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COMMITTEE ON BIOETHICS
COMITE DE BIOETHIQUE
(DH-BIO)

Developments in the field of bioethics
in member states and other states
Développements dans le domaine de la bioéthique
dans les Etats membres et les autres Etats

1 This document contains contributions in their original language. / Ce document contient les contributions dans leur langue d’origine.
**TABLE OF CONTENTS**

**TABLE DES MATIERES**

BELGIUM/BELGIQUE ................................................................. 3
DENMARK/DANEMARK ................................................................ 3
FINLAND/FINLANDE ................................................................. 4
GERMANY/ALLEMAGNE ............................................................. 4
GREECE/GRECE ........................................................................ 5
ITALY/ITALIE ............................................................................. 7
SAN MARINO/SAN MARIN ......................................................... 8
BELGIUM/BELGIQUE


Désormais, un mineur doté de la capacité de discernement qui se trouve dans une situation médicale sans issue de souffrance physique constante et insupportable qui ne peut être apaisée et qui entraîne un décès à brève échéance, et qui résulte d’une affection accidentelle ou pathologique grave et incurable, peut demander une euthanasie. Contrairement à ce qui est prévu pour une personne majeure, le législateur ne permet pas au mineur de demander une euthanasie pour une souffrance psychique, ni pour un décès qui n’est pas prévu à brève échéance.

Concernant les modalités, un pédopsychiatre ou un psychologue doit s’assurer de la capacité de discernement du mineur. Les représentants légaux du mineur (ex. parents ou tuteur) doivent quant à eux marquer leur accord sur la demande du patient mineur.

Précisons que cette extension de l’euthanasie aux mineurs ne concerne pas la rédaction d’une déclaration anticipée relative à l’euthanasie. Cette dernière permet à une personne de consigner par écrit, pour le cas où elle ne pourrait plus manifester sa volonté à l’avenir (ex. coma), sa volonté qu’un médecin pratique une euthanasie si les conditions légales sont remplies. Pour rédiger une telle déclaration, il faut toujours être majeur ou mineur émancipé.

DENMARK/DANEMARK

In the beginning of 2014 Danish Council of Ethics published a statement regarding the use of antibiotics. The statement aims to qualify the public debate on how to deal with the threat from rapidly growing resistance to antibiotics. The statement can be read on this webpage:


In December 2013 the Danish Council of Ethics has published a report regarding "International trade in human eggs, surrogacy and organs". In the report the Danish Council of Ethics looks at the ethical dilemmas associated with medical tourism, which involves Danes buying human body parts in other countries. The three cases, trade in human eggs, surrogacy and organs, have been selected because they differ in respect of some ethically significant parameters in terms of what might be called injury, including loss of function, to the person providing them. The statement can be read on this webpage:


Furthermore it can be mentioned that the Danish Government this spring is planning to introduce bills regarding the possibility for transgender people to carry out a “legal sex change” without castration/sex change operation. If the bills are passed the “legal sex changes” can be carried out by sending an application to Ministry of Economic Affairs and the Interior and if the applicant after a six months reflection period upholds the application, the person will receive a new social security number and be registered with the chosen sex in the Danish Civil Registration System.
FINLAND/FINLANDE

Government Bill on the new Self-determination Act:

The bill includes a proposal to enact a new law on strengthening the right of self-determination of social welfare clients and patients and on conditions for use of limitation measures (Self-determination Act). The proposed act would provide for strengthening the right of self-determination in social and health care services as well as for the conditions for use of limitation measures in connection with health care. The proposed act would also contain provisions on supervision and legal safeguards relating to the use of limitation measures.

The objective of the new act is to strengthen the right of self-determination of clients and patients and to reduce the use of limitation measures in social and health care. Even in situations where the use of limitation measures would be allowed as the last-resort means to provide social and health care in accordance with the law, the measures should always be dimensioned correctly and the mildest possible method should be chosen.

It is proposed that the provisions on limitation measures under the Self-determination Act should not be applied to the treatment against a person's will under the Act on Social Work with Substance Abusers, the treatment and examinations against a person's will under the Mental Health Act and the combating of communicable diseases under the Communicable Diseases Act. These provisions would neither be applied to child welfare, except for the provisions on a person's right of access to a home or other place of residence in order to find out the person's state of health or need for social welfare.

