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Bioethics and Human Rights

HUMAN RIGHTS AND BIOETHICS: COMPETITORS OR ALLIES? THE ROLE OF INTERNATIONAL LAW IN SHAPING THE CONTOURS OF A NEW DISCIPLINE

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Abstract: Bioethical norms that had constituted only a rather short chapter in the medical curricula are now integrated into universal human rights. This paper seeks to demonstrate the normative convergence between the fields of bioethics and human rights by discussing the recently adopted relevant international documents and some applicable cases from international law. Human rights case law relevant in this emerging legal domain is analyzed with the aim to tackle changes that have occurred in the fields of human rights and bioethics due to the convergence and interdependence between them. Bioethics and human rights are two different systems of norms but bioethics can enrich human rights by extending the traditional catalogue of rights in certain new fields. The theory of human rights nevertheless dictates some discipline in formulating new and new rights. Therefore it offers to bioethics, as an exchange, a more sufficient enforcement mechanism and international recognition.

Keywords: Human rights; international law; UNESCO; Oviedo Convention

INTRODUCTION

issues have emerged from the closed domains of academic circles and have appeared at the stage of international law, followed by increasing public attention. Bioethical norms that had constituted only a rather short chapter in the medical curricula are now integrated into universal human rights norms. A new kind of bioethics has emerged that does not merely describe ethically good or bad conduct, along with the presentation of underlying arguments and analysis, but

It has become evident over the course of the past fifteen years that bioethical

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also uses the language of rights and frequently formulates norms very similarly to human rights instruments. In some cases, bioethics is even disguised as human rights, and partly codified as rules of conduct to be abided by, forming an organic part of international law.

It should be stated as a preliminary remark that bioethics as such is not regarded as automatically transferable to human rights, not even in a codified form. But it is more and more common that bioethical norms take over legal expressions or even concrete legal techniques used in human rights instruments. In our days, the two domains cannot be considered entirely distinct any longer since various legal issues – such as the protection of research subjects, the rights of psychiatric patients or the rules on informed consent – have become already organic parts of both regulatory fields.

This paper seeks to demonstrate the normative convergence between the fields of bioethics and human rights by discussing the recently adopted relevant international documents and some applicable cases from international law. Human rights jurisdiction relevant in this emerging legal domain will be examined to judge the applicability of bioethical norms. Thus, it will be possible to identify the changes that have occurred in the fields of human rights and bioethics due to the convergence and interdependence between them.

Bioethics in the United Nations

As regards international bioethical norms, a UN specialized agency, UNESCO, the United Nations Educational, Scientific and Cultural Organisation, has been dealing with the ethics of science ever since 1970. In 1993 the International Bioethics Committee¹, a body of independent experts started to operate and the activity of this committee made UNESCO the key actor within the UN institutional framework in the field of bioethics. Such a priority role facilitates the reduction of parallel activities within the UN, and also entails higher financial support for this key area. As a further consequence, the priority role is also reflected in the so-called standard setting activities.

^{1.} The International Bioethics Committee (IBC) is a body comprising 36 independent experts. It has been in operation since 1993. IBC is the only UN body involved in bioethics. It does not adopt legally binding resolutions. Former IBC Chairs were Noëlle Lenoir, previously Justice of the French Constitutional Court; Japanese law scholar Ryuichi Ida and Canadian Deputy Minister of Health Michèle Jean. The present Hungarian member is György Kosztolányi paediatrist, Member of the Hungarian Academy of Sciences.

Over the course of the past ten years, the UNESCO Member States have adopted three significant, though not binding, international declarations in the fields of bioethics and human rights. The first such declaration from 1997 is titled *Universal Declaration on the Human Genome and Human Rights*² and it makes a clear reference to the Universal Declaration of Human Rights, one of the foundational documents of the United Nations. The *International Declaration on Human Genetic Data*, the second document from 2003, is also frequently cited in court cases. The latest of the three, the 2005 *Universal Declaration on Bioethics and Human Rights* was adopted unanimously on the 33rd Session of the General Conference of UNESCO.

Though this latter declaration sets general principles only, its importance is proven by the numerous references that have been made to it in various contexts. Thus, Article 6 of the Universal Declaration on Bioethics and Human Rights on "Consent" has been cited in the *Evans case*³ by the European Court of Human Rights among the "relevant international instruments," together with the *Convention on Human Rights and Biomedicine* of the Council of Europe.

