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The Human Genome Project and Eugenics

by

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The Human Genome Project is expected to provide information in the near future on the thousands of mutations that are responsible for inherited diseases, making possible the development of highly accurate genetic tests for diagnosis. On the other hand, therapeutical approaches to treat inherited diseases are not expected to develop at the same pace. In the absence of low-cost "cures" for those born with a genetic disease it is less expensive to avoid the birth of a fetus prenatally diagnosed as having such a condition. In a society driven by economical constraints, considerable pressure on parents to abort defective children is expected. As a result, it is a matter of concern that we are arriving to a kind of society that practices a new kind of eugenics in which the individuals take the decisions and the technological advancements provide the basis for eugenic goals to be achieved without the necessity of social control.

The Human Genome Project

The international effort of the human genome project, which seeks to map and sequence all of the estimated 3 billion bp that make up the human genome, is expected to provide a better understanding both of single gene defects and multifactorial or familial diseases, such as diabetes and cancer. There is a great potential for the possibility of improving the length and the quality of life and probably in reducing costs in health care by introducing new, less costly, and more accurate tests. It has been estimated that detailed mapping may be compiled in 10 to 15 years and that genetic testing and the possibility of genetic manipulation will become available and widely used for a variety of purposes. In fact, since its inception in 1990, due to the considerable advance of genetic technology, a great number of genetic tests have been developed in the last six years that make possible the diagnosis of diseases whose origin is genetic.

While for some researchers the genome mapping project is essentially an engineering – morally neutral – problem, many other scientists recognize the potential ethical and sociological problems that the acquisition of the new genetic knowledge will generate. While it is recognized that knowledge in advance of diseases allows those so affected to minimize their effects by altering unhealthy lifestyles, choosing health-enhancing diets and/or environments, taking appropriate medications and deciding whether or not to parent when the individual is at risk of having a genetically damaged child, there are considerable ethical and sociological issues associated with such knowledge, including the possibility of eugenics.

Eugenics

The term "eugenics" refers to the possibility of increasing the frequency of favorable genes in the population (positive eugenics) or of reducing the frequency of deleterious genes responsible for hereditary diseases (negative eugenics) because of human intervention. Presently there is a controversy over the extension of the term "eugenics".[1] For some, the term is restricted to state policies that effectively change gene frequencies using some type of coercion to lower the number of offspring with defective genes or to increase the number of offspring with favorable genes. For others, the intention on the part of the social policy, without coercion, is enough to consider it eugenic. For others, the term appropriately describes consequences and not just intentions. If unintended consequences are included, most medical genetics and individual mating decisions can be considered eugenic. A recent definition of the term "eugenics" is the "science that deals with all influences that improve the inborn quality of the human race, particularly through the control of hereditary factors."[2] This definition is general enough to include consequences and intentions. Another question is that moral and social analysis should be pursued to evaluate the consequences and the actions of governments and individuals in the use of genetic knowledge. Not all eugenic decisions are necessarily immoral, but a reflection must be done. Today, more than social control, the tendency is toward technological control, in which technological advancements provide the tools for people to take eugenic decisions without much ethical consideration.

At the beginning of the century there was a great eugenic movement in the leading countries in genetic research (United States, United Kingdom, and Germany). After the discovery of Mendel's laws of inheritance, the concept of biological determinism – by which it is believed that everything we do is controlled by our genetic makeup – dominated the scientific scene and was used to explain many of the social ills of the first quarter of the twentieth century, including prostitution, immoral behavior, degeneracy, drunkenness, unemployment, criminality and chronic alcoholism.[3] Medical, demographic and social policies were enforced insisting on immigration controls, genetic tests prior to marriage and sterilization of the mentally ill and those with criminal tendencies.[4] In the US, the mixture of social and economical problems after World War I, with increased unemployment, criminality, prostitution, alcoholism and an increasing number of individuals with mental disorders, made eugenic approaches appealing to professionals and lay persons. This led to the popularization of eugenic concepts and efforts to lobby both the state and federal government to enact legislation for eugenic programs.[5] One of the first eugenicists, Dr. Charles Davenport, studied the origin of Huntington's disease and concluded that it was introduced by one-half dozen individuals during the seventeenth century and that careful screening of immigrants may serve to halt incoming diseases.[6] This influenced the subsequent development of restrictive immigration laws in the United States, favoring the so-called Nordic and Anglo-Saxon stock from Northwestern Europe and Great Britain, while preventing immigration from Southern and Eastern Europe, particularly Jewish immigrants.[7] Many states passed laws to sterilize involuntarily persons with illnesses such as mental retardation, insanity, criminality, and, in some cases, even for chronic alcoholism, epilepsy, pauperism, prostitution; orphans and derelicts were also affected.[8] In 1927, the US