The service provider should promote the implementation of the right of self-determination in the context of the services provided to a client or patient. The new Self-determination Act would also include provisions on assessment of the client's or patient's ability of self-determination and on planning regarding the individual right of self-determination. At the latest when a client's or patient's ability of self-determination has been determined to be reduced in the way referred to in the act, an individual plan should be drawn up for the client or patient and appended to the plan in accordance with the Act on the Status and Rights of Social Welfare Clients or the Act on the Status and Rights of Patients.

The Self-determination Act would lay down provisions on the general conditions for use of limitation measures, such as requirements for necessity and proportionality and respect for human dignity. The act would also contain provisions on particular conditions to be imposed on each measure. The new act would also contain provisions on the procedure to be observed in making a decision or other solution regarding a limitation measure.

In connection with enactment of the Self-determination Act new provisions would also be added to the Act on the Status and Rights of Social Welfare Clients and the Act on the Status and Rights of Patients regarding provision of support in decision-making.

The purpose is that the proposed acts enter into force on 1 November 2014.

GERMANY/ALLEMAGNE

The German delegation would like to inform you, that the English version of the opinion of the German Ethics Council on "The future of genetic testing - from research to clinical applications" now can be found under the following link: http://www.ethikrat.org/files/opinion-the-future-of-genetic-diagnosis.pdf
Opinions -Recommendations - Reports
The Hellenic National Bioethics Commission has recently issued:

- a Recommendation on the issue of Do-Not-Resuscitate Orders: o study the issue, the Commission held relevant hearings with members of the scientific community
- an Opinion on the Management and Burial of Embryos Less Than 180 Days of Gestation, Human Body Parts and Cadaveric Preparations
- an Opinion on the Control of Non-Invasive Clinical Trials for Drugs
- an Opinion and a Report on Human Enhancement: effect on cognitive and mental state. According to this Report "Many psychiatric, neurodegenerative and neurodevelopmental disorders coexist with abnormalities in "normal" cognitive and mental functions. Autism, intellectual disability, attention deficit disorder, schizophrenia, depression but also neurodegenerative diseases, such as Alzheimer’s, Parkinson’s and Huntington's chorea, are associated with impairment of cognitive functions. Aging of the brain also leads to similar effects. The continuous and rapid scientific developments make it possible, to some extent, to intervene in the development of these diseases and delay their symptoms, mainly through pharmaceutical substances that aim to enhance cognitive functions. Therefore, the moral issue raised here, is whether these pharmaceutical substances could be used in healthy people in order to enhance their cognitive and mental characteristics". To study the issue, the Commission held relevant hearings with members of the scientific community
- a Recommendation on Participation of midwifes in artificial termination of pregnancy
- a Recommendation on the issue of Control on Medically Assisted Reproduction: although in Greece there is an exemplary legal framework (Act 3089/02 and Act 3305/2005, this has not been completely enacted. This gap has led to the inactivation for a long time of the National Authority of Medically Assisted Reproduction and consequently to illegal practices including trafficking of women, commercialization of ova donation, use of illicit drugs etc. The Recommendation recommended the urgent reactivation of the National Authority which indeed took place recently.

Activities: Bioethics goes to schools
The Commission organizes educational activities for schools (Secondary Schools and High Schools) related to bioethics

Educational Seminars
The Hellenic National Bioethics Commission for the second consecutive year, organizes educational seminars, which cover a wide range of critical issues including human reproduction, applications of genetics, clinical studies, euthanasia, cloning and nanotechnology.

The seminars are addressed to undergraduate and graduate students, doctors, biologist, lawyers, educators, health professionals, social scientists, journalists, and those who are simply interested in the ethical and social consequences of the scientific progress. Prominent guest scientists present a lecture every two weeks, followed by an open discussion. The program will run from January to June 2014.

Events
Life, Society and Nature before the challenges of Biosciences, discussion-event (27-01-2014)
Direct-to-consumer genetic tests, Meeting (17-01-2014)
Medical Liability and Bioethics II, Conference (14-03-2014)
Current activities
Accreditation of genetic laboratories/centers
Weekly meetings with patients associations

II. Legislation /Policy

Convention on Rights of Persons with Disabilities.
Greece ratified the Convention with Act 4074/2012. Relevant discussions had already started in the legal circles in order to achieve clarification, the National Federation of Persons with Disabilities has established a collaboration with the Centre of European Constitutional Law, the aim of which will be the further investigation of compatibility of Greek legislation with the UN Convention and the possibility of restructuring of certain Greek policies and laws under the prism of the Convention’s provisions.

