CHAPTER 8
NEW DIMENSIONS OF BIOETHICS IN THE UNIVERSAL DECLARATION ON BIOETHICS AND HUMAN RIGHTS:
RESPONSE TO ROBERTO ANDORNO

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I. INTRODUCTION

Roberto Andorno presented an elegant overview of the *Universal Declaration on Bioethics and Human Rights* adopted by UNESCO in 2005. He highlighted some similarities with the Oviedo Convention and analyzed the main skeleton of a new bioethics order by focusing on its main principles.

I agree with Andorno’s analysis of the structure and particular paragraphs of the *Universal Declaration on Bioethics and Human Rights*. Nevertheless, I think one should also explore the *nature* of this declaration and reflect on the underlying theoretical issue, namely the relation between bioethics and human rights. In order to analyze the human rights/bioethics dimension of the declaration I would like to start with this theoretical question. Then I proceed to examine broader, social dimensions and their relations to the declaration. At the end I would like to go back to the original question: is this Declaration a human rights instrument, a bioethics declaration or something else?

I think it is worth examining whether the *UNESCO Declaration on Bioethics and Human Rights* can be considered as a form of international biolaw, as Roberto Andorno suggests. There are at least three alternative interpretations: the first sees the Declaration as an instrument that belongs to a new generation of human rights extending their scope to bioethics; the second as a codified international bioethics document; and the third as something with a mixed character: a human rights and bioethics instrument. Besides reviewing and evaluating these interpre-

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1 This paper includes some reflections on Andorno’s paper, but draws extensively on my experience with the consultative processes of preparing the declaration. As Chief of the Bioethics Section at the Social and Human Sciences Sector of UNESCO, between 2004 and 2005 I had an occasion to follow closely the different phases of drafting of the UNESCO Declaration on Bioethics and Human Rights and to draft the Explanatory Memorandum to the Declaration.
tations, I would like to support the view that the Declaration is first and foremost a policy instrument which does not really add new rights and new elements to international biolaw and human rights but still serves as an important political agreement on encouraging Members States to develop ethics teaching and ethical review in various fields of their activity. Moreover, the Declaration also provides bioethics with non-normative perspectives: by emphasizing the social, educational, institutional and international dimension of bioethics.

II. BIOETHICS AND HUMAN RIGHTS: COMPETITORS OR ALLIES?

I think to assess the relevance and novelty, as well as the potential conceptual weaknesses of the UNESCO Bioethics Declaration, the difference between bioethics and human rights law should be elaborated. One should raise the question: what is the consequence when an international instrument claims to be a declaration of bioethics and human rights at the same time? Can we consider this document as a written codification of bioethics or shall we consider it as an international human rights instrument that follows the long tradition of a special branch of law, namely human rights? Or has UNESCO created something in between?

Roberto Andorno hints in the title of his presentation that this declaration is a step towards international biolaw. I believe that the contours of an international biolaw already existed before the UNESCO Declaration was formulated and in this respect we share the same view that numerous previous legal documents, binding or soft laws provided abounding materials for international biolaw.\(^2\)

More recently, there has been a tendency in medical ethics to seek coherence with the language and norms of international human rights on a global level. As Thomas Faunce suggests, when medical boards, clinical and research ethics committees begin to publish their interpretations, these publications will gradually build up a global ‘common law of medical ethics’ (Faunce 2005, p. 177).

In assessing the Universal Declaration on Bioethics one cannot avoid dealing with the question of what is the link between human rights and bioethics. Is it necessary that the two will merge in the long run? Should they compete for the same domain? Or are they fundamentally different? According to George Annas, the boundaries between bioethics, health law and human rights are permeable, and border crossing is common (Annas 2005, p. 159). Legal cases often constitute a basis of ethical analysis and dilemmas of bioethics increasingly reach courts.

\(^2\) In his forthcoming publication in the Journal of Medical Ethics Roberto Andorno states that the Universal Declaration on Bioethics and Human Rights is an important step in the search for global bioethical standards.

Sometimes violation of human rights occurs when a basic principle of bioethics is infringed. George Annas refers to the Charleston drug screening program in which the test results of urine tests were passed on to the police and, consequently, pregnant women were arrested and charged with drug possession if their pregnancy was 27 weeks or less, and with possession and drug distribution if the pregnancy was 28 weeks or more. Criminal cases were not initiated if doctors would not breach the principle of confidentiality.

Some people advocate for a marriage between human rights and bioethics. I think a fusion between the two is problematic not only from a disciplinary but also from a practical perspective. Moreover, I think that disciplinary differences also have practical dimensions: though people often refer to any right as a human right, rights in the Civil code or even in a national constitution are not necessarily human rights.

