Central European University  
Department of Legal Studies  
Academic year of 2005/ 2006  
5th Module  
1-credit  

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HUMAN RIGHTS AND BIOETHICS: A NEW GENERATION OF RIGHTS?  
Course Description  

Bioethics encompasses increasingly important norms in areas such as reproductive and end-of-life issues; biodiversity and environmental protection; genetic testing, biobanks, and genetic data storage. Bioethical norms also seek to regulate the conduct of scientific research; the access to and safety of technology solutions; the availability and quality of medical services, essential medicines, and other preconditions for health.

Although bioethics and international human rights have developed separately, some aspects of bioethics have recently been interpreted along human rights principles. The interrelation of the two disciplines provides an exciting excursion into a new legal and ethical domain.

International bioethical norms—even if they appear in the form of a convention—lack enforcement and often even implementation mechanisms. Human rights, although they are though enforceable, also frequently rely on non-binding bioethical norms.

During the course the students will analyze normative texts and cases that contain elements from both the human rights and bioethics perspectives. The Reader and the attached bibliography shall provide the basic literature for further studies. The course will develop legal and policy skills in the students who will have the opportunity to discover a new and rapidly developing field at the intersection of human rights and bioethics.

Course requirements

Students are required to participate in the discussion of the legal and policy issues implicated in the cases. Reading assignments and the schedule of the course are enclosed in the detailed syllabus. Course requirements include attendance at lectures and seminars.
Form of the exam: Written in-class exam.
1. March 30, 2006

Introduction

Principles of Biomedical Ethics and the Right to be informed


Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine of 4 April 1997 (“Bioethics Convention” or “Oviedo Convention”)
[http://conventions.coe.int/Treaty/EN/cadreprincipal.htm](http://conventions.coe.int/Treaty/EN/cadreprincipal.htm)

Recommended

Beauchamp, TL and Childress, Jf, Principles of Biomedical Ethics, 1994 Oxford University Press


Cases:


2. April 6, 2006

Right to life and Dignity: Frontiers of life


Recommended:


Cases:
Vacco et al. v. Quill et al.117 S. Ct.2293 (1997) 
Vo v. France 

3. April 11, 2006 

Right to health, right to health care 

Cases: 


Raymond Kohll v Union des Caisses de Maladie (Case C-158/96) [ 1998] 1 All ER (EC) 673, [1998] 2 CMLR 928 

4. April 13, 2006 

Confidentiality of medical information 


Cases: 

Doe v. Marselle 675 A.2d 835 (Conn. 1996) 
Case of Z. v. Finland 25/02/1997 

5. April 18, 2006 

Reproductive rights 
Corine Packer, The Right to Reproductive Choice A Study in International Law pp. 14 - 42 
Mary Warnock, Making babies, Is there a right to have children? Oxford University Press, 2002 pp. 27-84. 

Cases: 
Evans v. United Kingdom 

Recommended:


6. April 20, 2006

Rights beyond the body: cells, tissues and samples


Cases:
Netherlands (supported by Italy and another) v European Parliament (Case C-377/98)
Moore v. The Regents of University of California 793 P.2d 479 (Cal. 1990)

7. April 25, 2006

Global Aspects of Bioethics


Universal Declaration on Bioethics and Human Rights

Appendix

Recommended texts and cases

United Nations System
• Universal Declaration of Human Rights, 1948
• International Covenant on Civil and Political Rights, 1966
UNESCO
• Universal Declaration on the Human Genome and Human Rights, 1997
• International Declaration on Human Genetic Data, 2003
• Universal Declaration on Bioethics and Human Rights, 2005
WHO
• Resolution WHA50.37 (1997) on Cloning in Human Reproduction
• Resolution WHA51.10 (1998) on Ethical, Scientific and Social Implications of Cloning in Human Health
Regional Intergovernmental Organisations

European Union
• Charter of Fundamental Rights of the European Union, December 2000
• European Parliament`s Resolution issued of 7 September 2000 on Human Cloning

Council of Europe
• Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine of 4 April 1997 ("Bioethics Convention" or "Oviedo Convention")

Parliamentary Assembly of the Council of Europe
• Recommendation 1160 (1991) Preparation on a Bioethics Convention
• Recommendation 1425 (1999) On biotechnology and intellectual property
• Recommendation 1468 (2000) On Biotechnology
• Recommendation 1512 (2001) Protection of the human genome by the Council of Europe

Council of Europe Committee of Ministers
• Recommendation R (90) 13 on prenatal genetic screening, prenatal genetic diagnosis and associated genetic counseling
• Recommendation R (92) 1 on the use of analysis of Deoxyribonucleic acid (DNA) within the framework of the criminal justice system
• Recommendation R (92) 3 on genetic testing and screening for health purposes
• Recommendation R (94) 1 on human tissue banks
• Recommendation R (97) 5 on the protection of medical data

A.2.4. European Group on Ethics in Science and New Technologies
In December 1997, the European Commission set up the European Group on Ethics to succeed the Group of Advisers on the Ethical

The current project monitors only those opinions of the Group that are relevant in the field of the research:

- Opinion No.4 13/12/1994 The ethical implications of gene therapy
- Opinion No.6 20/02/1996 Ethical aspects of prenatal diagnosis
- Opinion No.9 28/05/1997 Ethical aspects of cloning techniques
- Opinion No.10 11/12/1997 Ethical aspects of the 5th Research Framework Program
- Opinion No.11 21/07/1998 Ethical aspects of human tissue banking
- Opinion No.12 23/11/1998 Ethical aspects of research involving the use of human embryo in the context of the 5th framework program
- Opinion No.14 14/11/1999 Ethical aspects arising from doping in sport
- Opinion No.15 14/11/2000 Ethical aspects of human stem cell research and use
- Opinion No.16 7/05/2002 Ethical aspects of patenting inventions involving human stem cells
- Report on the new fundamental rights related to technological innovation requested by President of the Commission, Romano Prodi.

