Seeing the IBC`s Role in Context

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Date: 02 December 1998
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Type: Speech
Subject: Human Genome Project
Organisation: UNESCO, International Bioethics Committee
Location: The Hague, The Netherlands

UNESCO INTERNATIONAL BIOETHICS COMMITTEE
FIFTH SESSION, THE HAGUE, THE NETHERLANDS 2-4 DECEMBER 1998
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IBC & THE FIFTIETH ANNIVERSARY

Because of a court sittings, I cannot join my colleagues in the Fifth Session of the International Bioethics Committee (IBC). I take this opportunity to send greetings from Australia, far away. And to offer a few reflections on the IBC - what it has achieved and where it stands.

The meeting in the Hague convenes on the eve of the fiftieth anniversary of the adoption, by the General Assembly of the United Nations, of the *Universal Declaration of Human Rights*. That *Declaration* has been described as the catalogue of fundamental rights "for six billion persons". Its influence has been enormous. Recent writings have demonstrated, contrary to uninformed suggestions, that in the preparation of the *Universal Declaration,* many delegates from developing countries (in what we now call the Third World or the South) reflecting the variety of human religious and ethical experience, played a vital part in framing its terms. A moment's reflection on the tremendous growth of the global movement for human rights and freedoms, will teach the abiding influence of that *Universal Declaration*. By seizing a critical moment in human history, by articulating deep-felt and universal principles and by effective follow-up in promoting and building national, regional and international institutions to convert its noble language into practical effect, the United Nations helped play a vital role of leadership, example and inspiration. At a time of such uncertainty and cynicism in the world, we in the IBC do well to remember that initiative and to draw encouragement from its success.

Elucidation of the content of human rights is a never-ending journey. Each new generation discovers from its own experiences new meanings to the principles already stated and new problems requiring the adoption of new principles. Within the United Nations, UNESCO continues to play a vital function in this regard, striving to be worthy of its high mission.

There is no doubt that some of the most profound challenges to human rights that face humanity today arise from science and technology, only recently developed or still unknown in 1948 when the *Universal Declaration of Human Rights* was adopted. Science and technology, as well as bringing enormous benefits, present puzzles and profound challenges

to humanity which engage UNESCO's attention and will do that of IBC. The most important technological developments of the past fifty years include those in the areas of nuclear fission, informatics and human biology and genetics. UNESCO is not only concerned with the scientific, social, educational and cultural implications of such developments. In accordance with its mandate, it is deeply involved in the elucidation of the ethics of such endeavours and of the moral dilemmas which they pose.

UNESCO is constantly exploring new frontiers. For example, in 1998, the Director-General of UNESCO (Professor Federico Mayor) set up the World Commission on the Ethics of Scientific Knowledge and Technology. But five years before this, in 1993, the IBC was created, on which we have the honour to serve. Our function include the drawing up of normative instruments bearing upon the protection of human rights with regard to issues raised by genetics and biology and reflecting upon the vast range of bioethical questions. The IBC is the only body of its kind within the United Nations system.

In the past, the deliberations of the IBC have not been confined to issues concerning human rights and the human genome. At its fourth session, the members of the IBC explored several topics, including ethics in food and plant biotechnology, the protection of human rights in the context of experimental treatment of human beings and the special issues presented to bioethics by concerns particular to women. The last topic is on the agenda again for this Fifth Session as benefits its universal importance. However, the IBC has certainly given much of its attention, since its establishment, to the human rights implications of the discovery, mapping and development of the human genome. Under the distinguished presidency of Madame Noelle Lenoir (member of the Constitutional Council of France) and well-served by its secretariat, headed by Mr Georges Kutukdjian, IBC devised the draft *Universal Declaration on the Human Genome and Human Rights*. That draft was adopted with certain modifications by a committee of governmental experts convened by UNESCO in July 1997. The recommendations were duly conveyed to the General Conference of UNESCO in November 1997. And on 11 November, the General Conference, unanimously and by acclamation, adopted this second *Universal Declaration,* together with a resolution providing for its implementation and follow-up.

Faced by scientific developments of such complexity and importance as those presented by the Human Genome Project (with all of its diversity and many ramifications) it would be easy to despair. It would be understandable to allow the chariot of unbridled science to take humanity where it will. But, neither in the field of nuclear fission nor informatics nor human biology and genetics, is that a path which humanity should contemplate. Complex and difficult although the tasks are, it is essential that human beings remain in charge of the ethical concerns and play a part in charting at least the broad rules by which science and technology go forward. By taking its initiative, and propounding its new *Universal Declaration*, UNESCO has sought to provide assistance, to offer a framework within which national bioethical regimes may be developed, to emphasise the essential unity of the interest of our species in these topics and to avoid the development of sharply inconsistent regimes and approaches or, worse still, the abandonment of the topic altogether as too difficult or impossible to bring under human ethical discipline.

