technology should have this goal: to preserve those legal, political, or moral concepts upon which there is broad social agreement. Biological diversity is a fact; political equality is a right.

An old social contract exists in which the conventional image of science is conceived as an autonomous activity, protected and supported by society. On the other hand, society has benefitted from scientific activity through technology. For this reason, the scientific community should enjoy its freedom to select its own problems and criteria.

Social studies of science and technology have shown that this is an official image which hides a very different reality. Science has not been able to develop beyond its social context. A recognition of this reality implies its being made known, and this demands the establishing of formal ways of interaction between science and society. This means putting science at the service of society and making negotiation processes explicit and participatory.[1] This is the old contract with society which makes science vulnerable to attacks not only by anti-establishment intellectuals but also by the anti-intellectual establishment.[48]

A new social contract for science should also fulfill the function of preserving the most important achievements of the old contract of social solidarity: privacy, individual rights, and equal opportunity. Only in this way can the *technologization* of the political sphere be avoided, and only in this way can science and its applications attain socially acceptable objectives.[49]

NOTES

1. J.L. Luján, and L. Moreno, "La tecnología como problema social" (Manuscript, 1995).

2. D. Kevles, *In the Name of Eugenics* (Berkeley: University of California Press, 1985).

3. J.A. López, and J.L. Luján, El Artefacto de la Inteligencia (Barcelona: Anthropos, 1989).

4. The reader should be reminded of the title of one of Burrhus Frederic Skinner's works, *Beyond Freedom and Dignity*.

5. S. Jasanoff, "Biology and the Bill of Rights: Can Science Reframe the Constitution?" *American Journal of Law and Medicine,* 13 (1987):249-289.

6. According to Lewontin, Kamin, and Rose, an analysis of contemporary biological determinism should concern itself with the following statements: (1) social phenomena are the sum of particular behaviors of individuals; (2) it is possible to treat these behaviors as entities, as localized properties in the brain; (3) it is possible to measure these properties and individuals can arrange themselves on a unilinear scale according to the quantity possessed of such properties; (4) the cause of the possession of these properties can be divided environmentally and genetically; (5) treatment of derivations from the "norm" of these properties may consist of eliminating genes or using drugs to suppress or stimulate a particular region of the brain. See R.C. Lewontin, S. Rose, and L. Kamin. *Not in Our Genes* (New York: Basic Books, 1984).

7. R.C. Dreyfuss and D. Nelkin, "The Jurisprudence of Genetics," *Vanderbilt Law Review,* 45 (1992):313-348.

8. A marker can identify concrete areas in DNA (genes), a nitrogen base sequence which is recognizable by way of restriction enzymes, or a DNA segment for which no codifying function is known. Genetic maps consist of situating the relative positions of markers and genes on the chromosomes.

9. In a wider sense, gene therapy can consist of: (a) inserting a gene in an indefinite location of the genome; (b) substituting one gene for another; (c) inducing the mutation of a gene; and (d) influencing the regulation of a specific gene. Different methods exist for the insertion of genes: (1) gene injection; (2) utilization of a DNA virus (case of SV40); (3) employment of RNA virus; (4) use of a calcium phosphate precipitate; (5) electroporation; and (6) membrane fusion. See H. Müller, "Human Gene Therapy: Possibilities and Limitations," *Experientia,* 43 (1987): 375-378.

10. I.M. Verma, "Gene Therapy," *Scientific American*, November, 1990, pp. 68-84.

11. T. Friedmann, "Gene Therapy - A New Kind of Medicine," *Trends in Biotechnology,* 11 (1993):156-159.

12. Individuals who may at first be subject to "genetic discrimination" are: (1) asymptomatic carriers of one or several genes that increase the probability of developing a disease; (2) heterozygote (carriers) of some recessive genetic condition or one that is linked to the x chromosome that will not become manifest during their lives; (3) those who possess one or more polymorphisms which are not known to be related to any disease; and (5) relatives of individuals with genetic diseases. See M.R. Natowicz, J.K. Alper, and J.S. Alper,. "Genetic Discrimination and the Law," *American Journal of Human Genetics* , 50 (1992):465-475.

13. P.R. Billings, M.A. Kohn, M. de Cuevas, J. Beckwith, J.S.Alper, and M.R. Natowicz, "Discrimination as a Consequence of Genetic Testing," *American Journal of Human Genetics*, 50 (1992):472-482.

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