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OCTOBER 1997 ISSUE ON BIOETHICS

GENETICS AND DISCRIMINATION

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Article 6 of the draft *UNESCO Declaration on the Human Genome* declares:

"No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity".

What is the meaning of this provision? Why has it been included in the draft?

For centuries, scholars and writers have been striving to express fundamental human rights. The attempt actually goes

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back to ancient civilisations. In modern times, it is reflected in Britain's *Magna Carta*, in the French *Declaration of the Rights of Man and of the Citizen* and in the United States *Bill of Rights*. In the international community the endeavour gained momentum after the *Universal Declaration of Human Rights* was adopted in 1948. One of the golden threads that runs through all of these documents is the principle that each human being has an inherent dignity, basic rights and fundamental freedoms which no government, no individual or powerful corporation has the right to take away.

Another golden thread is that human beings should not be discriminated against upon the basis of irrational considerations over which they have no control: their gender, their race, their skin colour, their sexuality, their age etc. An abiding theme of the United Nations human rights instruments has been the insistence upon safeguarding equal opportunity for all, so that everyone can make the journey through life without suffering irrational and unjust disadvantages because of immutable characteristics of nature.

Sadly, the century that has witnessed the advent of this global movement for human rights has also seen unprecedented efforts of oppressive governments and others with power to diminish human dignity on the basis of genetic characteristics. The Nazi Holocaust against people of Jewish ethnicity and other victims is a well-known example. "Ethnic cleansing" in several

parts of the world has stained the recent history of humanity. But the eugenics movement earlier in the century, which enforced sterilisation of people with supposed mental or physical disabilities, also involved infringements of basic human rights. Only today are we discovering the gross affronts to human dignity perpetrated in the name of "genetic cleansing".

Advances in technology present many new challenges to human rights. Informatics is an obvious example. But so is the development of gene technology. As the Human Genome Project unlocks the secrets of how genes cause particular characteristics in human beings, it is important that humanity should assert and protect the precious diversity of our species. It is that diversity in the human gene pool which has protected humanity in the past from the ravages of plague and pestilence. Advancing knowledge about the genome will lead to demands to eliminate foetuses with particular genetic characteristics. This should be permitted, if at all, only upon conditions which uphold the diversity of our species and maintain human dignity. Eliminating painful inherited diseases is one thing. But eliminating a particular race, people of a particular skin colour or sexual orientation, gender or personal characteristics would be quite intolerable. After all, our genetic diversity is what makes us human. We will need guidance in the future as to how far we can go with genetic manipulation and alteration of the human species. The draft UNESCO *Declaration* is the first step on the

path to global consensus upon this topic which affects human beings everywhere in the world.

On a practical level, it will be necessary in the future to address many hard questions. Should insurers be entitled to know about your genome? Should they have this right even if you yourself do not wish to know all the secrets of your medical future? Should employers be entitled to demand that workers undergo genetic tests? The answers to these and other practical questions may only be given in a way compatible with human rights, fundamental freedoms and human dignity. That is the important message which this article of the draft UNESCO *Declaration* conveys.

The mysteries of DNA and of the genome will certainly be unravelled by scientists. The result will be the encyclopaedia of medicine of the coming millennium. The use we make of this information is up to humanity. That use must be compatible with the fundamental human rights belonging to all human beings. But the basic quandary which is now presented to us is whether we can, and should, redefine the human species and change elements of its genetic makeup which have existed through long millennia until now. The central message which the UNESCO *Declaration* brings is that any such changes must conform to fundamental human rights and freedoms and to human dignity.

law. Research which does not have an expected direct health benefit may only be undertaken by way of exception, with utmost restraint, exposing the person only to a minimal risk and minimal burden and if the research is intended to contribute to the health benefit of other persons in the same age category or with the same genetic condition, subject to the conditions prescribed by law, and provided such research is compatible with the protection of the individual's human rights.

*Article 6*

No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.

*Article 7*

Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions foreseen by law.

*Article 8*

Every individual shall have the right, according to international and national law, to just reparation for damage sustained as a direct and determining result of an intervention affecting his or her genome.

*Article 9*

In order to protect human rights and fundamental freedoms, limitations to the principles of consent and confidentiality may only be prescribed by law, for compelling reasons within the bounds of public international law and the international law of human rights.

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C. RESEARCH ON THE HUMAN GENOME

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*Article 10*

No research or its applications concerning the human genome, in particular in the fields of biology, genetics and medicine, should prevail over the respect for human rights, fundamental freedoms and human dignity of individuals or, where applicable, of groups of people.

*Article 11*

Practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted. States and competent international organizations are invited to co-operate in identifying such practices and in determining, nationally or internationally, appropriate measures to be taken to ensure that the principles set out in this Declaration are respected.

