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Cultural Models and the Future of Bioethics

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CULTURAL MODELS AND THE FUTURE OF BIOETHICS

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I

In the middle of the nineteenth century, writing his *Souvenirs*, Alexis de Tocqueville looked towards the future and concluded that "*le grand champ de bataille sera la propriété.*"[1] As we draw closer to the next millennium, can we say today that one of the great battles, while not the only one, will be waged in the field of bioethics?

Comparisons are always dangerous, but Tocqueville was trying to capture the spirit of an age in which a conflict was clearly looming "*entre ceux qui possèdent et ceux qui ne possèdent pas.*" His notes date from the same period as Karl Marx and Friedrich Engels's *Communist Manifesto*, which spells out clearly the critique of private property, highlighting a radical clash of values and of interests. Bioethics is raising equally radical conflicts. I am not thinking so much of the fears embodied in the great negative utopias of this century, like Aldous Huxley's *Brave New World*, or the well-founded anxieties raised by eugenics, particularly in Germany for understandable historical reasons. I am referring rather to such stances as that taken up by the Catholic Church which bundles together abortion, contraception, euthanasia and reproduction technologies and rejects them wholesale, and to the cultural gap which separates the advocates and opponents of surrogate motherhood or the trade in human organs. And this once again raises the issue of property: who is the owner of cells? Can human genome sequences be patented?

The short history of bioethics shows that it is not going to raise controversies of various kinds (methodological, ideological and religious) but that it is bound to spark off tensions depending upon the different cultural models that are adopted, consciously or otherwise. This is an area in which the dilemmas of plural democracy emerge particularly starkly and acutely. And the tension not only stems from the value systems at issue

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1. Alexis de Tocqueville, *Souvenirs* (1850-51), *in* XXI OEUVRES COMPLÈTES 1 (1976).

(i.e., the fact that one is not free to dispose of the body, or at least certain of its parts at will, or whether the body can be viewed as a commodity), but also from the adoption of substantially different regulatory techniques (the law, or ethics, or codes of professional conduct). The status of the human body is therefore defined both by rules designed explicitly for it, and by the cultural models and by the representations of it that may be proposed. What follows are a number of cases illustrating this situation.

II

Analyzing the famous decision in *Roe v. Wade* in which the U.S. Supreme Court ruled on abortion in 1973, Guido Calabresi has highlighted the dangerous delegitimating effect of the statement that the U.S. Constitution affords no statutory protection to the fetus. For the Court not only established the woman's right in terms of privacy, but intentionally raised this latter argument, thereby encroaching into the dangerous area of conflicting beliefs, which is strictly outside its province.

As Calabresi wrote:

> [I]f the Court had simply denied that fetuses were alive, unpleasant arguments on metaphysics would have followed. The question of whether fetuses are alive would have been debated acrimoniously . . . , but they would have been debated within the Constitution. The argument would have been between people in the same polity, under the same *acceptable* Constitution, seeking to convince each other about an unprovable, metaphysical issue - whether a fetus is alive.
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> When, instead, the Court proclaimed that the truth of the beliefs did not matter - that anti-abortion beliefs as to commencement of life, *whether true or not*, are not part of our Constitution, of our legal system - it immediately made that Constitution unacceptable to the holders of these beliefs.[2]

The social acceptance of the ruling was therefore weakened because Catholics, primarily, saw it as an explicit and not only indirect delegitimation of their (religious) cultural model, which would not have been so blatant if the Justices had restricted their arguments to issues of privacy. This intrusion by the cultural model of the majority of the Justices, which was not necessary for the purposes of their decision, has had the effect of distorting the significance of the judgment.

2. GUIDO CALABRESI, IDEALS, BELIEFS, ATTITUDES AND THE LAW 95-96 (1985).

On the strength of these considerations, one can also see the sense and the scope of the cultural model of the judicial branch as distinct from the legislative branch of government. It is often argued that priority should be given to the courts because the law, at least as it is typically structured in the continental European tradition, is seen as the ultimate choice between contending values, almost wholly delegitimating the values that are sacrificed. But with judicial decisions the choice is never put across as definitive, because they refer to specific cases and not to the generality of cases, and also because the losing side (the value or the interest) can always hope that in a future case it will win the day.