Bioethics in the Council of Europe

Though the European Convention on Human Rights had been adopted as early as 1950, bioethics was codified at this level only in 1997. This bioethics convention was adopted under a fairly complicated title: *Convention for the Protection of Human Rights and the Dignity of the Human Being with Regard to the Application of Biology and Medicine, adopted by the Council of Europe in Oviedo, on April 4, 1997: Convention on Human Rights and Biomedicine* (hereinafter referred to as the Oviedo Convention). The Oviedo Convention of the Council of Europe has become the legally binding international bioethical norm. The significance of the Oviedo Convention is enhanced by the fact that since 1997, 21 states have ratified the Convention and further 13 states have signed it. 5

^{2.} The authoritative Hungarian translation is available in Világosság, vol. 40, no. 2 (1999).

^{3.} Evans v. the United Kingdom case; application no. 6339/05; judgement made on April 10, 2007.

^{4.} The Convention entered into force on December 1, 1999.

^{5.} As of July 2007.

The European nature of the document is expressed by the emphasis laid on *human dignity* as the fundamental value in biomedicine. Many authors attribute this approach to French influences. Susan Millns⁶ claims that the triad of *fundamental rights*, *human dignity* and *biomedicine* is rooted in French law. Indeed, the French act on bioethics was adopted in 1994, and the Explanatory Report to the Convention⁷ was drafted with significant contributions from Jean Michaud, a member of the French National Consultative Ethics Committee, who was at that time the chair of the Steering Committee on Bioethics of the Council of Europe (Comité Directuer pour la Bioéthique or CDBI).⁸

Article 2 of the Oviedo Convention states a frequently quoted principle that has also been inserted into other documents since then: the *primacy of the human being*. A separate chapter deals with consent, a key principle of bioethics. Article 5 sets out the general rule that a health intervention may only be carried out after the person concerned has given *free and informed consent* to it.

It is important to note that at the time when the Convention was being drafted, international attention was focused primarily on the new challenges posed by human genetics and genetic technologies. As a result, a separate chapter on the human genome has been included (Chapter IV). Pursuant to Article 11, any form of discrimination against a person on grounds of his or her genetic heritage is prohibited. One of the most specific norms is stated by Article 12, which entails, among other things, a prohibition to use genetic information for insurance purposes.

The Convention recognizes the *freedom of research*, but in all cases subject to the necessary conditions for conducting research as stated therein. Most debated among the member states is Article 18 on research on embryos *in* vitro

Considering the provisions in Article 26 it is rather difficult to imagine that some states have found certain rules of the Convention too strict, even though

^{6.} Susan Millns (2007) Consolidating Bio-Rights in Europe, in Francesco Francioni (ed.) *Biotechnologies and International Human Rights* (Oxford and Portland, Oregon: Hart Publishing), pp. 75–84.

^{7.} The official text is available at http://conventions.coe.int/Treaty/en/Reports/Html/164.htm

^{8.} This ethics committee consists of Member State delegates and operates next to the Council of Europe.

this Article allows for a fairly wide scope of restrictions. According to the Article concerned, the exercise of the rights and the related protective provisions contained in the Convention may be restricted as prescribed by law where necessary in a democratic society in the interest of public safety, the prevention of crime, the protection of public health or the protection of the rights and freedoms of others. Notwithstanding the above, no restrictions may be placed on Articles 11, 13, 14, 16, 17, 19, 20 and 21 of the Convention.

The Convention provides only for the minimum level of bioethical protection, and does not restrict or affect the possibility for any Signatory State to grant wider protection with regard to the application of biology and medicine than is stipulated therein.

A major procedural principle contained in Article 28 also determines the way for legislation by stating that the fundamental questions raised by the developments of biology and medicine should be properly discussed in public debate, in particular, in the light of the relevant medical, social, economic, ethical and legal implications, and any potential practical application should be subject to appropriate professional consultations.

