

COUNCIL OF EUROPE



CONSEIL DE L'EUROPE

Strasbourg, 23 November 2020

DH-BIO / Abr RAP17

**COMMITTEE ON BIOETHICS
(DH-BIO)**

17th meeting

3-6 November 2020

Kudo

Abridged report

I. Adoption of the agenda

1. The Committee on Bioethics (DH-BIO) held its 17th meeting online via the KUDO platform from 3-6 November 2020. The list of participants and the agenda of the meeting appear in Appendices I and II to this report.

II. Opening – Introduction

2. Mr Christophe Poirer, Director of Human Rights, informed the DH-BIO about latest relevant developments at the Council of Europe, in particular the Information document published by the Secretary General on public health crisis (SG/INF(2020)24) and the contribution of the Council of Europe to support member states. This was followed by an exchange with delegations.

III. Strategic Action Plan implementation in the light of new priorities

3. The Chair introduced the main proposals to update the Strategic Action Plan as proposed by the Bureau and reminded delegations about the priority proposals made by the Bureau in the light of the issues raised by the pandemic, which were supported by the DH-BIO, i.e. under the equity pillar:
 - extending the scope of the work on health literacy to other vulnerable groups than older persons;
 - to give priority to the development of guidelines on equitable access to vaccine, treatment and equipment, including ethical considerations concerning access to these as a limited resource;
 - in view of these new priorities and the additional workload this would create, the Bureau had also proposed to postpone until further notice the action to prepare an annual online newsletter.
4. The Committee welcomed the regular update of this document with a view to follow the continued implementation of the SAP.
5. The new proposals from the Bureau were discussed under point Equity of access to vaccine (see below).

IV. Examination of draft Working method document

6. The delegations welcomed the draft document on the working method of the Committee prepared by the Secretariat in coordination with the Bureau to improve the efficiency and facilitate the work of the Committee and the possible development of cooperation with other Council of Europe committees and other intergovernmental organisations.
7. In the absence of comments, the DH-BIO adopted the document on Friday 6 November 2020.

V. Gender equality

8. Dr Ina Wagner presented her report: “Integrating a gender equality perspective”.
9. The report was welcomed by delegations. The dilemma regarding the inclusion and exclusion of women in clinical trials, the role of research ethics committees in promoting inclusion, the lack of comprehensive data and research on gender in biomedicine in member states, and the need for greater efforts to understand the differences between women and men in diagnosis and treatment, were highlighted.

10. The DH-BIO thanked Dr Wagner for her work. The importance of remaining attentive to the integration of a gender perspective in the Committee's work was underlined, especially regarding the implementation of the Strategic Action Plan.

VI. Information on progress in the collection of examples of practices aiming at promoting voluntary measures in mental health care

11. The Secretariat informed delegations that Dr Piers Gooding, research fellow at Melbourne Social Equity Institute and Melbourne Law School (Australia), had agreed to support, as expert consultant, the Secretariat in the process of compiling the examples received. Dr Gooding would prepare a first outline of the compendium to be presented to the DH-BIO at its next plenary meeting.
12. Delegations who had not yet done so were encouraged either to submit replies to the questionnaires or to forward contact details of experts in the area of mental health-care, social work and related areas, who would be ready to share their experiences in the area of preventing recourse to involuntary measures/promoting voluntary practices in mental health care to the Secretariat.

VII. Additional Protocol concerning the protection of human rights and dignity of person with regard to involuntary placement and involuntary treatment within mental health care services

13. The Secretariat presented the changes to the draft Additional Protocol proposed by the Bureau on the basis of comments made by Delegations; together with the draft Explanatory Report revised by the Secretariat in light of the changes proposed.
14. Ms De Bruijn-Wezeman, Rapporteur of Parliamentary Assembly of the Council of Europe (PACE) on the deinstitutionalisation of people with disabilities, addressed the DH-BIO on behalf of the PACE Committee on Social Affairs, Health and Sustainable Development. The text of her intervention is attached as Appendix III to this report.
15. The DH-BIO heard interventions from the representatives of the European Disability Forum, including of Mental Health Europe, ENUSP (European Network of (Ex-)Users and Survivors of Psychiatry) and Inclusion Europe. The texts of these interventions are attached as Appendix IV to this report.
16. Delegations congratulated the Bureau and its Rapporteur, Ms Sarah Rueda (France), to the work achieved. The Committee expressed its general support for the document as revised by the Bureau and introduced a few changes to the text.
17. Except for two delegations who were against and two who abstained, all the other delegations expressed their readiness to take a formal vote on the finalised draft at the 18th DH-BIO plenary meeting (1-4 June 2021).
18. **Delegations were invited to submit comments on the newly revised draft, together with its revised draft explanatory report, by 30 November 2020.** The finalized draft would be sent to delegations by the mid December 2020 in order to allow sufficient time for consultation within member States with a view to the formal vote at the 18th plenary meeting (1-4 June 2021).

