

## **Genetic Intervention: Rights and Ethical Values**

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Progress in genetic engineering has given rise not only to high expectations and hopes of improving the quality of life, but also to entirely new problems and questions that highlight the need to safeguard adequately human rights, the rights of those who are unable to express their opinions and, also, in even more global terms, the rights of the environment and of the ecosystem .

Faced with the sensational innovations contributed by biological science, it is easy to note a separation and an ever wider gap between technical and scientific evolution on the one hand and the ability of society to respond to it on the other or, to put it more precisely, between scientific progress and the ability of the community to really perceive the innovations .

Of course, the incidence potential of the new biological technology on the cultural and social context is absolutely radical and innovative. The current biological innovations do not only change the usual biological parameters in the direction of principles and values hitherto considered unalterable, asserting the ability of man to determine freely what used to be mere naturalness. One obvious and significant illustration of this consists of the subversion of the traditional anthropological family system brought about by reproductive technology, which has upset the natural order of procreation and replaced the traditional relationships of biological parenthood with new systems based on freedom of negotiation (one only has to think of the possibility of surrogate maternity and the transfer of sex cells).

The important goals achieved by biomedical technology are, indeed, accompanied by ever new problems that are bound to increase the host of dramatic legal cases putting the ability of traditional legal tools to offer suitable answers to a hard test..

Thus, alongside the enormous potential and advantages associated with genetic intervention on living species and on man (new drugs, new therapeutic approaches, new possibilities of taking steps for the benefit of the environment in terms of reclaiming and cleaning the soil, water and air, of agriculture in order to improve vegetable species or varietal types genetically, of food, and so on), there are legitimate and disquieting questions about the risks of irreversible and unknown changes to the

natural equilibrium.

The current possibility, opened up by genetic engineering, to intervene on the most intimate parts of human beings in order to replace faulty genetic characteristics throws open the doors to treatment of diseases that up to now were incurable. The correction of serious genetic anomalies and the prospect of making an "anti-destiny" possible are also accompanied by the worries associated with the construction of a targeted genetic heritage and eugenic programming of the human race. Predictive medicine provides significant information concerning the occurrence of serious diseases, and early diagnosis make it possible, at least in some cases, to intervene and to make free choices in instances which in the past caused situations of mere necessity. But alongside their potential applications, the prospect arises of new forms of discrimination against people who are found to be carriers of specific genetic characteristics and new forms of social control.

The availability of genetic information provided by the various different "genetic tests" has brought up significant problems concerning who owns the information, as well as the sharing of this information with other parties. Thus, we ask ourselves whether this type of prediction can legitimise a person's right to be informed, even when dealing with a disease declared to be incurable and, also, when such a predisposition does not necessarily entail the occurrence of the disease, which might, possibly, be caused by many external factors.

Questions are also being asked as to the possibility of entitling employers and insurance companies to obtain compulsory statements concerning predisposition or otherwise to diseases. In these cases, putting our trust in the informed consent procedure does not seem to be sufficient to guarantee the protection of "weak" persons in relation to the possibility of forms of indirect social coercion that could force a person to release his genetic information. Indeed, individual choice, based on the principle of informed consent, can constitute a valid reference criterion only when there is no disparity between the power of the party requesting the information and that of the one meant to supply it (as in case of the need to take out insurance or enter into an employment contract).

An emblematic example of the complexity of the current problems resulting from genetic research concerns the influence of genetic tests not only on decision-making processes relating to more responsible procreation, but also on possible complaints on the part of any progeny claiming that their parents have handed down genetic damage that condemns them to live in a condition of disadvantage as compared with others.

Nowadays, alongside problems of birth-dependent or conception-dependent prejudice, due to which people resort to the courts because of

damage caused to them by the birth of a disabled child or by the failure of contraception or of sterilisation so that they have a child, perhaps handicapped, who needs looking after, there is also the agonising problem known as *wrongful life*: faulty life, undesirable life. This is a term used to indicate the case of a person who, having been conceived in circumstances that bind him or her to a fate of suffering, asks his or her mothers or parents to answer to them for the damage and the lesions caused by the fact that they conceived him or did not abort him. In this type of litigation, the party claims that he has a lesion and, consequently, damage that could have been avoided only on condition that he had not been conceived or, in any case, had been aborted. The first of these cases was the famous *Curlender vs. Bio Science Laboratories* lawsuit, which the damages claimed originated from the fact that the parents had been incorrectly informed that they were not carriers of Tay Sachs's disease. Following this information, they had conceived and given birth to a son with a fatal progressive generative disease of the nervous system.

