



CONFERENCE OF INGOs
OF THE COUNCIL OF EUROPE

CONFERENCE DES OING DU
CONSEIL DE L'EUROPE

SUMMER SESSION HUMAN RIGHTS COMMITTEE

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Strasbourg, 25 October 2016

DRAFT SYNOPSIS OF THE MEETING HELD ON 21 JUNE 2016

FOR THE ATTENTION OF THE MEMBERS OF THE HUMAN RIGHTS COMMITTEE

1. The Chair, Michel Aguilar, **welcomed** the new INGOs and stated that this summer session would be eventful.

The Human Rights Committee:

2. **Adopted** the draft agenda

3. Unanimously **approved** the draft synopsis of the meeting held on 28 January 2016
[\[CONF/HR\(2016\)SYN1\]](#)

4. **Heard** Iamvi Totsi, Vice-Chair of the Committee, on her visit to the Port of Piraeus, Greece, where she had looked into the reality of the living conditions of the refugees who had temporarily settled there. Her statement covered the following:

- Half the Greek population lives below the poverty line. In 2015, approximately 900 000 migrants entered Greece and the country does not have the financial resources to deal with the problem;
- Most of the refugees are Syrian, but they also include Afghans, Iraqis, Somalis and others. The smugglers charge an average of 1000 dollars per person;
- There are not enough doctors to cope with the complexity of the interventions needed;
- Large numbers of refugees are arriving on the Greek islands and the logistics are inadequate;
- The treaty signed in March 2016 by the European Union and Turkey has reduced trafficking. However, it complicates the situation because people are put in the "hot spots".
- Local NGOs (Smile of the Child, Metadrasi, etc.), which do a remarkable job on the ground, must be included in the financing of the different institutions.

Heard more specific information from the Chair concerning his representation of the Conference of INGOs before the Committee on Bioethics of the Council of Europe (DH-BIO). (See Appendix 1 – report by Michel AGUILAR). On this matter, he recalled the importance of the role and place of INGOs in such committees of experts and invited the NGOs to participate in the dialogue and contribute their expertise, which enriched the committee's work.

5. **Noted**, regarding the organisation of side events, that, by January 2017, the Standing Committee would have put in place rules for the improved participation of all INGOs.

6. **Referred to** the vote on the Communication Charter at last January's Conference, establishing precise criteria on the Conference's functioning and involvement in the work of the steering committees and committees of the parties at the Council of Europe, which were likely to give greater visibility to the work of all the INGOs.
7. **Heard** Ion Manole, Executive Director of the organisation "Promo LEX" and member of the International Federation of Human Rights Leagues, on the situation of human rights defenders in Transnistria (Moldova), following the report on the fact-finding visit made by the Chair of the Conference of INGOs last autumn, which had made it possible to establish relations with civil society. In his presentation, Ion Manole highlighted the worrying situation of human rights defenders in the Transnistrian region in the absence of an international legal framework establishing safeguards in that region.

Adopted, with the proposals made by the committee, the draft recommendation on "Protection of Human Rights Defenders in the Transnistrian region of the Republic of Moldova: the case of 'Promo LEX' Association established in the Republic of Moldova", by 33 votes to 3 with 7 abstentions. This draft recommendation would be adopted by the Conference of INGOs on 24 June 2016.

8. **Heard** H  l  ne Garrigues (European Committee for Home-based Priority Action for the Child and the Family, EUROCEF) and Geert Priem (European Council of Police Trade Unions, CESP) on the Council of Europe [Strategy for the Rights of the Child \(2016-2021\)](#), adopted by the Committee of Ministers on 2 March 2016 and presented at the High Level Conference on the subject held in Sofia on 5 and 6 April 2016. The presentation mostly concerned actions taken by the Council of Europe to promote children's rights, based on the international Convention on the Rights of the Child. The following main challenges had been identified: poverty, inequality, violence, a justice system made for adults, familial and parental difficulties, racism, hate speech, radicalisation, growing up in a digital world and migration. The five priority areas which had been retained were: equal opportunities for all, participation for all, a life free from violence, child-friendly justice, the rights of the child in the digital environment.

Decided to establish a working group on "The rights of children", for a three year period, whose aims would be to draw up a compendium of good INGO practice and to put in place innovative actions for the attention of policy makers at the local level.

9. **Heard** Benoit Van Keirsbilck, Director of the NGO "Defence for Children International" (DEI), Belgium, who presented the practical guide drafted within the framework of a project financed by the European Commission and the Council of Europe entitled "[Children's rights behind bars](#)". This Guide, which carries the sub-title "Monitoring places where children are deprived of liberty", aims to reinforce the control mechanisms of all kinds regarding places where children may be deprived of their freedom. Field research had been carried out in 14 European countries in order to analyse the practice and functioning of the control mechanisms, which were moreover few in number, and the complaint mechanisms accessible to young people deprived of their liberty.