VIII. Genome editing technologies

19. Dr Ingo Härtel (Germany), Rapporteur on genetics and genomics, reminded about the origin and steps already achieved in the examination of ethical and legal issues raised by

developments in genome editing technologies in relation to Article 13 of the Oviedo Convention. He also reminded about the current works by other bodies and organisations.

20. The Chair of the DH-BIO underlined the important role of the DH-BIO in international discussion on the ethical and legal issues raised by genome editing technologies, in particular because of the Committee's responsibility for the Oviedo Convention which comprises the only legally binding provision on genome editing at the international level.
21. She then presented the different options identified by the Bureau on the way forward which are submitted to the Committee:
 - Option 1: There is a need for revision of Article 13 in accordance with Article 32 of the Oviedo Convention.
 - Option 2: There is a need for clarification of certain terms/aspects without modifying the text of Article 13.
 - Option 3: There is no need for revision or clarification of Article 13.
22. Except for two delegations who reserved their position, all the delegations who expressed their position supported the option providing for clarifications on terms of aspects of the provisions of article 13 without revising its wording.
23. **Delegations were invited to specify to the Secretariat the terms and/or aspects that would need to be clarified by 15 January 2021.**

IX. Children's participation in decision-making on matters relevant to their health

24. Dr Annagrazia Altavilla, consultant, presented the concept note and questionnaire on relevant legislation and practices relating to children's participation in decision-making on matters relevant to their health. This was followed by an exchange with delegations.
25. **Delegations were invited to share the concept note and questionnaire, as finalised by the Secretariat, with colleagues working on the relevant subject matter and to submit replies to the online questionnaire, as well as other useful information on the subject matter, by 31 March 2021.**
26. **Delegations were also invited to provide the Secretariat with the contact details of experts who would be ready to share their knowledge and experience in this area.**

X. Equity of access to vaccines

27. Taking into account the priorities agreed, the Bureau considered that in the current fast-moving scenario of vaccine development, DH-BIO could have more impact preparing, in a short time frame, a draft text focusing on equity of access to vaccines. The work will then continue on therapeutics and equipment, in particular in context of scarce resources.
28. The Secretariat presented its background document, providing delegations with an overview of the current scenario of development and regulation of vaccines against COVID19. Prof. Kristof Van Assche (Belgium), consultant, introduced the outline for a draft text on equity of access to vaccines providing an ethical framework on the basis in particular of the principles laid down in the Oviedo Convention.
29. During the discussion delegations supported the relevance of a work on vaccine while emphasising the need to ensure added value and not duplicate work already undertaken by other organisations such as WHO and EU.

30. Jennifer De Temmerman, Member of the Committee on Social Affairs, Health and Sustainable Development of the Parliamentary Assembly of the Council of Europe, reported on the work she is currently carrying out on ethical, legal and practical considerations in relation to COVID19 vaccines, with a fast-tracking process. The Committee will hold a hearing on this topic during the next Committee meeting on 1 December.
31. With the exception of one delegation who abstained, all delegations supported the proposal to focus first on equity of access to vaccine. All delegations, except two who voted against, were in favor of drafting a statement.
32. Finally, delegations supported to work thereafter on guidelines on equity of access to treatments and equipment in the context of scarce resources, as a next step after the preparation of the statement on vaccines, except one who was against and five who abstained. A preliminary outline will be prepared for the June meeting which will be submitted to the DH-BIO for agreement on the way forward.
33. For the preparation of the statement on equity of access to vaccines, a drafting group will be established as soon as possible. **Delegates were invited to express their interest in joining the drafting group, by Friday 13 November 2020.**
34. The Secretariat proposed to explore possible collaboration with the European Directorate for the Quality of Medicines (EDQM) for the quality aspects of medicinal products, on the basis of the requirement of “appropriate quality” laid down in Article 3 of the Oviedo Convention. The drafting group will discuss this issue and, where appropriate, the Secretariat will contact the EDQM.