National Bioethics Committee Opinions

French National Consultative Commission
N°001
- Opinion on sampling of dead human embryonic and fetal tissue for therapeutic, diagnostic, and scientific purposes.

N°008

N°009

N°016

N°017
- Opinion concerning the dissemination of DNA analysis identification techniques (genetic fingerprinting).

N°018
• Update on studies undertaken by the Committee regarding gamete and embryo donation
N°019
• Opinion on embryo research aiming to achieve pre-transfer genetic diagnosis for which a moratorium was declared in 1986.
N°020
• Opinion on present organisation of gamete donation and its consequences.
N°021
• Opinion that the human body should not be used for commercial purposes.
N°022
• Opinion on gene therapy.
N°024
• Opinion on embryonic and fetal reduction.
N°025
• Opinion regarding the application of genetic testing to individual studies, family studies and population studies. (Problems related to DNA “banks”, cell “banks” and computerisation).
N°027
• Opinion that the human genome should not be used for commercial purposes. Report. Thoughts relating to ethical problems of human genome research.
N°028
• Opinion on blood transfusion with reference to not making commercial use of the human body. Report.
N°030
• Ethical issues raised by mandatory genetic testing for female participants in the Albertville games.
N°031
• Opinion on screening for infection by the AIDS virus.
N°032
• Opinion on whether a trial is required to confirm the efficacy of centoxin.
N°033
• Opinion concerning the identification of patients suffering from glaucoma in France and on chromosomal location of the causative gene or genes.
N°036
N°037
• Opinion on the detection of the risk of fetal trisomy 21 by blood tests in pregnant women.
N°040
• Opinion on the transfer of embryos after the decease of a husband or partner. Report.
N°042
• Opinion on the evolution of practices concerning medically assisted procreation. Report. 
N°045
• Ethical questions arising from the transmission of scientific information concerning research in biology and medicine. Report. 
N°046
• Opinion and recommendations on “Genetics and medicine: from prediction to prevention”. Report. 
N°052
• Opinion on the creation of human embryonic organ and tissue collections and their use for scientific purposes. 
N°053
• Opinion on the establishment of collections of human embryo cells and their use for therapeutic or scientific purposes. Report. 
N°054
• Reply to the President of the French Republic on the subject of reproductive cloning. 
N°058
• Informed consent of and information to persons accepting care or research procedures 
N°060
• Re-examination of the law on bioethics. 
N°061
• Ethics and xenotransplantation. 
N°064
N°67
• Opinion on the preliminary draft revision of the laws on bioethics. 2001-01-N°072
Opinion on Reflections Concerning an Extension of Pre-implantation Genetic Diagnosis, 2002-07-04 
N°68
• Congenital handicaps and prejudice 
N°69
• Medically assisted reproduction for couples presenting a risk of viral transmission 
N°70
• Consent for the benefit of another person 
N°71
• Opinion on functional neurosurgery for severe psychiatric disorders 
N°72
• Reflections Concerning an extension of preimplantation genetic Diagnosis 
N°74
• Umbilical cord blood banks for autologous use or for research
N°75
• Ethical questions raised by the development of ICSI
N°76
• Regarding the obligation to disclose genetic information of concern to the family in the event of medical necessity
N°77
• Ethical issues raised by collections of biological material and associated information data: “biobanks““biolibraries”
N°82
• Composite tissue allotransplantation (CTA) of the face (Full or partial facial transplant)
N°83
1. Generalised prenatal screening for cystic fibrosis
N°85
• Information regarding the risk of blood transmission of Creutzfeldt-Jakob disease
N°86
• Problems connected to marketing self-test kits for HIV screening and diagnostic disease
N°87
• Treatment refusal and personal autonomy
N°88
• Age determination methods for legal purposes.
N°89
• Opinion on preservation of the bodies of foetuses and still-born infants. Reply to a referral from the Prime Minister.

The Italian National Bioethics Committee
• Bioethical guidelines for genetic testing 19 November 1999
• Opinion of the national bioethics committee on the European protocol on biomedical research 19 November 1999
• Declaration on the possibility of Patenting human embryo cells 25 February 2000
• Opinion of the national bioethics committee on the therapeutic use of stem cells 27 October 2000
• Protection of the human embryo and foetus The Italian National Bioethics committee statement concerning the preliminary draft Protocol of the bioethics committee of the council of Europe 31 March 2000

Nordisk Komité for Bioetik
• Opinion from The Nordic Committee on Bioethics on “Ethical issues in human stem cell research.” 10–11 October, 2000.

British Advisory Committee on Genetic Testing (ACGT)
• Code of practice and guidance on human genetic testing services supplied direct to the public
• Advice to Research Ethics Committees - Points to consider in ethical review of medical research involving genetic testing, October 1998.
• Report on Prenatal Genetic Testing

http://www.drze.de/
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