The participation of children was also a matter in which the committee took a considerable interest, in particular within the framework of justice systems for minors and for minors deprived of their freedom. On this matter, DEI Belgium had published a book entitled "*Au travers des barreaux*", which analysed the perception of young people deprived of their liberty. In conclusion, he indicated that his organisation had called on the United Nations General Assembly to launch a worldwide study on the situation of children deprived of their freedom. The United Nations had adopted a resolution on this subject in December 2014. [Website of the campaign for the study](#)

10. **Heard** the Committee's Vice-Chair indicate, with regard to the creation of a working group on "Digital technology and human rights", that the volume of private and public digital data had hugely increased and that such data circulated constantly on all the social networks and the Internet. By using Big Data in a clever manner, it was possible to extract enhanced information on tastes, health, consumption patterns, public opinions, family life, the community life of persons, etc., but the data could also be used for organised crime, cyber terrorism, etc. Doctors and lawyers had expressed their concerns regarding Big Data, stating that personal data protection was, today, an illusion. How much of our freedoms and private

life are we prepared to sacrifice in order to benefit from the advantages of Big Data ? Can there be some regulation? Another issue to be examined was the connectivity of networks in relation to their structure (top down/bottom up) and citizens' equal access to digital technology. Is it enough to extend our current rights to these new places or must we invent them ?

Heard Jacques Dayan, professor of paediatric psychiatry, on "Teenagers and Digital Technology". He briefly presented an all-round view of the issues raised today by the widespread availability of the Internet, from a psychological, cognitive, social and behavioural viewpoint. The problems posed by this tool would depend on its use: how do the tool and brain change each other? How should we understand the thinking of the Russian psychologist Lev Vygotsky who had worked on the notion of the object, which he called mediated interactions, i.e., the role of action in the transformation of interactions, but also of the brain?

Decided to create a working group on digital technology, to be led by Iamvi Totsi.

11. Heard Jean-Bernard Marie (*Conférence des Commissions Justice et Paix d'Europe*), the representative of the Conference of INGOs before the Steering Committee on Human Rights, who emphasised the following points:

Two texts had been adopted last March by the Committee of Ministers:

- the Recommendation to member States on human rights and business, which must be promoted by the INGOs together with the Working Group on "Co-development, human rights and migration" ;
- the guidelines on "Human rights in culturally diverse societies".

The work for the biennium of the Steering Committee for Human Rights, which had started in January 2016, was being carried out in five groups:

- the Drafting Group on social rights ;
- the Drafting Group on female genital mutilation and forced marriage: a questionnaire had been sent to INGOs asking for their experience in this area and, in particular, their proposals and suggestions;
- the Drafting Group on civil society and national human rights institutions, with a call to INGOs to make proposals;
- the Drafting Group on migration and human rights;
- the Drafting Group on freedom of expression and links to other human rights.

Noted that representatives of the Standing Committee would be nominated to monitor and accompany the work of Jean-Bernard Marie in these various drafting groups.

12. Took note of the progress made by the committee's working groups:

- During this session, the Working Group "Against Hate Speech" would hold its meeting at the European Youth Centre on the subject of speed dating, in order to enable a constructive exchange between young people and the Conference of INGOs ;
- The Working Group on "Extreme Poverty and Human Rights" would organise, on 17 October, the International Day for the Eradication of Poverty, in Strasbourg at the Council of Europe. The theme would be "Youth facing poverty and social exclusion: civil society and its answers" with the participation of Greek and Polish guest delegations;
- The Working Group on "Disability": following the recommendation presented by the Conference of INGOs, an ad hoc committee had been set up by the Council of Europe which would implement a strategy on disability over the coming six years.

Maritchu RALL
Committee Rapporteur

9th meeting of the Committee on Bioethics (DH-BIO) of the Council of Europe
31 May – 2 June 2016
Report by Michel Aguilar

Notice to the representatives of the INGOs.

Dear colleagues,

It is likely that not everybody will have the time or even the desire to read this report. Please allow me to draw your attention to the need for the Conference to contribute to the work of the DH-BIO, which focuses on human rights and democracy.

The DH-BIO is interested in receiving input from the NGOs specialised in the areas concerned.

Please do not hesitate to provide those in charge of the Conference's Human Rights Committee with any relevant studies and your expert opinions so that the Conference to take full advantage of its status as a guest participant within the DH-BIO in an advisory capacity.

Introduction

The DH-BIO is comprised of delegations of experts appointed by the member states. Certain other participants are invited in an advisory capacity: the Parliamentary Assembly, the Office of the Commissioner for Human Rights, UNESCO, various Council of Europe committees, the Conference of INGOs.