National Action Plan on Human Rights
Under the auspice of the Ministry of Justice took place the finalization of the National Plan on Human Rights. The official launching of the document however, met with severe criticism from various NGOs as well as from the Greek Society for Human Rights. The criticism mainly focused on the insufficient reference to issues of domestic violence, mental health, trafficking of human beings and racism.
ITALY / ITALIE

Opinions issued by the Italian National Committees for Bioethics

I. Year 2014

- Pediatric Biobanks
- Lifestyles and protection of health

Year 2013

- Health “within the walls”
- Conjoined twins and separation surgery: bioethical aspects
- Mental disability in developing age and autism
- Intensive care unit "open" to family visits
- Illegal trafficking of human organs from living donors
- Donation of the corpse for scientific research
- Neuroscience and pharmacological cognitive enhancement: bioethical aspects
- Human rights, medical ethics and enhancement technologies in military contexts

Abstracts and complete texts, translated in English, available on the website http://www.governo.it/bioetica/eng/motion.html

Normative framework

On heterologous fertilization

Recent judgment delivered by Italy’s Constitutional Court (the publication of its reference number is underway) modifying Article 4 of Law 40/2004, whereby lifting the ban on heterologous fertilization.

Cross-border healthcare: Legislative Decree approval

December 4th 2013 – The Italian Council of Ministers, upon the proposal of the Minister of Health and of the Minister of European Affairs, approved the final draft of a Legislative Decree implementing Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of the patients’ rights in cross-border healthcare.

Decree-Law 36/2014 – clinical trials of off-label use of drugs

Decree-Law No. 36 of March 20, 2014, « Urgent Provisions governing the use of narcotic drugs and psychotropic substances, prevention, treatment and rehabilitation related to drug abuse problems, referred to in the Decree of the President of the Italian Republic No. 309 of October 9, 1990, and concerning the use of less expensive drugs for the National Health Service» was published in the Official Gazette No. 67 of March 21, 2014.

Surrogacy abroad – The Court of Brescia condemns an Italian couple for alteration of civil status

Contrary to the Decisions issued, in the last months, by the Courts of Milan and Trieste,
the Court of Brescia ruled that any act intended to declare the newborn as the child of a woman different from the one who actually gave birth to the baby constitutes an offence of alteration of civil status, also in the event of a formation of the birth certificate abroad and eventual registration in Italy.

SAN MARINO/SAN MARIN

Public debate:
• On December 2013 was held in San Marino a public panel discussion entitled: “The respect for human rights and the promotion of inclusion”, organized by the Minister of Health and Social Security, by the Minister of Education and Culture, by Institute for Social Security, in collaboration with the National Bioethics Committee of Republic of San Marino.

The UN Convention on the Rights of Persons with Disabilities (2006) marked a reversal cultural approach to persons with disabilities, no longer based on different beliefs and conventions that govern individual countries, but on the universal recognition of the human rights: it is a switch from a policy of assistance to a policy of inclusion and mainstreaming.

The Republic of San Marino was among the first States that have ratified this historical international document in February 2008 and, in the context of the promotion and application of the UN Convention, has taken steps to undertake a number of initiatives in this respect, since document “The bioethical approach to persons with disabilities”, approved by the National Bioethics Committee of Republic of San Marino, on February 25, 2013.

The seminar of December 2013 is placed in this groove, with the aim of illustrating the impact to citizens in the bioethical, cultural, social and political system that involves the promotion of inclusion.

• On April 2014 was held in San Marino a three-day Conference entitled: “Pain and nursing care. Detect, prevent, treat and manage pain” (http://www.assdolore.org/).

The Conference has received the patronage of the National Bioethics Committee of Republic of San Marino, because the treatment of pain takes on a high bioethics value, especially in decision-making process regarding medical treatment in end-of-life situations, also in the light of what is stated in the draft “Guide” of DH-BIO.