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UNESCO's aim in offering the *Universal Declaration on Human Rights and the Human Genome* was nothing if not bold. Yet if one is contemplating the new challenges to human rights in the coming generation, there can be few which are more important and more urgent than those which relate to human biology and genetics. For these will define who are the "humans" of the coming millennium to whom human "rights" belong. The mission of the IBC is, therefore, of enormous importance not only for the United Nations and UNESCO but also for the entire human family. We of the IBC should see our role historically. We should be as bold and as practical as Mrs Eleanor Roosevelt, Professor René Cassin and their intrepid colleagues who drafted the *Universal Declaration of Human Rights* in 1948 and who worked tirelessly thereafter to translate its fine words into institutions and effective action.

A CALL TO ACTION

It has been a great honour to serve on the IBC in the past. In fact, I provide a bridge to the Ethics Committee of the Human Genome Organisation, which is chaired by Professor Bartha Knoppers (Canada). It is my experience that each of these bodies works with integrity and independence but with their members' feet planted firmly on the ground. With a suitable sense of awe at the enormous challenges which are presented by the dynamic forces of science and technology. And also a sense of urgency to address the current ethical issues with an understanding of the best scientific knowledge which alone can form the valid foundation of accurate ethical assessments.

We in the IBC cannot afford the luxury of hand-wringing any more than we can retreat to the comfortable negativism of the Luddites. Overwhelmingly, biological research will be for the benefit of humanity. It behoves us all, in international bodies such as the IBC, and in national bodies concerned with bioethical issues, to respond to the challenges of bioethics efficiently, knowledgably, in a principled way, thoughtfully and in language which ordinary people and their elected leaders (and not just scientists) understand and act upon.

One of the distinguished members of the IBC, Judge Mohammed Bedjaoui, formerly President of the International Court of Justice, acknowledged that the role assumed by UNESCO, its IBC and the new *Universal Declaration on the Human Genome and Human Rights* involve "by no means an easy task". He asserted, rightly in my view that:

"A legal framework for potential new practices or those already engaged in which concern the human body is absolutely essential in that it protects man in his freedom and dignity ... '[H]uman dignity' ... is an expression which seems simple: one immediately apprehends its prospective import, if not its exact meaning. But paradoxically, it is also an expression full of fragility, for in the name of the same argument of 'human dignity' some refute the legitimacy of euthanasia, whilst others claim it as the ultimate right of those who wish to 'die in dignity'!

UNESCO's *Universal Declaration,* developed by our Committee, fully accepts the difficulties of language, concepts and applications. But it provides a framework for national and

international follow-up. It identifies the key basic rights of the individual which need to be defended. It specifies criteria by which (at least at this stage of our knowledge) some activities should be forbidden and others promoted and encouraged. It gives expression to some fundamental rules for humanity in an area which touches closely the human future. It gives guidance to national bioethics committees and it encourages them to take action, finding basic unity around common, practical themes. The machinery of implementation and the detailed national expression of laws and practices will vary greatly from one country to another. However, at least a framework to ensure consistent and compatible national initiatives has been offered. I consider that the UNESCO *Universal Declaration* is a most important contribution to this area of discourse. Much work lies ahead in follow-up and implementation. And also in other fields where normative reflection is needed.

Fifty years ago, no one was sure where the *Universal Declaration of Human Rights* would lead. The challenges to, and divisions of, humanity were enormous. Who would have thought, then, that the mighty network of national and international human rights rules and institutions would be established, in such a relatively short time, gathering around those principles to which the *Universal Declaration of Human Rights* gave such eloquent expression? Now there is a second *Universal Declaration*. We who serve on the IBC may be proud of its achievement. We should, I believe, rededicate ourselves to the great privilege which our appointment has afforded to us. We must follow the new *Declaration* up with resolution and imagination. But new and equally perplexing challenges lie ahead for the IBC. They will require the soundest briefing of the members in the most advanced scientific and technological developments in question. They will necessitate strong support for the Secretariat so that it (and therefore the IBC) enjoys the resources to tackle the enormous responsibilities entrusted to it. They will oblige us to see our role historically and to be as bold in the IBC as Mrs Roosevelt and her valiant colleagues were in 1948.

Embargoed until

Friday 4 December 1998