The variety of expertise brought together ensures that the discussions are particularly fruitful: lawyers, doctors with various specialisations, researchers, the heads of national advisory committees, and so on.

Key points

- 14 states have ratified the Additional Protocol to the Convention on Human Rights and Biomedicine on the transplantation of organs and tissues of human origin.
- On 28 February 1996 the Russian Federation became a member of the Council of Europe (CoE). On the 20th anniversary of this event, an international conference entitled *Ethical and legal aspects of organ donation* was held in Moscow. The event may be viewed in streaming through the following link:
<http://tv.coe.int/COE/video.php?v=20160426emten>
The Additional Protocol to the Oviedo Convention on the fight against organ trafficking has not yet been ratified by a sufficient number of countries for it to enter into force. Combating this trade is a matter of the greatest importance. The proceedings of this conference should be published in mid-June 2016. The Russian Federation intends to organise other conferences on bioethics issues, including access to medical files, end-of-life care and informed consent.

Turkey will hold a conference on end-of-life decision making on 25 October 2016. Armenia will hold a conference on the same subject in 2017. The conference in Turkey will be hosted by a private university in partnership with the Council of Europe. It will deal with medical and legal issues, and will focus in particular on protocols concerning end-of-life care from the viewpoint of human rights and advance directives regarding healthcare. The viewpoints of medical students, patients' close relatives and doctors will also be examined.

- A document is currently being drawn up concerning non-resident living donors, who are particularly vulnerable. A specific issue to be addressed is medical and psychological support for such persons when they return to their own country.

It will be accompanied by documents concerning donations and transplantations which will shortly be presented to the Committee of Ministers (CM). See the following link: https://www.edqm.eu/sites/default/files/medias/fichiers/resolution_cmres201355_sur_l_etablissement_de_procedures_pour_la_collecte_et_la_diffusion_de_donnees.pdf

The principle of prohibition of financial gain from human body parts (cf. Article 21 of the Oviedo Convention) is being addressed by a dedicated ad hoc working group, which is considering the various Council of Europe instruments of relevance to this question along with the case law of the Court (ECtHR). The member states are required to criminalise the unlawful removal of body parts. The Charter of Fundamental Rights reiterates the provisions of the Oviedo Convention. See Directive 2002/98/EC: http://ec.europa.eu/health/files/eudralex/vol-1/dir_2002_98/dir_2002_98_fr.pdf

It is necessary clearly to determine the measures that can be deemed acceptable in order to promote donations of body parts.

- In the case of human body parts, it is proposed that the term “*donation*” be replaced by “*altruistic transfer*”.
- Pharmaceutical companies purchase human tissue. As there are not enough donors, they offer up to €2,000 as compensation in order to encourage donations. Here too the semantics have been called into question, and it is proposed that the person whose tissue is removed be referred to as a “*participant*” rather than as a “*donor*”.

Where the removal of tissue requires the donor to miss work, or involves a period of sick leave as a result of subsequent psychological difficulties, then appropriate compensation should be provided for. For example, Romanian women who donate their oocytes in Spain do not benefit from any follow-up after returning to their home country.

In Strasbourg, a city located in a border region between three countries, it is frequently noted that individuals who are willing to serve as subjects in research projects move from one country to another in order to participate in experiments. By participating in multiple experiments, these individuals may in some cases put their lives in danger.

A certain degree of confusion is often noted concerning the issue of financial gain. While travel expenses and, where appropriate, loss of earnings on the part of donors are reimbursed, no payment is made for biological material.

It is necessary to clarify the relations between donation of body parts and research. A distinction needs to be drawn between donation for the purpose of research and a donation intended for a specific recipient. France distinguishes between donations of gametes and oocytes and organ donations. In some countries much higher payments are made for genetic material. In France the law treats gametes in the same way as embryos.

- Presentation concerning transgender and intersex children. NGO OII Europe
This question touches upon medical, legal and political issues. Particular attention is drawn to the need to treat the specific needs of transgender and intersex persons separately. They must not be confused! Please refer to the definitions and also to the website of the NGO OII Europe: <http://oiieurope.org/>

In many countries bodily integrity is violated by mandatory surgery and hormone treatments. This is not too distant from eugenics. A good number of treatments can be deemed degrading and reveal both malicious attitudes and neglect.

On a social level, the children and young persons concerned are shrouded in secrecy. These young persons do not have any role models (sportspersons, musicians or others). The secrecy gives rise to a feeling of shame.

One cannot talk about children without talking about their environment. The need for psychological support is evident for children and for the parents who regret surgery performed at a young age. Hormone treatment leads to osteoporosis and results in stigmatising precautions being taken at school due to fear of fractures and in absences from schooling.

During the first six weeks of gestation, every embryo is totipotent. We have thus all been intersex.