XI. Election to the Bureau

35. The Committee elected Dr Ritva HALILA (Finland), as Chair for a one-year term, renewable once.
36. The Committee elected Dr Siobhan O’Sullivan (Ireland), as Vice-Chair for a one-year term renewable once.
37. The Committee then proceeded to the election of three Bureau members. Among the four candidates proposed, the Committee re-elected Dr Rodica Gramma (Moldova) and Prof Pierre Mallia (Malta), for a second two-years term, and Dr Assunta Morresi (Italy) for a two years-term renewable once.

XII. Decisions taken by the DH-BIO at its 17th meeting

38. In agreement with the delegations, the list of decisions taken during the meeting was sent to the Committee members and approved by written procedures.

XIII. Dates of the next meetings

39. The DH-BIO agreed on the following dates for its next meetings to be held in Strasbourg:
 - 18th meeting of the DH-BIO: 1-4 June 2021
 - 19th meeting of the DH-BIO: 2-5 November 2021

XIV. Other business

Comments of DH-BIO on PACE recommendation 2176(2020) “Ethics in science and technology: a new culture of public dialogue”

40. The delegations generally supported the recommendations made by the Parliamentary Assembly in its Recommendation 2176(2020) and adopted the comments prepared by the Secretariat based on relevant work carried out by the DH-BIO.

Representative and rapporteurs

41. Dr Assunta Morresi was entrusted with the task of representing the DH-BIO in the Committee CD-P-TO.
42. Delegations were reminded that the Committee of Ministers, in addition to a rapporteur on Children Rights and a rapporteur on Gender Equality, had invited intergovernmental committees to consider the possibility of appointing rapporteurs on Disability issues and on Roma and travellers' issues. Prof. Constantinos Phellas (Cyprus), who had expressed his interest, was designated as Rapporteur on disability issues. **Members of Member states Delegations were invited to express their interest in becoming DH-BIO Rapporteur on Roma and travellers' issues by Friday 13 November 2020.**

Questions put to the ECHR under Article 29 of the Oviedo Convention

43. The Secretariat informed the DH-BIO that the European Court of Human Rights, in June 2020, had invited the Member States to submit written comments on the request lodged at the end of 2019 under Article 29 of the Oviedo Convention, in light of a number of questions formulated by the Court relating to the existence of jurisdiction of the Court and, for the Contracting Parties to the Oviedo Convention, on national provisions regulating the matters covered by the request for an advisory opinion. The Court had received written comments from 24 member States. The Court would keep the DH-BIO informed about the further developments of the procedure.

Appendix I List of participants

MEMBER STATES / ETATS MEMBRES

Albania/Albanie -

Andorra – Mr David PÉREZ SURRIBAS, President of the National Committee of bioethics

Armenia/Arménie - Ms Lusine KOCHARYAN, Head of Medical Care Policy Department, Ministry of Health of the Republic of Armenia
apologised/excusée

Austria/Autriche - Mr Stefan SCHWAB, Ministry of Justice, Vienna

Dr Isabelle HASSLER, Federal Chancellery of Austria / Co-ordination Science, Research, Technology, Education, Social issues, Health, Secretariat of the Austrian Bioethics Commission
apologised/excusée

Dr Renate FALLY-KAUSEK, Medical Officer, Federal Ministry of Health
apologised/excusée

Azerbaijan/Azerbaïdjan - Dr Gulnara BALAKISHIYEVA, Ph.D. in molecular biology, Senior Researcher at Department of Fundamental Problems of Biological Productivity, Institute of Molecular Biology and Biotechnology, Azerbaijan National Academy of Sciences

Mrs. Shafa GASIMOVA, Head of Humanitarian Issues Division, Humanitarian and Social Issues Department, Ministry of Foreign Affairs

Belgium/Belgique - Mr Paul COSYNS, Universiteit Antwerpen, Dienst Psychiatrie van UZA, Emeritus Professor

Bosnia and Herzegovina/Bosnie-Herzégovine - Mr Dalibor PEJOVIC, Head of Unit for Statistics and Analytical Affairs and Reporting in Health, Department for Health
apologised/excusé

Ms Dunja ŠMITRAN, Ministry of Civil Affairs of Bosnia and Herzegovina
apologised/excusée

Bulgaria/Bulgarie - Ms Sylvia TOMOVA, Ministry of Health, Legal Directorate, Chief Legal Advisor
apologised/excusée

Croatia/Croatie - Dr. Vanja NIKOLAC, Head of Service, Service for blood, tissues and cells inspection, Ministry of Health