So far there has been very little agreement on the content of international or universal bioethics. With the new UNESCO Declaration the situation may change and the document may serve as basic reference and the same purpose as the Universal Declaration of Human Rights after the Second World War. At the moment, however, no one could argue that schools of bioethical thinking or professional codes have the same degree of influence as international human rights.

Though bioethics and bio(medical) law have mutually borrowed statements, norms, principles and perhaps even methods from each other, I believe that the majority of scholars and theorists regard ethics and law as two distinctive disciplines. Law typically operates with binding norms; most of the legal documents have been formulated in concrete norms rather than principles (principles in law regularly serve as tools in helping the interpretation in the lack of concrete norms). Ethics, including bioethics, however, usually promotes ethical sensitivity and often remains on the level of principles that may be balanced against one another in cases that are treated as ‘hard cases’; laws are based on regulated democratic decision-making practices in pluralist societies; the winning norm, however, does not any longer have this pluralist characteristic. Ethics necessarily involve pluralism even in the phase of ethical decisions. As different schools compete, various kinds of answers can be given to specific problems. For instance, utilitarian bioethics focus more on the outcome of the ethical decision-making while deontological ethics provides answers that are based on moral duties.

Furthermore, unlike in the case of law, where certain specific and consistent terminologies and techniques of interpretation have developed, schools of ethics use legal categories divergently if not inconsistently. For lawyers, to take an example, the distinction between persons and things, property and possession, rights and interests are extremely important and these categories can not be used interchangeably. In ethics, the notions of property, ownership, and person are used often in a symbolic sense and in a slightly different context than in the law. For
example, while most legal systems claim that only already born human beings are persons, Christian bioethics may consider the foetus as a person regardless the dominant legal view.

One of the most influential regional instruments for Europe is the Oviedo Convention that—though it relies on bioethics—provides not only ethical principles but also some concrete legal norms in its formulation and structure. Moreover, neither in its title nor in its content claims that is a bioethical instrument; it confirms instead that it can be regarded as a special human rights instrument in the field of biomedicine.

The Oviedo Convention includes many quite specific norms, such as in case of predictive genetic tests in Article 12 of the Convention:

Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counseling.

Before someone positioned me among the hard core legal positivists, I want to emphasize that I feel very strongly about the ethical component of laws. I believe that good laws should be based on the careful analysis of the social impacts, including ethical impact of the laws. Without ethical analysis laws would not achieve any form of social justice and they would fail in the long run.

Up till now, the ethical component in laws related in the field of biotechnology and biomedicine are often overlooked. People often ask "does law deal with ethics? "Many people react with surprise, amusement, or cynicism when they see those two words: law and ethics together in the same sentence" (Scott 2000, p. 245). Being aware of the distinctive features of the two disciplines, I believe laws should be based on a multi-phase assessment. Normally, this assessment includes a feasibility study, concerning the economic impact of the norms, but it should be based on a wider consideration of the harmony with already existing social and ethical norms within the society. In this sense, ethics and law cannot be separated; a strong criticism based on ethical consideration should not be simply swept aside based on the fact that it is a different discipline. But also vice versa, an ethical code that disregards law and even do not provide the minimum protection that the law already provides would not be acceptable in a society.

III. THE MODERN REGIME OF HUMAN RIGHTS

The modern regime of human rights began in the aftermath of the Second World War. The Universal Declaration of Human Rights, adopted by the UN General Assembly in 1948 was a direct response to the atrocities of the war. Even now human rights still have a reactionary character, meaning that it responds to the past abuses and develops legal mechanism and norms that will prevent similar atrocities in the future.

Perhaps that was the reason why some decades after the Second World War, growing scepticism could be observed in relation with the effectiveness of human rights, especially after the breakdown of the state-socialist regimes in Central and Eastern Europe. Severe violations of human rights silenced or ignored came into light—such as the violation of rights on the Gulag archipelago or the execution of teenagers after 1956 in Hungary—but these violations still did not provoke significant international attention until recently. During the war in Yugoslavia the attitude gradually changed. It has become evident that international human rights legislation will not be effective unless specific provisions for enforcement and compliance are introduced. After September 11, based on the discourse on the newly introduced constraints on privacy and liberty rights, attention towards human rights increased world-wide. Similarly, though the disputed interpretation of religious freedoms and cultural diversity recently challenged the universality of human rights but in the same time these confrontations also raise awareness towards the importance of human rights.

Now human rights courses at universities enjoy again popularity and it seems that human rights regained their prominent role. It is true, however, that references to human rights do not everywhere enjoy the same status and significance. Moreover, a stronger consideration of cultural diversity (and cultural relativism) recently posed new challenges to the universality of human rights. Some critique is based on the way human rights instruments are adopted. Member States in various international bodies are represented by a delegation of the executive branch of power (government experts) and the legislative branch of power (Parliament) may only be involved in a later phase of ratification.

