The Genome: A New Frontier for Human Rights

Justice Kirby Collection

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As we reflect on the extraordinary achievement, fifty years ago, of the adoption of the *Universal Declaration of Human Rights,* we are brought to a realisation that the categories of fundamental human rights are never closed. Actions which were once seen as perfectly compatible with human dignity (such as slavery, no votes for women and criminal punishment of homosexuals) come to be viewed as serious affronts. There is a further reason why the discovery of basic human rights is a never ending journey. New problems (such as global warming, water scarcity, world over-population and HIV/AIDS) present urgent dynamics for human rights thinking. Science and technology (such as nuclear fission, informatics and the discovery of DNA and the genome) present novel challenges which cannot be ignored.

From the start, UNESCO has been a major contributor to the exploration of the new frontiers of human rights. The Preamble to its Constitution recognises that "peace must be founded ... on the intellectual solidarity of mankind". Since the early 1970s, UNESCO has been one of the main promoters of trans-disciplinary and multicultural debate about the ethical implications of developments in the life sciences. In 1993, the Director-General (Professor Federico Mayor) established the International Bioethics Committee (IBC). This is the only body within the United Nations system which engages in ethical reflections on research in biology and genetics. It comprises 36 members from all parts of the world and many disciplines. Their most important work to date has been the drafting of the *Universal Declaration of the Human Genome and Human Rights.* It was adopted by UNESCO in November 1997. Fifty years after the work of Mrs Roosevelt and her colleagues, a second *Universal Declaration* is before the world community for its endorsement.

The UNESCO *Declaration* is concerned with the consequences which flow from the discovery of our genetic map: our physical characteristics, our proneness to genetic disease and our future health history may be discovered in our genes. Overwhelmingly, this development will be for the benefit of humanity. But it also presents risks and dangers to human rights which UNESCO's *Declaration* addresses.

The *Declaration* states the basic rights of individuals affected by research on the human genome. These rights are derived from a unifying concept: the obligation to respect the dignity of each precious individual and to prevent discrimination on genetic grounds; to protect privacy and to ensure that free consent is obtained for the use of the individual's genetic data.

The new *Declaration* also expresses the principles which should govern research on the human genome. One of these, which has proved controversial, is Article 11. It states that

"practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted". Following the cloning of the sheep "Dolly" by Scottish scientists, this provision is concerned with the perceived risk that attempts may be made to clone an entire individual: producing a genetic mirror image of the person concerned.

When the new UNESCO *Declaration* was adopted, it was realised that genetic discoveries were advancing at a remarkable pace and that follow-up to the *Declaratio*n would be needed. It calls for the IBC to monitor the implementation of the principles in the *Declaration*. It also calls for the establishment, at the national level, of independent ethics committees to assess ethical, legal and social issues raised by research on the human genome. In November 1998, in Tokyo, Japan, I told the Summit of National Bioethics Committees of UNESCO's vision. UNESCO's *Declaration* states the core principles for the rights and duties of individuals, of scientists and of national governments. The objective is to encourage people everywhere, and their governments, to become more aware of the many ethical dilemmas which research on the genome presents.

Possible human cloning is but one quandry. There are many others: Should insurers have access to the individual's genetic profile? Should employers have unlimited access? Should the State? Should corporations be entitled to patent a discovery that a particular gene is a cause of Alzheimer's Disease? Of baldness? Is this a just reward to the corporation to encourage huge investments in pharmaceutical and other activities essential to convert scientific knowledge into practical cures? Or is it a new imperialism, whereby a wealthy few gain monopoly rights over the genetic heritage of all mankind?

Now that the UNESCO's *Declaration* is before the world community, we have an obligation to promote knowledge about it. And to encourage national governments, and the global scientific community, to consider and voluntarily comply with, the core principles which it states. Because it is not a treaty, the new *Declaration* has no legal binding force. But should there be some fundamental rules which the international community adopts to prohibit by law certain lines of scientific experimentation with our genes? Such as the creation of human/animal hybrids? Or the manipulation of the human germline to alter irretrievably the genetics of future generations? Or the elimination of the "gay gene", if it is found to exist? Or experiments on living human subjects without benefit for them, such as the Nazi doctors practised? Or cloning of an entire human being? UNESCO's follow-up of its *Declaration* will require nation-states and the international community to address, and answer, these questions. UNESCO's initiative is based on the understanding that, in some matters of scientific and technological experimentation, to remain silent and not to provide legal and other rules, is effectively to make a decision.

The main obstacles to the utility of the new *Declaratio*n arise from widespread ignorance of the scientific developments which are rapidly occurring, a feeling of inability to affect them, a belief in the inevitability of science and an unwillingness, in hard economic times, to do anything which might frighten away biotech industries and their potential profits and investments. The reality is that most research on human genetics (and virtually all of the patents) exist in a handful of countries of the developed world. Yet what is done affects,

potentially, the entire human species. The principles upholding human dignity, as expressed in the new *Universal Declaration on the Human Genome and Human Rights,* are common to people everywhere.

At the Summit in Japan, some of the participants told me that it would be difficult to secure consensus about all of the controversial questions dealt with in UNESCO's *Declaratio*n. They pointed to cultural, economic, religious and other differences and to the feeling of fatalism which exists in most countries so far as scientific research is concerned. I cannot agree. Twenty years ago, when transborder data flows presented pressing new challenges to individual privacy and other rights, a number of regional and international organisations developed "core principles" to govern privacy protection and data security. Those principles have profoundly affected the laws of many countries with differing legal traditions, cultures and religious and other beliefs. I believe that it can be the same with the "core principles", defending human dignity, in the context of genetic research.

In a sense, therefore, UNESCO's new *Universal Declaration* provides an important test for the international community. In the face of scientific advances which may bring many benefits but present quandaries of global concern, are humans capable of responding effectively? Can international bodies, such as UNESCO and its IBC, provide the means to agree on basic principles about human rights in the future? Can there be any more fundamental issue for human rights in the new millenium than protecting the integrity of the human species which enjoys those rights? Or do we simply surrender the future to whatever scientists imagine and multinational corporations invest in?

In the ashes of the Second World War Eleanor Roosevelt, Rene Cassin, John Humphrey and their bold companions had no doubt as to what the answer should be to such questions. They completed the *Universal Declaration of Human Rights*. No surrender of fundamentals. A search for the common ground. Criteria of the dignity and solidarity of all human beings. The challenges before them were no less daunting than the challenges we face today. Their achievement is an inspiration for us. The problems now are no less puzzling. We should be as bold and as brave and as confident as they were.

The catalogue of fundamental human rights is never closed. We are on a journey of enlightenment exploring their frontiers. Every new decade reveals new challenges to which humanity must respond. UNESCO has answered the challenge. Will humanity pay heed?