The judicial decision is therefore seen as an instrument which, particularly in a plural society or at least one which is characterized by a "polytheism" of values, avoids definitively delegitimating any one of the contending positions, and prevents any of the conflicts that might otherwise stem from that definitive delegitimation. It also guarantees closer adherence to specific situations, preventing the rule from becoming rigid and enabling it to continually adapt to a world in a constant state of flux, as a result of scientific and technological innovation.

We might apply this construction to the controversial ruling of the *Bundesverfassungsgericht* resolving the question of the constitutionality of the 1992 German Abortion Act which had tried to reconcile the highly restrictive law in force in West Germany with the liberal law of the former DDR.[3] This judgment has been criticized as hypocritical and for male chauvinism, because it continued to affirm the unlawful nature of abortion while at the same time holding that any woman resorting to abortion, under specific conditions, could not be punished. But it can also be construed differently, seeing it as an attempt to avoid delegitimating any of the contending cultural models (or values): the Catholic cultural model is satisfied by the fact that abortion is always deemed to be unlawful, and the model based on the woman's freedom of choice is also acknowledged, albeit at the price of considering the woman to be responsible for committing a transgression which is not punishable because of a particular condition (weakness?) on the part of the woman.

With regard to the model governing judicial decisions, however, the traditional problem in the culture of continental Europe still remains: Whether, and how, this model should be laid down in terms of norms, and

3. *Bundesverfassungsgericht of May 28, 1993, in* NEUE JURISTISCHE WOCHENSCHRIFT 1751-79 (1993). *Cf.* G. Hermes and S. Walther, *Sehwangersehaftabbrueht zwischer Recht und Unrecht, in* NEUE JURISTISCHE WOCHENSCHRIFT 2337-47 (1993).

above all *principles* (one only has to think of the reference to *privacy* made in the U.S. Supreme Court's judgment mentioned earlier). What it is essentially intended to avoid is that the courts should be considered to be empowered to act at their entire discretion, without needing to provide any rational justification or to act consistently with the overall system of directives to which they are subject. But the way this issue is being faced has been substantially changed ever since European legal circles began talking in terms of the State based upon the rule of *constitutional* law, and not the rule of law, without further qualification. In this way, constitutional principles constitute the basic framework of reference for the legal system, and give it consistency and unity; and the judges, who are required to apply these principles to concrete cases, see their social-political role enhanced and they are given greater scope to act in such a way as to avoid at least exasperating the conflict between different cultural models.

III

Recommendation No. 934, adopted in 1982 by the Parliamentary Assembly of the Council of Europe stated that Articles 2 and 3 of the European Convention on Human Rights implied the right to inherit genetic features that have not undergone any form of manipulation. However, in order to prevent this from being construed to imply a ban on preventing any form of gene therapy it was proposed to draw up a list of serious illnesses that would justify granting an exception to the ban on resorting to this kind of therapy.[4] A similar approach was set out in the report of the *Bundestaq* on gene technologies, emphasizing the need for a "clear list" of hereditary diseases for which gene therapy would be admissible.[5]

The cultural model and the concern underlying proposals of this type are evident. As the report to the resolution adopted by the European Parliament points out, the concept of disease and hereditary disease is difficult to appraise in either legal or medical terms, and one therefore has to accept the risk that mere deviations from genetic normalcy might be defined as hereditary diseases or defects. It was therefore an attempt to prevent gene therapy from being used for the purposes of selection or for obtaining embryos with "appropriate" characteristics, thereby opening up the way leading to dangerous eugenic policies. A model of genetic

4. *See* Recommendation No. 934, No. c; EUR. PARL. DOC. A 2-327/88, No. 25.

5. *Bericht der Enquete-Kommission 'Chancen und Risiken der Gentechnologie' des 10*, Deutschen Bundestages, at 183 (1987).

normalcy is rejected in preference for a model emphasizing the right to an identity, and hence the right to be different.

