

UNITED NATIONS EDUCATIONAL, SCIENTIFIC AND CULTURAL
ORGANISATION

AD HOC WORKING GROUP CONVENED PURSUANT TO
RESOLUTION 29C/17 ON THE INTERNATIONAL BIOETHICS

COMMITTEE

25-27 MARCH 1998, PARIS

IBC - LOOKING AHEAD

The Hon Justice Michael Kirby AC CMG

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THE CHALLENGE BEFORE THE GROUP

The purpose of this meeting is to formulate proposals to the Director-General of UNESCO concerning the statutes to govern the future work of the International Bioethics Committee (IBC). The original Committee, on which I had the honour to serve under the

Australian Representative on the *ad hoc* Working Group. Past member of the UNESCO International Bioethics Committee 1996-7; Member of the UNESCO Jury for the Prize for the Teaching of Human Rights. President of the International Commission of Jurists.

most distinguished Presidency of Madame Noelle Lenoir (France), has completed its task. Its principal achievement was the proposal for the *Universal Declaration on the Human Genome and Human Rights*. That proposal was accepted by the General Conference of UNESCO on 11 November 1997. It is a major achievement. A great deal of the credit for this achievement must go to the tireless work of Madame Lenoir.

Nevertheless, it is now imperative for us to make proposals for the future constitution of a new IBC. It is essential that the IBC should retain its independence of government. As Madame Lenoir has often said, ethical questions are not matters of political negotiation and bargaining. Often ethical opinions will be extremely upsetting to politicians. Yet there may be a need for better dialogue between governments and the IBC. This need arises, in part, because of the sensitivity of the issues with which the IBC works; the need to follow up the recommendations of the IBC with domestic law and policy; and to ensure that the member States of UNESCO, and their governments, understand the complexity of the topics on which the IBC must work. Dialogue is always a healthy thing. Constituting a body which permits dialogue but on terms that respects the independence and integrity of the IBC and its members, is the challenge before the *ad hoc* working group.

Inspired by the contributions which have been made to the Working Group I wish to suggest five points that are relevant to our deliberations. They are not the only points that must be considered.

But I trust that they will be given due reflection not only by the Working Group but also by UNESCO when the Working Group has dispersed.

FIVE MATTERS FOR CONSIDERATION

1. *Composition and function*

The first point is one that has been made by the delegate of the Netherlands. It is impossible to design the composition of an international bioethics committee without having a clear conception of what that body will be doing. If it is expected to be a bioethical institution, it must have a particular mixture of expertise and the independence that is necessary to allow the free and intellectual reflections that are essential to bioethical concerns. Clearly, with independence comes a power to initiate one's own programme. But equally clearly, if that programme is to be of practical utility to UNESCO, the member States and humanity, the IBC must take into account the programme priorities of concern to member States. It must also be subject to some form of intellectual auditing so that the utility of its work is constantly reviewed. This was a point made by the speaker from the Mission of the United States of America. I agree with him.

A practical limitation on the future IBC will be the funds that are available for it to perform its work. It is unrealistic for us to make suggestions of a multitude of new functions if the IBC does not even

have the funds to meet annually. Although I was a member of the IBC for more than a year and attended a meeting of its Legal Commission, no actual meeting of the IBC itself took place during my service. I expect that the principal reason for this was a lack of funding. The programme and work of the IBC must therefore be tailored to the funds which are available within UNESCO for its performance. But those funds should be adequate so that the IBC is not mere window-dressing. Some improvement in the dialogue between the IBC and the member States of UNESCO is necessary. The clearest illustration of this need arises from the treatment of the vexed subject of cloning. Although the IBC itself did not include reference to this particular topic in its draft of the *Universal Declaration*, it soon became apparent, from the meeting of the government experts in July 1997, that they wished reference to be made to the topic. The result was that reference was so made in the language of the *Universal Declaration* as adopted. This was done, I have to say, without formal reference back to the IBC for its opinion. Although I accept the decision and believe it represents an appropriate statement of the position at this stage of human knowledge, the procedures were obviously defective. Some better institutional arrangement is therefore necessary if a constructive dialogue is to be established between the independent IBC and the member States with their own priorities, concerns and diverse opinions.

2. *Developing technology*

It is interesting to notice how many of the issues for human rights now revolve around technological developments. It would be a mistake for the *ad hoc* working group or for the IBC to consider that advice and recommendation on bioethical concerns affecting the life sciences can be stated with absolute accuracy as applicable for all future time. I learned this in my first work on the implications of technology for human rights. I refer to the Expert Groups of the OECD which I chaired on the subjects of Transborder Data Flows and the Protection of Privacy (1978-1980) and Data Security (1990-91). The Guidelines which were developed by the first working group were highly influential in the lawmaking of several countries of the world, including my own. But such has been the development of information technology since 1980 that many of the principles laid down in the OECD Guidelines are out of date or at least in need of review. The technology has moved on. Ethical principles must endeavour to keep pace.