Cyprus/Chypre - Prof. Constantinos N. PHELLAS, Chair of the Cyprus National Bioethics Committee, University of Nicosia

Czech Republic/République Tchèque - (Ms) doc. PhDr. Ing. Hana KONEČNÁ, Ph.D. , Jihočeská univerzita v Českých Budějovicích, Zdravotně sociální fakulta, Katedra klinických a preklinických oborů

Doc. JUDr. Tomáš DOLEŽAL, Ph.D., LL.M., Head of the Department of Private Law and Head of the Research Unit for Medical Law and Bioethics, Czech Academy of Science, Institute of State and Law

Denmark/Danemark - Ms Anne-Sofie DUELUND LASSESEN, Legal officer, Ministry of Health

Ms Sabine GODSVIG LAURSEN, Ministry of Health

Ms Anne Cathrine BOLLERUP

Estonia/Estonie - Dr Aime KEIS, Assistant, Chief lecturer of medical ethics, Faculty of Medicine, University of Tartu

Finland/Finlande - Ms Ritva HALILA, M.D., Ph.D., docent, Senior Medical Officer, General Secretary, National Advisory Board on Social Welfare and Health Care Ethics (ETENE), Ministry of Social Affairs and Health

Ms Anneli TORRONEN, Ministry of Social Affairs and Health

Ms Mia SPOLANDER, Legal Officer, Unit for Human Rights Courts and Conventions, Legal Service, Ministry for Foreign Affairs

France – Karen ROCHET, sous-direction des Droits de l'Homme, Ministère des Affaires étrangères

Guilaine GANRY, bureau du droit des personnes et de la famille, Sous-direction du droit civil, Ministère de la Justice

Docteur Mélodie BERNAUX, bureau bioéthique, produits et éléments du corps humain, de la politique des produits de santé et de la qualité des pratiques et des soins, Ministère des solidarités et de la santé

Lucie BOZEC, bureau bioéthique, produits et éléments du corps humain, de la politique des produits de santé et de la qualité des pratiques et des soins, Ministère des solidarités et de la santé

Marion JABOT, bureau bioéthique, produits et éléments du corps humain de la politique des produits de santé et de la qualité des pratiques et des soins, Ministère des solidarités et de la santé

Maialen MALLET, bureau bioéthique, produits et éléments du corps humain, de la politique des produits de santé et de la qualité des pratiques et des soins, Ministère des solidarités et de la santé

Docteur Jacques MONTAGUT, ancien membre du CCNE, personnalité qualifiée

Georgia/Géorgie - Dr Givi JAVASHVILI, Head of Family Medicine Department, State Medical Academy of Georgia, Chairman of the National Council on Bioethics

Germany/Allemagne - Dr. Thomas BAUERMANN, Federal Ministry of Justice and Consumer Protection, Division III B 6

Dr. Ingo HÄRTEL, Federal Ministry of Health, Division 316

Mr. Carlo GRIMM, Federal Ministry of Education and Research, Division 611

Prof. Dr. Elmar DOPPELFELD (Honorary chair of the "Permanent Working Party of Research Ethics Committees in Germany Inc.")

Prof. Dr. Dr. Thomas HEINEMANN, Philosophical-Theological University of Vallendar (PTHV)

Greece/Grèce – Prof. Stamatia GARANIS-PAPADATOS, Professor, Dept. of Public Health Policy, School of Public Health, University of West Attica, Athens

Dr. Foteini TZAVELLA, Sociologist, Assistant Professor in Sociology of Health, Department of Nursing, School of Health Sciences, University of Peloponnese

Hungary/Hongrie - Prof. Ernő BÁCSY, MD, PhD, DSc, Medical Research Council of Hungary

Iceland/Islande - Mr Rögnvaldur G. GUNNARSSON, Legal Advisor, Ministry of Welfare
apologised/excusé

Ms. Thorunn STEINSDOTTIR, Legal Advisor, Ministry of Welfare

Ireland/Irlande - Dr Siobhan O'SULLIVAN, Chief Bioethics Officer, An Roinn Sláinte Department of Health, Teach Hawkins

Italy/Italie - Prof. Assunta MORRESI, Prof. Associato di Chimica Fisica, Dipartimento di Chimica, Biologia e Biotecnologie, Università degli Studi di Perugia

Prof. Laura PALAZZANI, Lumsa, Facoltà di giurisprudenza, Roma

Latvia/Lettonie - Dr. Vents SĪLIS, