



Noëlle Lenoir

## Developing normative instruments in bioethics

### Personal story

A lawyer by training, I served as Director of Regulatory Matters on the Government Committee on Data Protection from 1982-1984. Since 1984, I have been a member of the Conseil d'Etat, the highest administrative court in France, and in 1988 I served as 'Commissaire du Gouvernement' to the 'Conseil d'Etat', which is the equivalent to public prosecutor or solicitor general in other courts. That same year I was appointed Chief of Staff of the Ministry of Justice where I served until 1990. I have always had a great interest in the relationships between science, human rights values and the law. This is why I was appointed by the French Prime Minister to review French and international bioethics laws in 1991. The report I presented to the President and to the Prime Minister entitled, 'Aux Frontières de la Vie: Pour une éthique biomédicale à la Française' contained various proposals and became the 'Foundation for French bioethics law', later adopted by Parliament in 1994.

On this basis, Federico Mayor, the Director-General at the time, asked me to create and chair the first International Committee on Bioethics of UNESCO (ICB). I am very grateful to Federico Mayor and praise his visionary approach. From 1992-1998, I had the honour of being involved with this committee and with UNESCO. By 1997, we had drafted the Universal Declaration on the Human Genome and Human Rights, which was approved by the UN in 1998 for the 50<sup>th</sup> anniversary of the UN's Universal Declaration of Human Rights. With my mandate fulfilled,

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I chose to leave UNESCO to allow somebody else from another country to take the lead of the ICB.

Indeed, at the time of my involvement with UNESCO, I was a judge at the French Constitutional Court where I served as the first woman ever to be appointed to such a position. I was also the first woman and youngest person on the French Supreme Court for constitutional matters, and chaired the European Group on Ethics in Science and New Technologies for the European Commission, which advised the EU on biotechnology and on ethical issues and regulations related to Information and Communication Technology.

By and large, two main ideals still hold true for me today: the universal nature of human rights; and, the rejection of discrimination. As part of my functions with UNESCO, I had the opportunity to work with, abide by, and translate both into reality, thereby conjugating respect for multiculturalism, such as language, religion and ethics, with the idea of universality.

In the International Committee on Bioethics, everyone could speak freely. It was a place where languages, cultures and ethics clashed, where one learned about others and their beliefs and where a set of guidelines were drawn up to bring people together in harmony with UNESCO's Constitution.

#### **Developing normative instruments in bioethics**

In all honesty, I am worried today by the emergence of a form of cultural relativity. Respecting cultural diversity does not mean we should abandon the idea of universality. Yet many authoritative States, whose power is based on military force or religion, try to impose their conception of human rights to justify the repression of political opponents, the negation of women's rights, the labour of young children and so many other things. This is a grave deviation from the UNESCO ideals, especially when the members of UNESCO themselves ignore these ideals.

UNESCO was created for the 'peoples of the world'. In that sense, the International Committee on Bioethics was a place where all persons (not only governmental officials) could speak, teach and learn. I did all I could to ensure that this continued.

It is my opinion that peace comes through the stabilization of democracy and democracy needs to be learned. This is a role UNESCO already fulfils admirably and yet it still needs to push the building blocks of democracy further through peaceful means. This means education, which is UNESCO's greatest challenge.

The Committee's role in gathering information and seeking common ground for all was an extension of this idea: getting to know the minds of men in order to better bring them together. Personally, I believe that democracy needs to be taught

at two different levels. Not only in respecting democracy in other countries, but also in your own neighbourhood, in your own village and in your own country. In that sense, UNESCO needs to teach everyone love and respect for democracy at a personal level first.

I believe that the most important achievement of the Committee was its ability to gather very large quantities of information, while consulting hundreds of people all around the world, then organizing it so as to be able to draw up a set of comprehensive guidelines for all. This was to become the Universal Declaration on the Human Genome and Human Rights. As indicated by its title this declaration is meant to be universal and should apply to all. Human beings, even though different, come together around common values.

### **Break the cycle of obscurantism**

I do not believe that my experience with UNESCO changed my view of the world, although it may have refined it. Human rights, democracy and respect for women are basic and key elements in any society. If I have learned anything with UNESCO it is that it is extremely important for us to know more about other cultures. Ignorance breeds fear and UNESCO is designed to fight that fear. Never has the condition of women around the world been so contrasted. On the one hand, we have women chancellors and presidents and, on the other, we have what can only be referred to as a form of slavery.

If I were to rejoin UNESCO today it would be to tackle this issue. Women tend to be the first victims and agents of obscurantism. The first signs of obscurantism are often the negation of women's rights. Women are the first victims and the first agents of its transmission, through their educational role. Consequently, only through education can anything be achieved. UNESCO already does much along these lines, but I believe it should advertise these points more and give further opportunities to women around the world to be heard. Giving people more examples of how things should be and inspiring more of them, would break this cycle of obscurantism.

### **A new ambitious project for women**

I believe a UNESCO Charter of unacceptable women's sufferings should be drawn up. It should include the infanticide of girls, honour killings and excision. Member States should then be required to sign and ratify this document in terms that give its content as much concrete effect as possible, for example, using language, such as 'I forbid' instead of 'I will respect', to lay a real onus on signatories and to ask them to take on a real undertaking with strict and automatic sanctions. Today, too many States do the opposite of what they say and agree to. The language used must be unequivocal and not open to misinterpretations.

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I believe that UNESCO should set a hard deadline, such as 2015, by which all women of the world should have at least the right to vote and the right to a proper education. As States tend to speak more freely when at UNESCO, this is the perfect platform from which to launch such an ambitious and important project.