But even this proposal harbors a risk. The purpose of drawing up a list of the only serious diseases for which gene therapy would be authorized would be to prevent mere deviations from genetic normalcy from being considered diseases. But a list of this kind would eventually establish a model of genetic normalcy, in contrast to it. The list of diseases, drawn up with the precise purpose of preventing pure eugenic interventions, might be perceived by the public as the list of cases in which *it is necessary* (or at least opportune) to act, and actually encourage gene therapy in cases where it is permitted. This would therefore present us with yet another cultural model which, deliberately or otherwise, might be used as the basis for discriminating against, or socially stigmatizing, the individuals who suffer from the listed diseases.

IV

This might therefore pave the way to a "back-door" planning of normalcy, casting doubt on the right to be different, and hence on the very right to an identity. There is a very strong temptation to stave off this risk by providing a radical version of the right to an identity in the form of a "right to disease." By this we are not referring merely to the right not to suffer discrimination merely on account of suffering from a particular disease. We go further than that, and ask that this right should be considered to be an "ordinary" component of social organization, reversing the very notion of normalcy by directly associating it with the possibility of ensuring that "healthy" and "sick" individuals are able to live together in the same social organization with equally full rights. In other words, the opposition healthy-sick is replaced by a *continuum*, which tends to negate the legitimacy of roles based on an individual's health.

However, a model of genetic normalcy has always existed in every culture whether in the form of an ideal of beauty, or by attributing some "institutional" status to a person's physical condition: this can reach either the extreme of eliminating the deformed, or conversely of reserving special consideration to certain diseases (viewing epilepsy as a "sacred sickness," and a manifestation of the divinity). Complex relationships are therefore established between the relevance of disease and the construction of normalcy, mediated by cultural models that are not always immediately evident.

V

Confrontation or conflict between different cultural models becomes particularly evident when dealing with the question of access to reproduction technologies. An examination of European legislation immediately reveals the way in which cultural diversity has created widely differing normative models: these range from the extremely liberal legislation in Spain and the United Kingdom (which leave the decision to resort to reproduction technologies exclusively to the free choice of the woman concerned) to the much stricter legislation in such countries as Sweden, Norway, Austria and France[6] (where access to these technologies depends on certain eligibility criteria such as age, sterility, the existence of a partner, and in some cases the partner's consent).

The adoption of the liberal model as opposed to the prohibitionist model cannot be explained in terms of traditional cultural stereotypes or by merely looking to the political majorities that have enacted the legislation. Spain and Sweden are useful comparisons in this respect. Traditional stereotypes would tend to suggest that Swedish freedom in the sphere of morality contrasts with Spanish Catholicism, and yet their respective legislation creates a completely contrary image: the Swedish law is restrictive, and the Spanish law extremely liberal. This apparent paradox cannot be explained by examining the political conditions in the country, because the legislation in both countries was enacted by a parliament dominated by a large Socialist majority. Our attention, then, should be directed towards their different social dynamics: the dynamics which, in Sweden, produced a law with a strong emphasis on responsibility for procreation, extending the maximum possibility for seeking paternal responsibility and the resultant obligations; and those in Spain in response to a total need for liberation, and hence rejecting any authoritarian legislative model, particularly as a reaction to the long years of the anti-liberal legislation of the Franco regime.

These remarks confirm the obvious need to take account of a whole set of extremely complex cultural factors in order to understand the reasons for the legal rules in this very sensitive area, which raises the whole issue of the anthropology of the body and one's self image, the rationale of interpersonal relations and the kinship system. This being so, I believe that the restrictive legislation governing access to reproduction technologies must also be examined in order to ascertain whether, behind differ-

6. The French laws are expected to complete their passage through Parliament by May 1994.

ent types of arguments there may perhaps be an emerging desire to establish a model relating to the woman's body which, 1) relegates it to strict medical control, as a reaction to the earlier "liberation" made possible by contraception and the legalization of abortion, 2) emphasizes a benchmark, such as sterility, which is highly culturally conditioned, and 3) links the woman's reproductive power to the family model.

The prohibitionist rationale has already begun to trigger off a reaction against it, however. Returning to a practice that was well-known in Europe when the ban on abortion in certain countries caused women to travel to countries with more liberal legislation, for which the expression "abortion tourism" was coined, we are now seeing cases of "procreation tourism." Single women are leaving Sweden, where they are denied access to reproduction technologies, and are going to Denmark and the United Kingdom. And the first effect of this situation is the evident delegitimation of their national legislation.