Intersex persons are neither male nor female. Violations result from the attempts to find a way of classifying the child as either one or the other. Contrary to a common misconception, the mind of a child is not a *tabula rasa* at birth.

There are bodies which display misleading physical characteristics, i.e. the body of a newborn baby does not necessarily reflect its sexual identity. Moreover, a newborn baby does not have a sexual orientation, which will only emerge at a later stage.

Surgery at an excessively young age results in significant physical harm and gives rise to a feeling of shame. In addition, there is a significant risk that the sexual identity of the body may not correspond to the sexual orientation that emerges at a later stage. Gender identity is different from sexual attraction.

It is necessary to strike the best balance between the medical and the non-medical realms. However, nothing is happening in this area. Where surgery is performed this results almost systematically in sterilisation. The question of informed consent is extremely delicate when the child is too young, the parents are not properly informed, or not informed at all, and the medical community is particularly uncomfortable.

Institutional transphobia is associated with limited knowledge and a lack of earmarked budgets.

These situations result in psychological problems such as severe depression, drug addiction and marked suicidal tendencies. The individuals concerned should be consulted before taking any action, so as to avoid an increase in their suffering, instead of outsiders deciding for them.

According to the representatives of OII Europe, no surgery is necessary for prepubescent children. One should wait in order to better ascertain the needs of the child. The type of therapy known as *regularisation therapy* should be abolished.

A distinction should be drawn between the genetic sex, the anatomical sex, the hormonal sex and the physical sex.

Another blind spot: intersex persons and transsexuals over the age of 60. Here the neglect is absolute!

- Emerging technologies.

Bioethics is by nature multi-disciplinary and the DH-BIO covers the work of various Council of Europe committees. Ethical issues affect individuals as well as society as a whole. The problems are complex and it is difficult to arrive at a consensus. The DH-BIO's role is above all to provide added value in debates concerning complex issues.

With regard to emerging technologies, an ongoing dialogue with the public is needed. New technologies are not always known and not always understood. The public must be correctly informed in order to understand fully and to be able to formulate opinions.

The DH-BIO has plans to draw up a practical guide, since the emerging technologies do not fit in with existing criteria and the problems raised are new to public debate. They raise fundamental ethical questions. The guidance document could set out both the process of reflection that has taken place within the DH-BIO and a conceptual framework for other future work. This could be a fundamental document for the conference being held in 2017 to mark the twentieth anniversary of the Oviedo Convention.

Technology has a twofold aspect: the expectations and the fears that it engenders, especially as the results of its usage are still unknown.

The working group on emerging technologies has adopted a methodology:

- Rejection of a casuistic approach
- Engaging with common issues that raise shared major challenges.
- Identifying principles that could assist in resolving shared challenges.

Some comments based on the above considerations:

- The technologies were developed in France but have been marketed by the USA. This reflects a mismatch between the expertise and public opinion. It is accordingly necessary to raise awareness and to educate the public regarding ethical issues. This is why a practical guide would be of interest.
- There is a need for reliable data in order to feed public debate and also for the data to be processed properly.

- In 2017 UNESCO will publish a report on ethics and robotics. Since robots are designed by people, they are susceptible to error.
 - There are currently innovations on the market that originate from industrial development rather than research, and, as a result, their effects on society have not been debated. An example is connected medical devices.
 - The possibility of determining the approach behind a given technological development is not necessarily a scientific prerequisite. The approach may not have had a scientific basis.
 - According to liberal thinking, a good technology is one that enables innovation and improvement. Where is *human enhancement* leading? What is a “*normal*” starting point? Regardless of the technology, the inner issues remain the central problem. “With or without technological support, I stay the same”.
 - Do individual improvements benefit society?
 - Is somebody who refuses the benefits of technology a pariah?
 - What is the status of those who are unable to access technology?
 - Technology requires us to take back control of questions of governance. Article 28 of the Oviedo Convention calls for public debate. However, it is difficult to use the normal reference frameworks for emerging technologies. It can be noted that there is much public debate, but very few of these debates are incorporated into decision making processes.
- Mental disorders and compulsory treatment.
The DH-BIO has confirmed its commitment to working towards the protection of human dignity and human rights in relation to compulsory treatment, taking account of the reservations expressed by the Parliamentary Assembly and the Commissioner for Human Rights. Compulsory treatment can prove necessary in urgent situations where the individual himself/herself or his/her surroundings are at risk. However, alternative measures should be developed. Here too, the DH-BIO needs to receive contributions from the various competent committees and from organisations active in the defence of human rights.

Since the recommendation dating from 2004 has failed to influence certain countries, the DH-BIO will probably seek to incorporate the most significant contributions into a higher ranking legal instrument: an additional protocol.

- The DH-BIO will invite the relevant NGOs to become involved according to the various topics under study: technology, persons with disabilities and so on.

The Conference’s comments are awaited with interest.