*Article 12*

a) Benefits from advances in biology, genetics and medicine, concerning the human genome, shall be made available to all, with due regard to the dignity and human rights of each individual.

b) Freedom of research, which is necessary to the progress of knowledge, is part of the freedom of thought. The applications of research, including those in biology, genetics and medicine, concerning the human genome, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole.

**D. CONDITIONS FOR THE EXERCISE  
OF SCIENTIFIC ACTIVITY**

*Article 13*

The responsibilities inherent to the activities of researchers, including meticulousness, caution, intellectual honesty and integrity in carrying out their research as well as in the presentation and utilization of their findings, should be the subject of particular attention in the framework of research on the human genome, because of the ethical and social implications. Public and private science policy-makers also have particular responsibilities in this respect.

*Article 14*

States should take appropriate measures to foster the intellectual and the material conditions favourable to freedom in the conduct of research on the human genome and to consider the ethical, legal, social and economic implications of such research, on the basis of the principles set out in this Declaration.

*Article 15*

States should take appropriate steps to provide the framework for the free exercise of research on the human genome with due regard for the principles set out in this Declaration, in order to safeguard respect for human rights, fundamental freedoms and human dignity and to protect public health. They should seek to ensure that research results are not used for non-peaceful purposes.

*Article 16*

States should recognize the value of promoting, at various levels as appropriate, the establishment of independent, multidisciplinary and pluralist ethics committees to assess the ethical, legal and social issues raised by research on the human genome and its applications.

## E. SOLIDARITY AND INTERNATIONAL CO-OPERATION

### Article 17

States should respect and promote the practice of solidarity towards individuals, families and population groups who are particularly vulnerable to or affected by disease or disability of a genetic character. They should foster *inter alia* research on identification, prevention and treatment of genetically-based and genetically-influenced diseases, in particular rare as well as endemic diseases which affect large numbers of the world's population.

### Article 18

States should make every effort, with due and appropriate regard for the principles set out in this Declaration, to continue fostering the international dissemination of scientific knowledge concerning the human genome, human diversity and genetic research and, in that regard, to foster scientific and cultural co-operation, particularly between industrialized and developing countries.

### Article 19

a) In the framework of international co-operation with developing countries, States should seek to encourage that:

- i) the assessment of the risks and benefits pertaining to research on the human genome is ascertained and abuse is prevented;
- ii) the capacity of developing countries to carry out research on human biology and genetics, taking into consideration their specific problems, is developed and strengthened;
- iii) developing countries can benefit from the achievements of scientific and technological research so that their use in favour of economic and social progress can be to the benefit of all;
- iv) the free exchange of scientific knowledge and information in the areas of biology, genetics and medicine is promoted.

b) Relevant international organizations shall support and promote the measures taken by States for the aforementioned purposes.

## F. PROMOTION OF THE PRINCIPLES SET OUT IN THE DECLARATION

### Article 20

States should take appropriate measures to promote the principles set out in the Declaration, through education and relevant means, including *inter alia* through the conduct of research and training in interdisciplinary fields and through the promotion of education in bioethics, at all levels, in particular addressed to those responsible for science policies.

*Article 21*

States should take appropriate measures to encourage other forms of research, training and information dissemination conducive to raising the awareness of society and all of its members of their responsibilities regarding the fundamental issues relating to the defence of human dignity which may be raised by research in biology, in genetics and in medicine, and the applications thereof. They should also undertake to facilitate on this subject an open international discussion, ensuring the free expression of various socio-cultural, religious and philosophical opinions.

**G. IMPLEMENTATION OF THE DECLARATION**

*Article 22*

States should make every effort to promote the principles set out in this Declaration and should, by means of all appropriate measures, promote their implementation.

*Article 23*

States should take appropriate measures to promote, through education, training and information dissemination, respect for the aforementioned principles and to foster their recognition and effective application. States should also encourage exchanges and networks between independent ethics committees, as they are established, to foster full collaboration.

*Article 24*

The International Bioethics Committee of UNESCO should contribute to the dissemination of the principles set out in this Declaration and to further the examination of issues raised by their applications and the evolution of the technologies in question. It should organize appropriate consultations with parties concerned, such as vulnerable groups. It should make recommendations, according to UNESCO's statutory procedures, addressed to the General Conference and give advice concerning the follow-up of this Declaration, in particular the identification of practices that could be contrary to human dignity, such as germ-line interventions.

*Article 25*

Nothing in this Declaration may be interpreted as implying for any State, group or person any claim to engage in any activity or to perform any act contrary to human rights and fundamental freedoms, including *inter alia* the principles set out in this Declaration.