However, even if one accepts the model of freedom of choice for the woman regarding when and how she wishes to reproduce, the problem still arises as to whether this choice should be restricted when it becomes possible to determine the "quality" of the child. At what point must freedom of choice yield to chance?

There are already legal rules and documents containing principles and rules that prohibit the predetermination of the characteristics of the unborn child, such as its sex or the color of its eyes or hair, which thereby indicate a limit beyond which freedom of choice may not go. But even if these forms of direct intervention are excluded, we must also consider cases in which the *in vitro* creation of embryos makes it possible to discard any that suffer from specific diseases, and proceeding subsequently to implant only those embryos that are deemed to be healthy. The benefits of this technique are evident in terms of the elimination of certain diseases, such as thalassaemia, and the reduction in the number of abortions carried out by couples who felt that they were at risk. On the basis of these considerations one of the most stringent pieces of legislation, the *Embryonenschutzqesetz* enacted on December 13, 1990, in West Germany, made provision in section 5 for an exception to the ban on predetermining sex in cases in which "this is intended to prevent Duchenne muscular dystrophy from occurring in the unborn child or some other serious gender-related hereditary disease recognized as such by the responsible authority appointed by the laws of the Länder."

It is nevertheless evident that it is possible to move on from this sub-

stantially therapeutic model to one which is more directly cultural, using techniques relating to embryos and prenatal diagnosis in order to select individuals endowed with certain specific features. One case that deserves attention occurred in Italy at the beginning of 1994, when a white child was born to a black woman who had asked the doctor to implant the egg of a white woman in her. The reason for this choice, which provoked heated debate, was entirely cultural, to ensure that her child would not suffer from social discrimination or stigmatization in an environment in which the mother perceived the risk of a racist-inspired model becoming entrenched.

Problems of this kind are bound to lose their exceptional character and become even more complicated as the increased possibility of acquiring more information about the unborn child, or determining the features of an embryo come up against a cultural model of the kind which lays down liability for torts. Let us take the case of parents who are given genetic information on the fetus as a result of prenatal diagnosis. First of all it is necessary to see whether the parents are free or not to obtain this type of diagnosis. It might seem obvious to say that this may be a right but not an obligation. But in many cases parents have been held liable for any damage caused to their child following procreation: damage or harm that could have been prevented either by appropriate therapy or by preventing conception (and some have even spoken of "the right not to be conceived"). If the legal system tends to recognize damages of this kind, the parents would find themselves under a legal obligation to submit to a precautionary genetic examination.

Similar conclusions may be drawn from considering the position of the doctor responsible for the pregnant mother. It has been said that doctors may have liability in the case of *wrongful birth* (". . . a claim that a health care provider violated a legal duty owed to a parent to give information or to perform a medical procedure with due care, resulting in the birth of a defective child") or of *wrongful life* (. . . a claim by, or on behalf of, a person born with predictable physical or mental handicaps that, but for the defendant's negligence, the person would not have been conceived or, having been conceived, would not have been born alive). The failure to have a genetic examination carried out, or the failure to notify the parents of the result of that examination are thereby a source of a tort, which places the doctor under an obligation establishing a particular relationship under which he is obliged to give information to the woman (or to the couple).

Exactly the opposite situation obtains according to those who maintain

that prenatal diagnosis must be banned or only admitted if the mother, or the parents, undertake not to seek an abortion if malformations or the late onset of a disease are ascertained (and the results of the tests should only be made known if one of these diseases is revealed). This approach is clearly vitiated by an ideological bias, and it would be difficult to implement. Above all, the consequences might prove to be even more serious than the effects it is intended to prevent. For some research has shown that couples at a high genetic risk are inclined towards abortion; but if unrestricted access is given to prenatal diagnosis, this possibility would only be limited to cases of diseases which are actually identified, thereby reducing recourse to abortion. Moreover, to make it lawful to conduct such tests only in cases in which it is presumed that particularly serious diseases might exist creates the specific danger of establishing a cultural model that introduces powerful social stigmatization of the people who suffer from those diseases, thereby encouraging forms of genetic selection.