Bioethics Case Law at the European Court of Human Rights

Since the Oviedo Convention entered into force, regular references have been made in the case law of the European Court of Human Rights to the European standards of bioethics. Naturally, this does not mean that there had not been previous cases that were partly related to bioethics. In several cases prior to 1997, e.g. in cases regarding abortion, DNA paternity testing or the rights of psychiatric patients, the Strasbourg Court had encountered bioethical dilemmas much before the Oviedo Convention was adopted. Nevertheless, the Oviedo Convention has obviously given a great impetus to the development of uniform interpretations in this field. Though no independent, internationally enforceable sanctions are available for the violation of the Convention, it is obvious that the European Court of Human Rights takes into consideration the provisions of the Oviedo Convention when interpreting European standards.

Pursuant to Article 23 of the Oviedo Convention, Member States shall provide appropriate judicial protection to prevent or to put a stop without delay to any unlawful infringement of the rights and principles set forth in this Convention. Although no independent judiciary forum is set up for the purposes of the Oviedo Convention, at request, the European Court of Human Rights may give

a consultative opinion, regardless of any judiciary proceeding, in legal questions in connection with the interpretation of the Oviedo Convention.

In most cases, issues concerning bioethics fall within the scope of Article 8 of the Convention on Human Rights. Determination of paternity and descent also requires the interpretation of Article 8, for instance in cases where the father had refused to submit himself to a DNA test, due to which the determination of the child's descent was drawn out for an unreasonably long period of time. The Court's interpretation for Article 8 leaves a wider margin of appreciation for the member states.

A parallel Article of the Oviedo Convention with regard to the same subject is Article 10, which provides for the protection of private life and the right to information. Pursuant to that, everyone has the right to respect for private life in relation to information about his or her health. Everyone is entitled to know any information collected about his or her health. At the same time, where a person wishes not to be so informed, that wish should be observed as well. In exceptional cases, in the patient's interest, the Act may restrict the exercise of the rights specified in paragraph 2.

The Pretty v. the United Kingdom⁹ case, a case that arose in connection with the authorization of assistance in suicide, could have become a typical instance for the legal recognition of bioethical dilemmas; still, the Court refrained from going beyond the legal approach, and based its judgment mainly on case law. In the Pretty case, the judges of the Strasbourg Court investigated whether the prohibition of active euthanasia violated Article 2 of the Convention on Human Rights. The 43-year old applicant was suffering from a serious degenerative disease due to which she was paralyzed from the neck downwards. She requested the Court to give an authorisation for her to end her life in dignity and to guarantee her husband freedom from prosecution if he assists her in committing suicide. She claimed that the right to life also includes the right to self-determination in life-related issues. Consequently, life is a right and not an obligation. Similarly to her reliance on the right of life, the applicant's other reference that the prohibition of euthanasia interfered with the individual's rights to private life under Article 8 was also unsuccessful. She claimed that, besides the free choice of lifestyle, Article 8 also comprises the free choice of the way of ending life.

^{9.} Pretty v. the United Kingdom case; application no. 2346/02; judgement made on April 29, 2002

Ms. Pretty further cited Article 14 of the Convention on Human Rights claiming that due to the mere fact that the nature of her disease prevented her from ending her life in dignity, and because she required others' assistance to do so, she was deprived of the exercise of this important freedom in a discriminative way.

In similar cases involving new biotechnologies, the Court's interpretation has been less straightforward, and, in addition to the traditional answers based on human rights and constitutional law, bioethical norms have been cited more frequently. A splendid example for that is the Evans case. The case *Evans v. the United Kingdom*¹⁰ concerns the right of disposal over embryos.

In this case, the applicant turned to the Strasbourg Court because, according to British law, her ex-partner was entitled to prohibit the further storing and utilisation of the embryos provided by the two of them. The claimant held that this qualified as a violation of Articles 2, 8 and 14 of the Convention on Human Rights. The brief description of the case is as follows. The applicant's eggs had been retrieved, as it was still possible to do so before both ovaries had to be removed due to bilateral ovarian cancer. Both partners had signed the prior informed consent, and then eleven eggs were retrieved by which six embryos were successfully created. However, in 2002, the couple separated. The man reported this, and requested the destruction of the embryos. The clinic informed the claimant of the man's wish, adding that pursuant to law, such a statement entailed the destruction the embryos.