Despite these difficulties and criticism, human rights instruments enjoy strong recognition and even political influence in various domains. In the minimalist sense they are indicative of an international consensus in certain domains.

IV. THE CONTEMPORARY NOTION OF BIOETHICS

Bioethics is a much more recent field, although it preserved some continuity with the ancient Greek medical ethics. By now it is certain that bioethics is not only a field of (usually interdisciplinary) study but it refers also to international and national norms adopted usually not by the legislator but by professional bodies, ethics committees, national consultative institutions. Many professional bodies
play a significant role in drafting legislation as their suggestions and proposals often serve as a basis of law. However, on the national level, a distinction can (and should) be made between norms that have a legal significance and enforceable norms that are important but lack legal enforceability.

In its short history, the term bioethics has at least two different meanings, one wider than the other. The term was used for the first time by Potter (with a background in biology) in 1970 (Van Rensselaer Potter 1971, 1988). He advocated a comprehensive and global view of bioethics, as the moral analysis of the present and future of life. Hellegers, on the other hand, used the term ‘bioethics’ for the first time in an institutional way for an academic field of learning and a movement regarding public policy and the life sciences. Bioethics in this view is a new way of approaching and resolving the moral conflicts generated by the new scientific and technological advances in medicine. This more restricted view has become dominant in the theory and practice of bioethics.

V. ANALYSIS OF THE UNESCO DECLARATION ON BIOETHICS AND HUMAN RIGHTS: BIOETHICS DIMENSION

One of the most important characteristics of the Declaration is that it applies principles instead of concrete rules. Though principles are often used in bioethics, even in comparison with the two previous declarations adopted by UNESCO, in this instrument generalized, guiding principles can be observed. Guiding principles can serve as sources of legislation but in comparison with concrete rules, principles would better comply with the rapid advances and changes in biomedical sciences. Ethical principles always require further interpretation since the norms implicit in principles have to be translated into concrete rules.

The ancient ethical codes were often expressed in the form of an oath. One of the most well known oaths, the Hippocratic oath has already defined some principles that have become the basis of early ethics teaching worldwide. However, modern bioethics is indisputably grounded on the values enshrined in the Universal Declaration of Human Rights. But other texts of different legal force have established rules for the protection of persons in the wider field of biomedicine. The principle-based approach encompasses various schools of ethics, including the deontological as well as the utilitarian theories (Joseph Fletcher, Richard M.

Hare, Peter Singer, among others). Furthermore, the rule–principle distinction was elaborated not only in ethics but also in legal theory. According to Ronald Dworkin (Dworkin 1977, p. 24), rules are applicable in an all-or-nothing fashion, while principles do not operate in this manner. Principles have a dimension that rules do not have, the dimension of weight and importance.

Moreover, principles do not determine legal outcomes in all cases in which they apply, though they can influence legal outcomes through adding normative weight to one outcome as opposed to another. Beauchamp emphasized:

That neither rules nor judgments can be deduced directly from principles, because additional interpretation, specification, and balancing of the principles are needed in order to formulate policies and decide about cases. (Beauchamp 2001, p. 480)

Since the landmark work by Beauchamp & Childress (2001), the principles of biomedical ethics play a very important role in studying ethics, analyzing cases, and making legal policy in the field of various biomedical issues. Although these principles were contested and challenged many times, the approach seems to be still a useful tool. Principles often provide warrants for more specific rules, which specify more concretely the type of prohibited or required action. (Childress 2001, p. 61–71) However, in the field of new technologies (assisted reproduction, genetic testing, gene therapy, and so on) there is an ongoing debate on to what extent these principles can be used, interpreted or further developed. Since the first publication of Beauchamp and Childress’ four basic principles in 1979 (respect for autonomy, non-maleficence, beneficence and justice) laws, policy documents often refer to new principles inconsistently.

VI. HUMAN RIGHTS DIMENSION

In many Articles of the Declaration strong elements of human rights can be observed, especially in Articles 3, 6, 9, 11, 27, and 28. It is not surprising at all as the Preamble has already made an attempt to establish a continuum with the previously adopted human rights norms relevant in the scope of the Declaration.

§1. HUMAN DIGNITY

During drafting the Declaration and based on the public consultation, human dignity was recognized as a principle of general importance from which further principles, such as the principle of autonomy, can be derived.
Consensus on the actual content of the human dignity concept appears to be rather limited. Nevertheless, even though it poses considerable problems to put the principle into practice, the principle has recently enjoyed currency in the biomedical and legal contexts (Gewirth 1992, p. 10–28). For example, the concept is employed fifteen times throughout the *Universal Declaration on the Human Genome and Human Rights*. In the present Declaration human dignity is recognized as a fundamental, core principle upon which other principles rest. Respect for human dignity flows from the recognition that all persons have unconditional worth, each having the capacity to determine his or her own moral destiny (Hill 1992, p. 49). To disrespect human dignity would allow for treating a person merely as a means (Beyefeld & Brownword 1998, p. 662). Although, at least in the continental Europe, respect for human dignity is part of constitutional rights, in the UNESCO Declaration it seems to refer to ethics as it is distinguished from human rights. (“Human dignity, human rights and fundamental freedoms are to be fully respected.”