The California Court of Appeal found the laboratories guilty, sentencing them to pay damages not only to the couple but also to the son. Furthermore, in an *obiter dictum*, it was added that if the parents had indeed been informed beforehand of their genetic situation, they could have been sued by the son himself. According to the Court, parents had a duty to avoid causing handicaps in their children, including by abstaining from bringing them into the world. The commitment demanded of law to establish the balance of benefits against prejudice capable of justifying legitimising procreation is indeed arduous.

But we are only just beginning. If today the law is asked to take care of not allowing a human life to be brought into the world in conditions of greater disadvantage than others, perhaps the time will come when the legislator will be asked to define the extent to which and the limits within which human life may (or shall) be endowed with conditions, resources and benefits making it more advantageous. If, today, the law is asked to tackle the issue of the shortcomings of a life that make it undesirable, in the near future, increasingly dominated by competitive growth, it will be required to define the limits of a race towards special equipment, arrangements and advantages, that is to say towards a surplus of genetic complement able to express itself as and turn into increasingly evolved personal and professional performance. Truthfully, why should the wish that any parent has to give his children the best possible conditions, that will be able to help them in some way in the future, be morally reprobable? This already happens done when parents force their children into tiring and demanding educational projects intended to give them, over the years, special capacities and abilities guaranteeing them better opportunities. Parents often have lifestyles (smoking, drinking, practising dangerous sports, and

so on) that expose their children to danger and risks. But these are accepted without objections since they are any case felt to conform to the parents' values, moral conception of life.

What is more, it is true that conceiving a child is considered a fully legitimate aspiration even when the parents' lifestyle exposes their children to risks or even knowing that procreation will entail genetic damage or congenital defects. Why, then, should conception and genetic practices implemented for the purpose of giving offspring a better chance be denounced?

The theoretical and practical questions raised by the continuous invasiveness of what is artificial into what is natural and by the sensational and hitherto unthinkable opportunities for interfering with the vital processes of living beings and of man challenge constantly the substance, the role and the concrete possibility of the law to intervene and its right to interact with the on-going progress of science and technology. The ancient bonds of need and man's subjection to the laws of nature have been upset. Over a very short span of time, unheard of possibilities have opened up: reproduction technology, the removal of tissue and organs for study and research purposes, the cloning of living beings and even of human embryos, early diagnosis and so-called artificial life.

Innovations succeed one another at such a rapidly accelerating and frenzied rate that a response from society is not possible. Moreover, it is actually not even possible to process all this critically, because the human cognitive and perceptive system is such that it takes far more time to bring experience to maturity. So to what extent is it possible to use words such as information, awareness, acceptance, denial and social control? To what extent is it possible for the law to provide a link and a tool for reconciling technical and scientific evolution with respect for man's will, individual freedom and dignity.

The issue that must be tackled once again is not only that of defining precise rules but, also, and perhaps this is even more dramatic, the extent to which laws and regulations can be of any use. Time is needed to draft and approve them, partly because they require a real understanding of the new reality, which completely escapes traditional and age-old patterns of logic. This means that on the one hand the juridical tools at our disposal need to be adapted and up-dated, and on the other that brand-new categories suiting the new reality are needed for interpreting them. The time that all this takes does not fit in with the timing and urgency of scientific research, the laws governing which seem to be defined increasingly by the very progress of research rather than by man. This is because regulation is the result of a process of acquisition and reflection

according to a paradigm that is hardly as dynamic and accelerated as the current evolution of technology and science and its surprising and even more bewildering results. The gap between science and society seems to be widening due to the difficulty of developing rules that, in order to be efficient, require a global and trans-national effort. In the meantime, technical and scientific development is moving forwards and growing stronger, thanks to a united and combined effort that really does overcome territorial barriers.

Another aspect that makes it difficult for the legislator to intervene is the peculiarity of a sector such biological technology, in which alongside the intimidating and real risks connected with its development, the potential for applications benefiting mankind is equally obvious. What is feared, that is to say, is that inappropriate regulatory action would cause problems even greater than those we want to solve.

The complexity of the problem leads to reflection on the final possibility of safeguarding more effectively fundamental community values, not leaving social control up to regulations alone but resorting instead to different and varied social regulation and control systems.

This means that the role that technology now has is forcing us to abandon a sectorial and private dimension of knowledge, which as such is episodic and territorial, in favour of structured, differentiated and circular approaches.