The applicant held that the British law, by permitting the withdrawal of the man's consent, and thus the elimination of the embryos, violated several articles of the Convention on Human Rights, including those on the right to life, the right to private life, and the right to family life. The appeal court confirmed that the fundamental principle of the 1990 British Act required that the consents from both partners should be effective for the entire duration of the treatment.

The applicant argued that being deprived of the right to carry to term the already existing embryos is disproportionate to the harm caused to her ex-partner's private life that involves that he must accept his becoming a genetic father in spite of his changed opinion.

The Court drew up a detailed comparison of the applicable legal solutions in

^{10.} Evans v. the United Kingdom case; application no. 6339/05; judgement made on April 10, 2007.

the member states of the Council of Europe. Under the heading "relevant international norms", the Court made reference to Article 5 of the Oviedo Convention. This provides that "A health intervention may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may withdraw consent at any time."

Further references were made to the principles set by CDBI in 1989, and Article 6 of the 2005 UNESCO Declaration. ¹¹ The quoted provisions, if at all relevant to the exercise of the right of disposal over frozen embryos, imply that the implantation and carrying of the embryo created from a sperm and an egg is a medical intervention, what is more, it should be considered as a medical intervention performed on two persons simultaneously, thus the creation of the embryo requires consent from both.

The case *Vo v. France* attracted great international attention as it pointed towards the possibility of giving an even higher level of protection to the life of the fetus, corresponding to the protection granted under Article 2 of the Convention on Human Rights. ¹² Evidently, this would have influenced the court judgments in cases connected with abortion, and would also have called into question the Europe-wide consensus on the legal interpretation of the human being.

The case originated in the consequences of a name-swap. Two Vietnamese patients were waiting in consultation hours in a French hospital. Though their names were different, the French doctor perceived them as very similar to each other. While the 6-month pregnant Ms Thi-Nho Vo, the later applicant in the case before the Strasbourg Court, was waiting for a check-up examination, Ms Thi Thanh Van Vo came to see this doctor in order to get her intra-uterine contraceptive device removed. The doctor attempted to carry out the intervention on the pregnant patient, having mistaken her for the other woman. As a result of the intervention, the amniotic sac ruptured. The applicant had to be taken

^{11.} Article 6 – Consent states that "any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information. The consent should, where appropriate, be express and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice."

^{12.} Everyone's right to life shall be protected by law.

into hospital; however, the pregnancy was lost. She initiated a court action in France on grounds of manslaughter. The doctor was convicted of negligent assault by the Criminal Court of Lyon, and later he was given amnesty. The French government held that Article 2 of the Convention on Human Rights was not applicable to the negligent extinguishing of a yet unborn child's life.

The case drew increased attention because the applicant assumed that the loss of her viable fetus due to her doctor's negligence was to be considered as a violation of Article 2 of the Convention on Human Rights, and the French authorities had imposed a sanction that was disproportionate to the protection of life.

The Court quoted the relevant sections of the Oviedo Convention under the heading "European law". France signed the Convention as early as in 1997, the year of its adoption, but still has not ratified it. The reference to the Oviedo Convention does not provide much guidance in this regard. Even though the start date of human existence is being debated in bioethics, similarly to the status of the embryo or the fetus, this Convention does not reflect any newer or more detailed approach than the Convention on Human Rights does. Nevertheless, the Court analysed several provisions of the Oviedo Convention, including Article 1 on "The aim of the Convention, Article 2 on "The primacy of the human being," Article 18 on "Research on embryos" and Article 19 on "The interpretation of the Convention." It also touched upon the Additional Protocol that prohibits human cloning. In addition, it is evident from the Explanatory Report that, even though the Oviedo Convention does not define the term "everyone" ('toute personne'), this term has the same meaning here as in the Convention on Human Rights.

Still, it can be stated that the bioethical implications are formulated rather vaguely in the *Vo case*, as it is hard to understand why the rules on embryonic research in vitro are relevant to the death of a 6-month old fetus due to the doctor's negligence. However, Article 18 of the Oviedo Convention is also cited among other international norms, even though different bioethical and legal rules are applicable to research and examination, and a fetus is not the same as an embryo outside the body (also called *in vitro* embryo), which is created in an extraordinary reproductive procedure.