§2. NON-DISCRIMINATION AND NON-STIGMATIZATION

The prohibition of discrimination has been elaborated in various legal instruments and one of the most eloquent and pioneer statements can be found in Article 6 of the *Universal Declaration on the Human Genome and Human Rights*. This article introduced a new ground of discrimination and stimulated similar legal instruments worldwide to prohibit discrimination based on genetic characteristics.

Discrimination, both in its direct and indirect forms, treats a morally neutral and immutable characteristic (such as skin colour, gender, genetic or similar characteristics) as having a negative impact and, based on that illegitimate distinction, similarly situated individuals are treated differently. In addition to various forms of discrimination, stigmatization is also prohibited by the declaration.

The history of medical research shows—even in the recent past—a disturbing pattern of discrimination against different groups, including ‘races’, ethnic minorities, and women. During the conceptualization of research and the establishment of control groups, culturally, morally or legally problematic categories may be used, and the avoidance of discriminatory practices requires communication between the relevant disciplines.

5 Immanuel Kant (1964) *Groundwork of the Metaphysic of Morals*, transl. by H.J. Paton (New York: Harper Torchbooks). In Thomas Hill’s interpretation: “Dignity cannot morally or reasonably be exchanged for anything of greater value, whether the value is dignity or price. One cannot then, trade off the dignity of humanity in one person in order to honor a greater dignity in two, ten, or a thousand persons.”

6 Article 3 of the Declaration.

7 Article 11 of the Declaration.

The elimination of discrimination is to be attained in the different areas of health care, biomedical research and health policy formulation. Not only the direct forms of discrimination (when one group of individuals is positioned in disadvantageous situation) but also the various indirect forms should be eliminated.

Discrimination may distort scientific progress. For instance, the routine exclusion of women from research trials has led to the fact that many of the conditions specific to women remained unknown or uninvestigated and that discoveries that were applicable to men were simply assumed to be applicable for women patients. There are many similar instances affecting stigmatized or disenfranchised groups.

Stigmatization often lingers even after the discriminatory laws and policies are abolished, but it may also occur before discrimination is manifested in more direct forms. While prohibition of discrimination can be more easily targeted by legal instruments, elimination of the stigma requires a longer process of social transformation in which ethics and ethics teaching can play a significant role.

VII. HUMAN RIGHTS AND BIOETHICAL (COMMON) DIMENSIONS

Following the Second World War, numerous provisions have been formulated within human rights law that not only repeated and confirmed principles of bioethics but also integrated with them. One of the well-known principles, the principle of autonomy and informed consent is also stated in numerous international laws. *The UN Covenant on Civil and Political Rights* (1966) states in Article 7:

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

§1. CONSENT

*Informé consent* is a fundamental element of contemporary bioethics. The right of individual self-determination has been the basis for court decisions in favor of informed consent of competent patients to health care procedures affecting themselves. Though the doctrine of informed consent is largely a creation of court decisions, it rests ultimately on ethical foundations.

8 Article 7 of the UN Covenant on Civil and Political Rights.

9 Article 6 of the Declaration.
Informed consent is perhaps the best known principle of contemporary bioethics. But it is also well known in cases of personal injury. In some countries even before it has become a norm in bioethics it appeared in the practice of the courts, for example in the common law system a patient could sue the doctor if the doctor treated him/her without prior consent.

Article 6(1) requires prior, free, informed and express consent of the persons concerned. This consent may be withdrawn at any time and for any reason. The term 'free' means voluntary consent 'without inducement'.

According to Article 6(2) regarding a decision or practice related to medical diagnosis and treatment the person concerned must receive appropriate information about the decision; must participate; and must consent. Although the requirement of express consent for diagnosis and treatment is under normal circumstances too stringent, as a general rule—as reflected in other international and various national legal instruments—an affected individual has to receive relevant, structured and individually tailored information that makes it possible for the individual to make a decision on whether or not to accept medical treatment, as well as to understand and cope with the diagnosis.

It is an important provision of the Declaration that consent may be withdrawn by the person concerned at any time and for any reason without any disadvantage or prejudice. Exception to this principle should be made according to national laws and in accordance with this Declaration.