In this case, a fundamental role can be played by information aimed at maturing a more balanced and harmonic relationship with technical and scientific development and with the assessment of its potential risks (limiting emotional responses to it).

In particular, education can contribute towards increasing awareness of fundamental rights and, consequently, enable them to be acknowledged, respected and defended. Educational training can have a primary role in maturing and training society's sensitivity towards human problems and in developing ethical responsibility, taken to mean the ability to see the moral values in the various different situations and a commitment to conceiving respect and promotion of these values as a duty. Education has a significant role in particular in genetic engineering. Today, in its broadest sense of physical and psychic well-being, the right to health takes on worrying and dangerous characteristics when it tends to be expressed as and identified with social acceptance, and leads therefore to peculiar ways of being in terms of physical well-being and social efficiency. This vision, which bases the integrity and well-being of mankind on his purification from any type of imperfection and on the assumption that people should correspond in full to the modern models of efficiency, is not only narrow but

very worrying. Indeed, while today this kind of well-being is pursued by cosmetic surgery, very soon it will be possible to achieve it by means of genetic and then eugenic engineering. Education must therefore turn its gaze to a broader horizon, more difficult and demanding, and consisting of full acknowledgement and acceptance of man in his diversity, and with his diseases. It must lead to the acknowledgement of the right to disease, stressing that disease cannot be a cause of social discrimination. Only if we reject the other approach will it be possible to reject a perverse market logic leading to progressive devaluation of the human body.

Professional control and discipline can also act as a valid support for ensuring correct and appropriate rules for behaviour towards people using these services, by means of guidelines for conduct.

In addition, a fundamental role of interacting with public opinion can be played by ethics committees and multi-disciplinary advisory bodies, aimed at enduring greater decision-making uniformity thanks to common principles of risk assessment.

None of these approaches is perhaps capable of being exhaustive as such. The effectiveness of these models can therefore only be expressed if they are not taken to be rigid and isolated. They can co-exist and be "networked" into different contexts within a single integrated system.

As a consequence of this attitude, responsibility is broadened. After involving the political, economic and religious institutions, it is also vested in the scientific community, called upon to consider the legitimacy of their action with regard to human rights.

The fragmentation of the various specialised activities and interaction between different skills may not and must not lead to aberrant shedding of responsibility for scientists' activities. Precisely because of the social magnitude of the repercussions their work may have and which may also affect future generations, they must agree to take on greater responsibility. Failing this, an individualistic attitude towards life will persist that cannot be reconciled with the social dimensions of technological innovation. But if they do, each scientist will - in proportion to his own levels of involvement - be made part of the scientific enterprise as a whole.

The recognition of personal and joint responsibility of all the parties involved (society, institutions and healthcare personnel) for their decisions and actions and for the consequences they produce is the proper path to be followed in the framework of this difficult commitment. It is a commitment that calls upon all of them to think, to reflect and to continue a dialogue that, precisely as a result of the divergence of opinions and cultural differences, and because of the spreading hegemony of

technology, is a high expression of faith in the very possibility of the co-existence of mankind.

It therefore becomes necessary to consider science and technology as a collective enterprise, that necessarily belongs to and involves not only an elite of scientists and technician, but all mankind and the whole ecosystem, towards which mankind has, in addition to needs, a duty to act responsibly.

To conclude, the law can provide a justification and a contribution insofar as it is not given a privileged role, not vested with a function of containment, of disciplining science and technology. It must find a way to co-exist with other branches of knowledge and be able to intertwine and mingle with them, with differentiated and alternative approaches, so as to contribute towards establishing a relationship between science and society along lines that will evolve more harmoniously.

Only in the framework of a plurality of mixed and hybrid knowledge will it perhaps be possible to approach such confrontational and impossible problems.

Man has, therefore, the duty, first and foremost, to adopt an attitude of understanding, knowing full well that only a holistic vision and horizontal knowledge characterised by sensitivity and a broad base can give rise to critical and adequate reflection.

That is to say, in this great adventure, it is necessary to think and to act in a co-operative, collective and circular manner. This will lead to the frontiers between different skills and kinds of knowledge collapsing into a general culture, even without technicians, in which the legal issues and sensitivity can co-exist with other sensitivities and other knowledge acquired in a broader dialogue. A dialogue in which the law is one voice among others, and among the many, and that, rather than claiming priorities, will dilute and blend in with other knowledge, to enable a structured, systemic and holistic approach to such elusive problems.