The increasing role of bioethics can be shown by the fact that, for the purpose of drafting this judgment, the European Court of Human Rights also considered the 2003 working documents of the CDBI, a body operating next to the Council

of Europe, and it further relied on the 1998 opinion delivered by EGE, a body operating next to the European Union.

According to the standpoint of the government, Article 2 was not applicable to a child yet unborn. However, the applicant argued that by excluding the possibility that a negligent abortion qualified as manslaughter, the French law was in violation of Article 2 of the Convention on Human Rights. Relying on evidence from natural sciences, the applicant held that today it is beyond doubt that human life does start with conception. If the law refuses to recognise the human existence of a fetus, it could be stated in the case concerned that the pregnant woman had not suffered any loss due to the negligence, which assumption is naturally unacceptable. However, the French government held that neither a metaphysical, nor a medical answer is available to the question concerning the point in time from which a human being should be legally considered as a person.

In any case, the Court, by referring to its earlier abortion-related judgments, recognised that this case was different from the aspect that the woman here concerned had not intended to interrupt her pregnancy, and the fetus was lost due to the doctor's negligent act. Precisely for the above reason, the main question was whether the extinguishing of the life of a fetus could be criminally sanctioned on grounds of the provision set forth in Article 2, which states that everyone's right to life is protected by law. Eventually, by a voting of 14 against 3, the Court ruled that Article 2 of the Convention had not been violated in the case.

In another case that concerned the deterioration of eyesight caused in connection with pregnancy, no reference whatsoever was made to the Oviedo Convention. The *Tysiac v. Poland* case¹³ investigated the prohibition of abortion due to medical indication, from the aspect of Article 8 of the Convention. It is true that the Oviedo Convention does not deal with abortion; still, also in this case, references to the Convention could have been based on the issues on informed consent, and the dignity and primacy of the individual just as well. Poland has not ratified the Convention either, yet it is evident from previous cases that this fact in itself should not be an obstacle, and the court may take the Convention into consideration as a part of the European law. The brief description of the case is as follows. The Polish applicant requested several medical examinations

^{13.} Tysiac v. Poland case; application no. 5410/03; judgement made on March 20, 2007.

during her pregnancy due to her serious nearsightedness and retinal disorders. Earlier, she had given birth two times by Caesarean delivery but during her third pregnancy she feared that due to further deterioration of sight, she would lose sight entirely if she had to carry her pregnancy. For that reason, she sought ophthalmologic opinion on several occasions. Still, none of the experts supported the termination of pregnancy even though they did perceive that the woman's sight was indeed severely endangered. Eventually, the applicant gave birth to her third child by Caesarean section. Within a few weeks after the child's birth, the applicant's sight was seriously deteriorated. Forensic experts stated that she had become seriously disabled, as a result of which she required permanent assistance. The applicant filed a criminal claim for grievous bodily harm against her former ophthalmologist. She claimed that the lack of proper expert opinion prevented her from requesting abortion, and due to having carried the pregnancy to term, she suffered serious deterioration of sight. Having found that the commitment of a criminal offence was not justified, the Court terminated the proceeding. Even the causal relationship between the delivery and the eye sight deterioration was disputed. Finally, the judges of the Strasbourg Court ruled by 6 votes against 1 that Article 8 of the Convention had been violated.

Similarly, no reference whatsoever was made to the Convention on Bioethics in *Gajcsi v. Hungary*¹⁴, a Hungarian case concerning psychiatric treatment, despite the fact that Hungary had ratified the Oviedo Convention. However, in this case, the Health Care Act served as a sufficient basis for the determination of the violation of law.

The *Glass v. United Kingdom* case¹⁵ concerns a cornerstone of bioethics, the interpretation of informed consent in case of patients not able to consent. The circumstances of the case show an extreme conflict between the patient's family and the doctors. The applicants, a minor having serious mental and physical disability and his mother initiated a court claim due to treatment performed in an English hospital without prior consent. The physicians of the English hospital ordered the administration of a great dose of diamorphine despite the expressed opposition of the minor's mother. The doctors found that the child's condition had been hopeless, and even though the family protested against

^{14.} Application no. 34503/03; judgement made on October 3, 2006; final 03/01/2007

^{15.} Case of *Glass v. United Kingdom*. Application No. 61827/00; judgement made on March 9, 2004.

the administration of diamorphine in an adult dose, taking into account the child's condition, they considered that this would be in his best interest. When the family found that the child's condition had deteriorated, and he was being covertly subjected to euthanasia, a fight broke out. Several family members attacked the doctors who got injured but, in the meantime, the mother successfully resuscitated her dying child. The child's condition improved and, in the end, he could leave the hospital. The applicants requested a statement that by taking measures contrary to the disposition of the representative, the doctors had violated Article 8 of the Convention.