Article 7 states that special protection shall be given to persons who do not have the capacity to consent. Such protection shall be based on ethical and legal standards, consistent with the principles set out in this Declaration and adopted by States. The domestic law of Member States should provide for consent to be given by members of the family, an official or court where the person concerned is incapable of doing so.

Some recent advances in science, such as genetic testing for late onset diseases, have raised increasing concerns about the right not to be informed. As the Declaration deals with bioethics in general, this issue was regarded as too detailed to be included among the principles. Article 5(c) of the Universal Declaration on the Human Genome and Human Rights already recognized this right by stating that:

[i] the right of each individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected.

A special Article, Article 10 is dedicated to this question in the International Declaration on Human Genetic Data, titled 'The right to decide whether or not to be informed about research results'.

The articles on consent and on persons without the capacity\textsuperscript{10} to consent are subjects of much criticism. Some people such as Anna Gercas argued that issues of non-therapeutic research carried out on children should follow the existing human rights norms as the UNESCO Declaration seems to be too narrow to protect them (Gercas 2006, p. 629).

\section{Privacy and Confidentiality\textsuperscript{11}}

Similarly to consent privacy and confidentiality have been recognized both by law and bioethics and as a consequence they appeared both in international human rights, as well as in bioethical norms.

A right to privacy guarantees a control over personal information in many ways. It restricts access to personal and medical information and it provides a claim of non-interference in various private spheres of the individual. Privacy extends beyond data protection, as certain private spheres of the individual that are not manifested in data processing can also be protected by the right to privacy.

Confidentiality refers to a special and often fiduciary relationship, such as that between researcher and research subject, or doctor and patient, and provides that the shared information shall remain secret, confidential and shall not be disclosed to third persons, unless a strictly defined, compelling interest justifies disclosure under domestic law.

Special methods and approach of bioethics can be seen in Articles 5, 17, 18, and 26. In addition to a number dual instruments there are several articles that extend the scope of bioethics and include also protection of environment, bioosphere and social responsibility.

\section{Equality, Justice and Equity\textsuperscript{12}}

Article 10 deals with three notions closely connected with one another. 'Equality' in a legal sense refers to the equal treatment of individuals in a similar situation while the term 'equity' refers to a discretion, which serves as a corrective mechanism to formal equality by looking at the special circumstances of particular cases. 'Justice' in the philosophical sense is a normative principle that refers to a judgment on the arrangement of institutions, society, groups of (or?) individuals.

A common definition of justice could be 'treating the equal equally and the unequal unequally'.

\textsuperscript{10} Articles 6 and 7 of the Declaration.

\textsuperscript{11} Article 9 of the Declaration.

\textsuperscript{12} Article 10 of the Declaration.
Principles of justice are essential to the structure of a constitutional democracy. Fairness and due process are part of democratic legal systems mandated by international human rights law and are closely related to the foundations of human rights. In addition to the general meaning, principles of justice play an important role in many decisions and practices in the field of bioethical issues, such as in allocating health care services and setting priorities in health care, both in general and in individual cases. Justice is included among the basic principles advocated by Tom Beauchamp and James Childress.

VIII. TWIN PRINCIPLES

One specialty of the Declaration is that many of its principles are drafted in pairs, such as human rights and human dignity, benefit and harm, autonomy and individual responsibility. Out of the fifteen principles of the declaration ten principles are formulated in this fashion. While the principle to respect autonomy stands alone in other bioethical norms, autonomy here is linked to social responsibility. “The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected.” This approach gives a collective dimension of the otherwise individual consent.

§1. AUTONOMY AND INDIVIDUAL RESPONSIBILITY

Respect for personal autonomy is strongly linked to and, according to certain interpretations, derives from the notion of human dignity. It is directly derived from binding international human rights law. Individuals cannot be instrumentalyzed and treated merely as means to a scientific end; they should be granted the authority to make autonomous decisions in all aspects of their lives where their decisions do no harm to others.

Respect for autonomy involves not just a respectful attitude but also respectful action. However, autonomy, in this interpretation, is not simply an invested right. It also has the dimension of responsibility towards others. Article 9 reflects the right of each person to make individual decisions, whilst at the same time respecting the autonomy of others. Some experts wanted to reinforce the emphasis on responsibility by including a reference to the duty to take such responsibility. However, this formulation seemed to be too forceful and might indicate a possible erroneous interpretation of autonomy which is not a synonym of ‘freedom’ or ‘liberty’. Autonomy refers to the concept of acting in accordance with voluntarily accepted principles but it does not liberate the individual from taking responsibility for his or her actions.