Supreme Court decided that the involuntary sterilization of the mentally retarded was constitutionally acceptable based on utilitarian philosophy:

> We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange indeed if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility society can prevent those who are manifestly unfit from continuing their kind.[9]

More recently, the US Congress Office of Technology Assessment, considering the social and ethical issues raised by the Human Genome Project, developed a similar view, though now advocating, instead of sterilization, reproductive strategies by genetic screening of human embryos and selective mating:

> Human mating that proceeds without the use of genetic data about the risks of transmitting diseases will produce greater mortality and medical costs than if carriers of potentially deleterious genes are alerted to their status and encouraged to mate with noncarriers or to consider reproductive strategies. New technologies for identifying traits and altering genes make it possible for eugenic goals to be achieved through technological as opposed to social control.[10]

In Nazi Germany the eugenic movement fostered an authoritarian vision of the doctor as a dictator, and programs of sterilization and extermination of the malformed, the handicapped and the mentally ill were initiated. Human genetics was a means for eugenicists to extend their power to the medical sphere. It was believed that scientific biological solutions would solve the problems of crime, poverty, and disease. The program was later extended to sterilize and in some cases to eliminate "undesirable" ethnic groups, such as the Jews.[11] Nazism realized that knowledge of population genetics was useful in order to build a racial utopia. Utilitarian reasoning was the basis of the Nazi eugenic policy.[12] Nevertheless, it has been pointed out that the eugenic movement in Germany was not a monolithic movement directed by the Nazi party, which culminated in the Holocaust and terminated after the eradication of Nazism. Eugenics and the associated science of human genetics had an intrinsic diversity during Nazism; there was an extensive background of eugenic views well before the Nazi period and it can be said that eugenic thinking still survives presently in the mentality of many people.[13]

Today, it can be said that there is a tendency among people living in postindustrial societies to use the available genetic technology to get the most perfect child possible. This results from the pressure of wanting a normal "perfect" child when the family size is small. Recombinant DNA technology, the mapping of the human genome and in vitro fertilization provide the technological capability for people to take eugenic decisions at their will. Economic pressures in society help to foster an eugenic mentality in families. Today, there is an acceptance of the use of forced sterilization to decrease the incidence of some medical conditions such as feeblemindedness and social ills such as welfare motherhood.[14] There is also a diminished tolerance of those born with disabilities as is exemplified in the emergence of a new form of litigation in which either children hold their parents responsible for their "wrongful life" or in which parents sue doctors for "wrongful birth".[15] Handicapped or ill individuals have sued the health care practitioners for damages stemming from the very fact of their existence and parents of an affected child have brought lawsuits alleging that their health care providers failed to meet the standard of care by neglecting to provide genetic information or the presence of malformations, that if known, would have led parents to choose abortion. Parents seek relief in paying the special costs of raising and caring for the child, as well as for the emotional and physical suffering incurred by all. Fearing lawsuits, practitioners in obstetrics present the option of abortion in connection with tests that detect genetic anomalies and malformations of the fetus.[16] There is the threat that the initial option of being tested may be transformed into an obligation. In a recent international poll on people's approval of gene therapy and genetic enhancement in countries such as Russia, India, Australia, New Zealand and Thailand, people gave eugenic reasons combined with economic ones for supporting prenatal genetic screening.[17]

Thus, for example, eugenic measures can be achieved by embryo selection in in vitro fertilization procedures by choosing the embryo to be implanted that does not carry deleterious mutations or that carries the desired qualities; by aborting embryos or fetuses with inherited diseases; by using germ-line gene therapy to replace, correct or supplement malfunctioning genes which will be inherited; by germ-line non-therapeutical genetic engineering enhancement; by sterilizing those tested as having a genetic disease. The creation of "improved" individuals by means of genetic engineering affecting the germ-line can be considered a form of eugenics since, in general, the reason for attempting such genetic alteration is for acquiring traits that are considered favorable, which will be transmitted to the next generation. On the other hand, somatic gene therapy does not constitute a form of eugenics since the genetic changes done in the individual with this therapy are not transmitted to the offspring. Nevertheless, for safety reasons germ-line gene therapy or enhancement is not feasible today, but states may have an interest in supporting programs that provide an incentive for genetic testing and termination of pregnancy for genetic diseases. Avoiding the conception of an infant with a genetic disease is generally less expensive than clinical management.