Yet the suggestion of imposing a ban is always raised whenever scientific innovations encounter cultural models that are already explicitly geared towards selection, as is the case in Indian society where the traditional elimination of female children can now be practiced by abortion, thanks to the techniques for the early sex identification of the unborn child. In the United Kingdom the problem of imposing this ban on Indian women living there was raised, but overruled, considering it unlawful to discriminate against those women in a country practicing different values, and where such a ban would be tantamount to discrimination against them, violating the fundamental criterion of freedom of choice. But in India, where the selective model is firmly established, the fear of its becoming more firmly entrenched has led to the introduction of rules restricting access to information on the sex of the unborn child.

VI

The cases mentioned above clearly confirm the relative nature of legal rules, depending on different benchmark cultural models. This relativity is even more evident today, and has even been enhanced by the way in which individuals and whole communities are able to move around the planet to settle in places whose prevailing cultural models are far from those of their countries of origin or those to which they habitually refer. What has to be established, however, is whether population movements of this kind can entitle individuals to remain true to their own cultural

model, or whether logic requires them to accept the model of their host country.

The personalization of the legal rule, and the fact that it tends to follow the person, is an ancient principle (*cujus regio, ejus religio*). Giving Sikh children the right to wear turbans in British schools, and recognizing a similar right in France for Muslim girls to go to school wearing the *chador*, show that this possibility still remains, and has been reiterated in court judgments in various European countries that have upheld rules of Muslim family law. However, the limit on their acceptance, and hence the rigid borderline beyond which it is not permitted to go, seems to be represented by the existence of fundamental and *universal* rights, not *against* but *for* those who live by different cultural models.

This is certainly not the appropriate place to reopen the controversy around the characteristics of a system of fundamental rights centered exclusively on western values or the authoritarianism which underlies the universalistic rationale, and the negation of cultural pluralism which would stem from it. But it may be useful once again to consider a concrete model, such as infibulation. It is well known that this practice continues to exist far beyond the shores of Africa, where eighty million women are affected by it, and that doctors in European countries have often found themselves faced by a request to infibulate young African girls (and there are grounds for believing that this is sometimes requested by families who would perhaps not practice it in Africa, but do so in Europe in order to establish a cultural identity in a different, not to say hostile, environment). What cultural and institutional strategy should be adopted to deal with a phenomenon of this kind?

In African cultures, infibulation ensures control over female sexuality and for this very reason it embodies a model which is gradually being rejected inside those same societies. It will probably be eliminated through cultural maturity rather than by resorting to authoritarian measures (the WHO has allocated substantial funds to an information program in this area). But the same problem, transplanted into European societies, is giving rise to increasingly more markedly punitive solutions, of which one good example is a recent conviction in a French court of a mother who had requested her daughter to be infibulated, and not only the people who had actually carried out the operation, as had previously been the case. Why should this model be rejected in European societies which have accepted Sikh turbans and Muslim *chadors* in its schools?

The most immediate response, and certainly by no means the least well-founded, is that infibulation is a form of mutilation which is unac-

ceptable in systems that punish such activities, considering them to be criminal offenses. But perhaps it is necessary to push the analysis a stage further. If signs of ethnic or religious identity are accepted in the schools, the function of the school as an institution providing public space for comparison is emphasized, giving it a role which is not only in line with the demands of a multi-cultural society, but one which will enable *all* those who attend school (including the staff members) to benefit from the experience of having direct familiarity with and gaining acceptance of the distinctive signs of "others." But in the case of infibulation the person is impoverished in her sexual sphere, which extends far beyond the actual mutilation itself, and this is something to be appraised in the broader framework of the inviolability of the woman's body, as a development of women's culture requires.

In this way we encounter new cultural models which both broaden and force the traditional system of fundamental rights. These models and these developments relating to women are bound to become increasingly important in the field of bioethics, but not only because the question of reproduction technologies is specifically about the woman's body. An encounter between cultures acquires new possibilities when it does not result in a duel between abstract universals, but begins with a consideration of an element of the real world: the body.

VII

The importance attributed to different cultural models can therefore be analyzed not only in terms of the criterion that values are relative. Problems of the compatibility and coexistence between different models arise simultaneously, as well as problems raised by the emergence of new unifying models.