§2. BENEFIT AND HARM

These twin principles have clear connection to the classical principles beneficence and non-maleficence. And indeed, the original title of this Article until the Fourth Public Outline of the Declaration was ‘Beneficence and Non-maleficence’. However, during the IBC-IGBC Joint Session held in January 2005, a general position developed favouring the avoidance of the use of these terms for two reasons. One was that these terms are not used by either policy-makers or the general public in various cultures and languages. Second, the two principles that originated from the ancient maxim of ‘do good’ and ‘do no harm’ (primum non nocere) mean something different when they are combined together. Therefore, the principle was changed by stating that any decision or practice shall seek to benefit the person concerned and to minimize the possible harm resulting from that decision or practice.

§3. RESPECT FOR CULTURAL DIVERSITY AND PLURALISM

Article 12 refers not only to ethical pluralism but also to cultural diversity on a global scale. Therefore this Article strengthens also the bioethics dimension of the Declaration. Human rights instruments aim to develop universally acceptable norms. They usually take into account cultural diversity when they deal specifically with cultural diversity and their main aim is to protect and promote diversity itself.

Recently some changes can be observed as Francesco Francioni noted that:

International law has not remained indifferent to this dynamic of culture within the State and between the States. Protection of minorities, as addressed in post World War 1 peace treaties and ad hoc treaties, has helped deconstruct the sovereign State by

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13 First sentence in Article 5 of the Declaration.
14 Article 5 of the Declaration.
legitimizing the claim to an international status of culturally distinct groups. (Francioni 2004, p. 1209)

Cultural diversity refers to the manifold ways in which the cultures of different social groups and societies find expression. From the diverse forms taken by culture over time and space stem the uniqueness and plurality of the identities and cultural expressions of the peoples and societies that make up humankind.

Respect for cultural diversity requires careful implementation. If ethical standards are dictated and simply copied in various legal systems, without adequate interpretation and adaptation, they may remain as mere legal transplants that will not function properly with other elements of bioethical principles in a given country. Therefore, the existence of cultural diversity, the importance of cross-cultural perspectives and the principle of pluralism are recognized by the declaration.

According to the Universal Declaration on Cultural Diversity of UNESCO, diversity reflects the uniqueness and plurality of the identities of the groups and societies making up humankind. As a source of exchange, innovation and creativity, cultural diversity is as necessary for humankind as biodiversity is for nature.

During the written consultation process, some countries expressed their fear that respect for cultural diversity could easily be used to override any other moral consideration. The text of the declaration therefore adds the proviso (as in the Universal Declaration of Cultural Diversity) that this principle cannot be used to limit the application of the other universal principles:

Such considerations shall not be invoked to infringe upon human dignity, human rights and fundamental freedoms nor upon the principles set out in this Declaration, nor to limit their scope.

If universal values are to enjoy widespread support and democratic validation and be free of ethnocentric biases, they should arise out of an open and uncoerced cross-cultural dialogue. (Parekh 1999)

From Articles 27 and 28 of the declaration it also follows that cultural diversity cannot call into question universal human rights.

IX. BROADER DIMENSIONS OF THE DECLARATION

So far I tried to explore the human rights and bioethics separate and common dimensions with the Universal Declaration. One conclusion that can be drawn from this analysis is that by applying broad principles the bioethics dimension seemed to be a stronger element in the declaration. However, the reference to discrimination, human dignity, the consent rules and reliance to human rights instruments show the human rights dimension of the declaration. In the following pages I would like to demonstrate that in addition to these two major elements further policy dimensions can be observed and they constitute perhaps the strongest and in some places the most innovative parts of the declaration.

While some critics argued that UNESCO conducted too expensive consultations, others argue that the political strength of the document lies in the multi-phased consultation process. The expert meetings and consultative discussions started at the beginning of 2004. The first questionnaire was launched and sent out on January 20, 2004. The purpose of this round was to gather preliminary views from Member States on the possible scope and structure of the future declaration by means of a questionnaire. On April 27–29, 2004, an Extraordinary Session of the International Bioethics Committee (IBC) was held with the title 'Towards a Declaration on Universal Norms on Bioethics'. The aim of this extraordinary session was to conduct hearings with concerned stakeholders starting with a debate on the scope and structure of the future declaration. This allowed IBC to have a complete overview of all convergent and divergent views when drafting the first outline of the future declaration. The Extraordinary Session was organized around hearings of representatives of intergovernmental organizations, international non-governmental organizations and national bioethics committees.

Also in April 2004, during the 169th Session of the Executive Board of UNESCO, the EB confirmed its support to the elaboration of a declaration on universal norms on bioethics and approved the timetable for its elaboration proposed by the Director-General in consultation with the Bureau of the IBC and the Intergovernmental Bioethics Committee (IGBC). On 30 April 2004 the Drafting Group of the IBC had its first meeting. This Drafting Group was entrusted with the elaboration of a declaration on universal norms on bioethics.