In the absence of low-cost "cures" for those born with a genetic disease, it is less expensive to avoid the birth of a fetus prenatally diagnosed as having such a condition. In today's society there is an increased tendency to favor abortion in cases where a prenatal diagnosis reveals a diseased fetus with a negative prognosis. For many, to abort an embryo with a genetic disease is regarded as a humanitarian act in order to ease the suffering of the family and the burden that it places on its members as well as on society. Attainting therapy on the fetus is not considered an ethical obligation. In the last few years there has been a trend in the US towards decreasing federal and state funding for newborns with congenital malformations and genetic diseases and for the elderly who are incompetent and chronically ill. Prenatal genetic testing is viewed positively from a public health standpoint because it offers a way to reduce the frequency of selected birth defects through abortion.[18] From a financial perspective, to identify the people who carry genetic diseases and prevent their birth is less costly than to maintain individuals alive with genetic diseases. This coincides with the risk-benefit approach currently being applied to most social and environmental problems. The availability of genetic testing gives prospective parents the power to choose the kind of children they wish to bear. In a society driven by economic constraints there is considerable pressure on parents to abort defective children, since they are the ones who are to bear the emotional and economic burden of rearing the children. According to the International League of Societies for Mentally Handicapped Persons, "invisible social, legal and financial pressures are already forcing women to abort disabled fetuses."[19] In Great Britain it has been suggested that for a genetics clinic to be funded, it should demonstrate that the number of births of babies with particular diseases and malformations is declining and the termination of pregnancies, because of those diseases and malformations, is increasing.[20] Clarke has expressed his concern that clinical management measures the efficiency of a medical genetics unit in terms of the number of terminations performed as a result of genetic counseling.[21] In China, a new law on maternal and infant health care requires premarital medical examination and where this shows "genetic disease of a serious nature which is considered to be inappropriate for child bearing from a medical point of view, the two may be married only if both sides agree to take long term contraceptive precautions or to take ligation operation for sterility." Where a pregnant woman is found to be carrying a fetus with a serious defect or genetic disease, the pregnancy is terminated.[22]

Ethical Reflection

Maximum respect for human dignity should be the guiding principle in all ethical decisions. Laws that permit abortion or active euthanasia go against human dignity because they involve the end of a life, when life constitutes a higher value than the suffering a human being will have to undergo if genetically injured. There is no life without some kind of suffering. Health is not an absolute end, but a subordinate goal; thus it is not the case that if you are not going to be healthy, it is better that you do not live; rather, health is a means for improving the quality of life for which we strive. It is necessary to emphasize the value and the importance of every human being. At the same time, society has the duty to try to provide the best environment possible to try to diminish the suffering of individuals born with diseases. If there are no institutions that care and help individuals with genetic diseases, all the burdens fall on family members who are pressured to avoid the birth of these individuals.

The *Magisterium* has condemned prenatal diagnosis when it is used with an eugenic intention that accepts selective abortion in order to prevent the birth of children affected by various types of anomalies since this attitude measures human life only under the parameters of physical well-being and open the way to legitimizing infanticide and euthanasia.[23] Prenatal diagnosis is only accepted as a means for early therapy or in order to "favor a serene and informed acceptance" of the unborn. Any eugenic intention accepting selective abortion is condemned.

Society's health care structure and the legal system should help prevent private decisions that lead to an eugenic effect in the population by eliminating individuals. On the other hand, even though it is an eugenic decision, there is nothing unethical in that individuals voluntarily decide not to parent when there is risk of having a genetically damaged child since this only implies a sacrifice for the prospective parents and not the termination of a life. Another question is that genetic screening programs' primary goals should be to help individuals avoid the consequences of their genetic inheritance and thus be for the benefit of the person. Individual families also have the responsibility to accept human life as it comes once conception has taken place, without judging which individuals deserve to live and which do not. It has been pointed out that approaching the technology of prenatal diagnosis can be a source of conflict for the parents. In one hand the technology assures the parents that the fetus is growing in relationship with the mother, and in the other hand it may be suggested that this life be ended.[24] This conflict would be removed if abortion were not an option.

It is a difficult situation for a parent to have offspring with a genetic abnormality which involves pain through the pregnancy and afterwards. The usual questions that come to mind are "Can I allow this to happen to my child? To what extent do I share responsibility for the sufferings of the fetus?" The question of what to do with a fetus suffering with an incurable illness is related to the question of what to do with an adult suffering an incurable disease; for some the solution is to be found in euthanasia. But we do not have absolute dominion over life, hence we can never actively take another's life because the person is suffering, since the life is a higher value than the evil of suffering. Life has been given to us and therefore it does not belong entirely to us. We do not have in our power to judge that somebody must not live because that person is suffering. What can be done in such cases is to use pain killers to diminish the suffering, and avoid medical interventions that merely prolong life without curing the disease. These standards are appropriate for both the adult and the fetus or embryo

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