In this case, in addition to the ethical guidelines of the British Medical Association and the British case law, the Court made references to Articles 5 to 9 of the Oviedo Convention. It should be mentioned though that these Articles are cited here without any further comments, not even the Explanatory Notes attached to the Convention are included. The Convention on Bioethics is mentioned in the part about the "relevant international material". As a matter of fact, Great Britain has not even signed the Convention on Bioethics, thus, "international" is a proper designation, and the term "material" is obviously wider than the term "international law" would be.

The applicants claimed that the English law had not given sufficient protection against injuries to private life in violation of Article 8, as it had been possible to give morphine or its derivatives to the child although the mother had expressed her opposition to that. The applicants further submitted that in cases where there is such a great discrepancy between the representative's and the doctors' opinion, it is not understandable why the dispute should be resolved in favour of the doctors. Such disputes should rather be resolved before court. Eventually, the Court stated unanimously that Article 8 of the Convention had been violated in the case.

CONCLUSION

On the whole, it can be stated that the inclusion of bioethical norms into human rights norms has not resulted in the collision of such norms, nor has it enhanced the relativity of international law. It must be conceded that consequent references to the Oviedo Convention have only been made in recent years in court, in particular by the European Court of Human Rights, and even then it was not mentioned as a legal norm but as a general standard accepted by most member states of the Council of Europe. At times, it is cited as an international document,

then as a European document, or expressly as relevant law. The assessment of the text has been uncertain as to whether it is ethical or legal in nature, yet it seems to have become indispensable to refer to it in cases having bioethical implications. Regardless of the fact that a number of Western European states, including Germany, France and the United Kingdom have not ratified the Convention, the Court has cited it in cases concerning such countries with equal relevance. It is important to mention that the Convention has generated disputes in most countries; thus, the lack of signing and ratification is not due to simple omission but should rather be seen as the consequence of concrete standpoints.

It is obvious that bioethics can only be successfully inserted into human rights norms if more and more such norms, formulated in accordance with the principles of human rights, become widely accepted that may be applied to concrete interventions. The content of the Oviedo Convention is being extended by Additional Protocols.

But one has to see that bioethical norms are frequently formulated as general principles. This does not mean that, in the case of such texts, the principles applied in the interpretation of law could be disregarded. These principles include grammatical, logical, systematic, historical and teleological interpretation. Accordingly, where grammatical interpretation of a bioethical norm clearly indicates that the norm is only applicable to a certain type of biomedical research, it may not be interpreted in a broader sense either. It is possible that the Oviedo Convention and also the legally not binding UNESCO Declaration would be taken more seriously if only the relevant provisions were cited. It seems that while some countries refer to the Oviedo Convention systematically, some others fail to apply bioethical norms even in cases where bioethics could provide some guidance in the interpretation of general human rights provisions.

In most cases, when the European Court of Human Rights determined a wider margin of appreciation for the member states with regard to the violation of Article 8, a sensitive ethical dilemma was involved. If, in the future, even more European norms shall be set in bioethical issues, it will remain to be seen whether this exerts an influence on judicial practice. The question depends mainly on the assessment of such norms by the European Court of Human Rights. If it regards these as belonging to the scope of human rights instruments, this would allow reliance on them to a much greater extent. However, seen as a part of bioethics, since ethical norms are regarded as a set of plural or at least divergent views as opposed to the enforceable legal instruments, they could not serve as

the basis for restricting the scope of deliberation, and would remain only one set of norms from among all other valid aspects to be considered.

Bioethics and human rights are two different systems of norms. Bioethics can enrich human rights by extending the traditional catalogue of rights in certain new fields. The theory of human rights nevertheless dictates some discipline in formulating new rights. Therefore it offers to bioethics, as an exchange, a more sufficient enforcement mechanism and international recognition.