On June 2–3, 2004 the IBC Drafting Group held its second meeting, which resulted in the first outline of the declaration. On June 24–25, 2004 the UN Inter-Agency Committee on Bioethics discussed the scope and content of the first outline of a text of the future declaration. At the end of this meeting and upon a proposal put forth by UNESCO, the Inter-Agency Committee decided to include in the agenda of its fourth meeting an item on the outline of the future declaration. On July 7, 2004 the IGBC held a meeting to gather information on the progress of the elaboration of the declaration.

The IBC Drafting Group held its third meeting on July 8–9, 2004 and elaborated the second outline of a text of the future declaration. On 23–24 August 2004: Eleventh Session of IBC representatives Confucianism, Judaism, Hinduism, Islam, Buddhism and Catholicism. In October 2004 further written consultation was conducted accompanied by Rotation Conferences. On February, 2005
the IBC finalized and approved the Preliminary Draft Declaration. On June 20–24, 2005 the Second intergovernmental meeting of experts finalized the draft Declaration. This meeting was conducted not only in English and in French but in all six working languages of UNESCO.

Looking at the brief history of the complicated drafting and political consultation process, the policy elements of the Declaration cannot be overlooked. The Declaration therefore does not represent an elitist, top-level bioethics or human rights instrument, rather it aims to seek consensus and raise awareness towards bioethical issues in a broader context of policy-making.

In the following, therefore, I proceed to examine these broader dimensions that are stated mainly in the Section on ‘Application of the Principles’ and in the Section on ‘Promotion of the Declaration’.

X. EDUCATIONAL DIMENSION

Although bioethics education necessarily belongs also to the bioethics dimension, Article 23 goes far beyond the mere statement and claims that States “should endeavor to foster bioethics education and training at all levels as well as to encourage information and knowledge dissemination programs about bioethics.” Thus, the Article deals specifically with bioethics education, training and information. This is not just a simple recognition of a relatively new discipline but it has also a broader policy dimension. The overall objective of the Article is to reinforce and increase the capacities of Member States in the relevant area of ethics education. In addition to this specific Article basically the entire Declaration serves also educative purposes.

XI. INSTITUTIONAL DIMENSION

§1. ETHICS COMMITTEES 20

Article 19 embraces both ethics and bioethics committees, on different levels and in different fields of research ethics; policy-making, quality assurance, and peer-review committees; utilization review and risk management committees; and scientific-review committees.

This reflects a current trend in which bioethics committees, however officially named, are beginning to accept a broader mandate, covering not only the ethical issues related to medicine and the life sciences, but also the ethical issues generated through the advances of science and technology in general. The Declaration intends to reinforce the role of such ethics committees in the fields within the scope of the declaration, including the domain of research ethics, and, furthermore, to strengthen the role of such committees in their interpretation of the principles of bioethics. In this respect, such committees have an essential role to play in the implementation of the declaration.

The need for independent, multidisciplinary and pluralist committees has already been stated in many documents. The declaration emphasizes the importance of these criteria for assessing the ethical, legal and social issues related to scientific research projects and technological development and for the development of guidelines and recommendations, in accordance with the principles set out in the declaration.

§2. ROLE OF STATES 21

When the Declaration addresses states it applies the word ‘should’ instead of ‘shall’, since the declaration cannot impose obligations on states in their activities to implement the declaration. The present declaration provides principles that may serve as contours for legislation, regulation, and policy decisions within the Member States. The interpretation and implementation of these principles require the active participation of States. Accordingly, the Declaration invites Member States to take appropriate measures, to encourage the establishment of ethics or bioethics committees, and to create processes for risk assessment.

XII. SOCIAL DIMENSION

In the first two Declarations in the field of bioethics, UNESCO tackled the major ethical problems related to genetics. In 1997 UNESCO reacted exceptionally fast to the challenges of the human genome project 22, to the debate on the access to human genome and reinforced the prohibition on the grounds of genetic characteristics. In 2003 UNESCO responded to the ethical challenges of creating huge biobanks and DNA collections by reinforcing the rights of confidentiality and privacy 23.

However, these two declarations have not covered many of the basic issues of bioethics. The 2005 Declaration, on the other hand, not only discussed these fun-

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21 Article 22 of the Declaration.
23 International Declaration on the Human Genetic Data adopted in 2003.
damental bioethical issues but went further and extended the scope of bioethics in the field of social matters.

In the following paragraphs I would like to illustrate this new dimension by referring to some Articles of the Declaration.

§1. SOLIDARITY AND COOPERATION

Article 13 reflects the commitment that the Declaration is based not only on the individualist concept of rights but also recognizes the importance of solidarity between individuals and across communities.

Serious inequalities in access to health care worldwide increase the importance of including solidarity as one of the principles of the declaration. The idea of collective social protection and fair opportunity should be a governing principle in policy decisions and it is an essential element of a population-based ethics.