The same is true in the area of biology. Anyone who has been watching the bioethical debates for as long as I have will be aware of the constant evolution of new problems with different challenges. For example, when I first entered public office the big debate in this area was "artificial insemination husband" (AIH), ie whether it was ethically permissible for a husband, without physical contact, to donate sperm in order to achieve a pregnancy with his wife. How simple the debates of those days now seem. That problem was

soon overtaken by artificial insemination donor (AID). But just as that debate was being solved, invitro fertilisation (IVF) came along. And now we have the dilemmas of the genome. The point I make is that technology does not stand conveniently still for bioethical committees or lawmakers. The technological advances are occurring so quickly that it is essential, if bioethical reflection is to have any practical utility, that it should be efficient, appropriately swift and properly provisional. It needs to be provisional because new technological advances present new and different problems to which bioethicists, including those on the IBC must regularly respond.

3. *Coordination of effort*

One point which has been repeatedly made is the urgency of securing coordination of effort in the field of bioethical reflection as it concerns the genomic sciences. I am a member of the Ethics Committee of the Human Genome Organisation, as is Professor Bartha Knoppers, like me, a former member of the IBC. But in addition to the work of HUGO there are many other bodies exploring the ethical issues of the genome. Work is being done in the World Health Organisation, the Food and Agricultural Organisation, the Council of Europe and the Commission of the European Union. It is unrealistic, as the delegates of Germany, Israel and the United Kingdom have stressed, to expect scientists in the area of the genome to have to conform to a multitude of voices on ethical issues. It is imperative, for the practical utility of bioethical reflection, that there should be coordination between those voices. They need not

sing precisely the same tune. But they should surely strive to sing in harmony.

It is also necessary to see the development of the human genomic sciences in the context of other technological developments which present somewhat similar problems. I refer especially to the Internet. The chief problem which is common to the challenge of the genome and the Internet is that which concerns the future role of governmental regulation by the nation states. As with the genome, so with the Internet, it is extremely difficult to find principles or mechanisms for enforcing internationally agreed ethical rules. If they are not liked by scientists or businesses in particular jurisdictions, they can simply be ignored. Technology can be taken elsewhere to more pliant states. The power of the science and technology is so great and so universal that it is difficult for a single nation state or group of states to speak to it. In this sense, the genome, like the Internet, presents an important dilemma for the future of the member States of UNESCO. How can they respond effectively to challenges of this dimension? It is feasible for the international community to devise responses that are swift, effective and universal? If the answer to that question is in the negative, the utility of international bioethical reflections is not lost. But its practical impact is likely to be limited.

4. *Human rights*

It is also important to see the work of the *ad hoc* working group in the context of the development of human rights more generally. 1998 represents the fiftieth anniversary of the adoption of the *Universal Declaration of Human Rights*. It is essential that we should perceive work on human rights and the human genome in the context of this important anniversary. We should realise that many of the greatest challenges to human rights in the future will stem from technological developments. I refer to those in the fields of information technology, nuclear fission, chemical weapons and the like. We need to perceive the inter-relationship of these technological challenges and the way they fit in to the picture of human rights for the coming millennium. We should seize the opportunity of the fiftieth anniversary of the *Universal Declaration of Human Rights* to scrutinise the work of the IBC and to place it in a wider context. UNESCO is already examining other technological implications for human rights. I am aware of work that is being performed on the implications of information technology for human rights. It will be important that the UNESCO initiatives in this regard should be coordinated. Genomic sciences would not have been possible without information technology. Some of the challenges of each technology are common. UNESCO should not place them in watertight compartments. If there is any agency of the United Nations Organisation which can perceive the linkages, it is UNESCO.

5. *Lateral thinking*

Last week in Australia I spent some time with the famous educator and lateral thinker, Dr Edward de Bono. Perhaps it is the time spent with him that has caused me to urge a measure of lateral thinking on the part of UNESCO and this working group. We should lift our sights from concern only with the operation of the IBC and the genome. We should see that work as an illustration of a number of problems of wider significance for the governance of humanity. In particular, we should be looking for the implication of genomic sciences for:

- * The effectiveness of government, both national and international.
- * The role of the media in explaining the challenges of complex technology without panic and banal sensationalism.
- * The dialogue of the sciences with each other and with the communities they serve.
- * The dialogue of scientists, ethicists and governmental experts with the civil society which is ultimately the object of all their labours.

I hope that we will not have come to Paris only to formulate a statute for the structural organisation of the IBC within UNESCO in

the future. That is an important task and it must be completed. But we should use this opportunity to encourage UNESCO to look beyond the particular concerns that have brought us together. To draw lessons of a wider character. To be practical and useful within the resources that are available. To realise that the last word is rarely, if ever, written upon the ethical implications of science. To seek to coordinate other initiatives which are addressing the ethical implications of other non-genomic sciences. To use the fiftieth anniversary of the *Universal Declaration of Human Rights* as an opportunity and a challenge to be as bold and brave as its authors were fifty years ago. And to think laterally, lifting our eyes from our immediate concerns to the fundamental question about human rights in the future. And of all these fundamental questions, can there be one which is more basic than this: Who will be the humans for whom human rights are defined in the coming century?