Accordingly, we are once again faced with the question of the type of rules that the various models tend to produce. Alain Touraine, proposing an interpretation of current trends, maintains that "*la société et l'Etat se séparent: la première se tourne vers l'éthique, le second vers l'économie internationale.*" But we have already seen how the society that turns to ethics often gives rise to a demand for a path leading from ethics to law, and hence from a transition from one order of rules to another. At the same time, the rationale of the (international) economy is encroaching into areas that should be left to ethics (bioethics), endeavoring to ensure that even these areas are unable to break free of market rules. Once again, in place of clearcut separation we find complex interlacing.

It is therefore better to conduct this analysis not on the basis of criteria that refer to exclusive duties incumbent on specific individuals, but rather to relations between regulatory models and the features of those models. Much is said about the limits of what I would call "juridification," which does not, however, give up an area of bioethics free of every form of institutionalization, since this is manifested, for example, in the increasingly more common form of ethics committees. Now, while there is no doubt that if we give up the claim to be able to regulate everything using the model of legal rules sufficient elasticity might be restored to the overall system of social governance, it is also true that even with the slow growth of legislation in the field of bioethics there is a risk that the resolutions adopted by ethics committees may appear to be a kind of lower-tier regulation, or sooner or later be bound to give way to the inevitability of being overtaken by the law.

But even for the juridical model it is not possible to propose any one single version here, any more than in any other field subject to strong innovative stresses. I emphasized earlier the different social "yield" of two models, both juridical in nature: the judicial model and the legislative model. I would now like to say that the criterion that distinguishes between the two cannot be schematically stated in terms of the fact that the judicial model is flexible and the legislative model is rigid. If the legislative model is technically built up as a "rule of compatibility" between different values, and not only as a "rule of supremacy" of any one of those values, it then becomes possible to have open, elastic and light-weight legislation, even in areas that one wishes to leave completely open to the influence of scientific and technological innovation, and to benefit from debate within society. A flexible discipline makes it possible to avoid excessively rigid laws, designed to last forever, being overwhelmed by the constant changes brought about by scientific and technological innovation; a light-weight discipline is the one which only deals with concrete issues, that cannot be resolved other than by using legal instruments, and which does not claim to be able to provide an answer to concerns that are purely ideological or merely a matter of non-specific social distress; an open discipline does not give pride of place to any one single point of view, but it is so structured that, in a broad legislative framework, discussion and dialogue between different models for social regulation and different values can continue. These are well-known issues to philosophers of law and scholars of legislative techniques, and they have led, for example, to the formulation of the so-called "general clauses" that do not analytically discipline a particular situation but

rather refer to notions modelled on the reality of social relations, and are destined to vary in time (such as "good faith" or "morality"), to which the judge is then responsible for attributing a meaning and scope in specific instances.

However, even having said that, the question is by no means settled. On the subject of procreation technologies, open and light-weight legislation is certainly the one which gives the free choice of the woman a central essential role (thereby making it possible for options linked to different values to co-exist) and only the questions that would otherwise not be satisfactorily solved for all the subjects concerned are regulated using biding provisions of law (e.g., the prohibition on subsequently denying the paternity of the child by a husband or partner who permitted the woman to be fertilized using the seed of a donor). But there are those who object that this model would lead to a substantial "biologisation" of the law, which should rightly safeguard a number of the values being challenged by the innovations stemming from biological research. And here it is evident that the reference to a function that is *proper* to the law merely conceals a clash of values, and a clash regarding the possibility of enabling a number of juridical categories to survive beyond the specific historical situation and the scientific paradigm which has inspired them.

A legislative model possessing all the features of flexibility and openness would also be a legislative model which, if based upon the market rationale, left complete freedom to dispose of one's own organs, thereby making it possible for those who feel that no one is entitled to dispose of their own body at will to co-exist with those who, conversely, wish to sell a kidney. But here one can at least emphasize the fact that the question of whether or not one is free to dispose of one's body or organs does not necessarily have to be construed in terms of the rationale of a monetary exchange (which reduces the body to a commodity), but should be able to find a specific benchmark in the rationale of basic rights in solidarity between individuals (and hence in the rationale of giving).