Furthermore, in the planning of health care systems special attention should be paid to vulnerable groups, such as minorities and indigenous people, by providing access to reproductive health services available according to law and to children in guaranteeing their access to health care.

Cooperation between and among individuals, families, groups and communities, with special regard for those rendered vulnerable, should be of special concern in the making of relevant decisions and the establishment of appropriate practices within the scope of this declaration.

§2. SOCIAL RESPONSIBILITY

The Preamble to the Declaration expressed the need for a new approach to social responsibility to ensure, whenever possible, that progress in science and technology contributes to justice, equity and to the interest of humanity. The expression of the social responsibility principle is designed to address the attention of policy makers in the field of medicine and life sciences to the practical concerns of bioethics, as viewed in most States and by general public.

Article 14 is included in the Declaration in order to reflect a new agenda for bioethics, taking into account a wider social dimension of scientific progress. The recognition of reproductive health and the health of children is one element of this dimension. The relevance of reproductive health can be seen by looking at health statistics: every year some eight million women suffer pregnancy-related complications and over half a million die.

Elimination of the marginalization and exclusion of persons on the basis of any ground, including gender, age, ethnicity and disability was recognized as different from the elimination of discrimination as stated in Article 11. Marginalization may be a result of discrimination, although not necessarily. Marginalization of a group of individuals may have disadvantageous consequences in the field of health, such as insufficient access to information, to health services and to the benefits of scientific development.

§3. SHARING BENEFITS

Article 15 includes a very important element of this social dimension by stating that benefits resulting from any scientific research and its applications should be shared with society as a whole and within the international community, in particular with developing countries. In points from a) to g) it further specifies the form in which benefit sharing can be realized. Sharing of benefits often appears in various legal documents on genetic resources. In its Article 1, the United Nations Convention on Biological Diversity emphasizes:

Fair and equitable sharing of the benefits arising out of the utilization of genetic resources, including by appropriate access to genetic resources and by appropriate transfer of relevant technologies, taking into account all rights over those resources and to technologies, and by appropriate funding.

Furthermore, Article 12(a) of the Universal Declaration on the Human Genome and Human Rights states that:

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

The International Declaration on Human Genetic Data devotes a special Article, Article 19, to the sharing of benefits and provides a useful tool for identifying various forms of benefits. Article 14 of the 2005 Declaration closely follows the structure of that Article.

The bioethics Declaration goes beyond the scope of genetics by including the sharing of benefits resulting from scientific research and its application in general. Of course, such sharing will in practice take place within the framework of international law and domestic law governing such matters. See Article 30.

24 Article 13 of the Declaration.
25 Article 14 of the Declaration.
26 Article 15 of the Declaration.
XIII. LEVEL OF INTERPRETATION

The questions related to the nature of the Declaration are reflected also in the dilemmas of interpretation, as well. Human rights laws have established methods of interpretation: textual, logical, structural, and historical. When certain rights are restricted, the principle of proportionality is in use. In the field of bioethics different schools have developed different methods of interpretation, thus when principles are interpreted, some kind of balancing has to be applied.

Article 26 provides a method of interpreting principles. “This Declaration is to be understood as a whole and the principles are to be understood as complementary and interrelated.” This method is partly similar to the model offered by Childress and Beauchamp named ‘balancing principles’ (Beauchamp & Childress 2001, p. 18). According to Childress and Beauchamp, principles require both balancing and specification and both perspectives address a dimension of moral principles and rules: weight or strength, in the case of balancing, and range and scope, in the case of specification. The UNESCO Declaration is not just a bioethics instrument but also a political one. It is based on the consensus made by the Member States with various backgrounds of political regimes. Perhaps because of this diversity, this Declaration applies a much broader scope for balancing and there is no specific weight given to human dignity or any other principle. “Each principle is to be considered in the context of the other principles, as appropriate and relevant in the circumstances.”27

XIV. CONCLUSION

I believe the UNESCO Declaration on Bioethics and Human Rights created a slightly new and perhaps controversial situation with respect to the division between bioethics and human rights. However, putting aside conceptual difficulties, I argue that the Declaration offered a very important political ground for the development of bioethics worldwide. The intention was not only to encourage the institutionalization of academic bioethics—although stimulating ethics teaching in various level was a clear motivation behind the declaration—but also to inspire the development of a new approach, that in the future may be called as bioethics-mainstreaming on various levels of decision-making. I believe that this is the most important achievement.

If someone uses the standards of international human rights or ‘pure’ bioethical norms, very little new can be seen from that angle, however if someone regards its policy aspects, I think the Declaration would have a very important contribution by focusing on new, policy dimensions of bioethics.

LITERATURE


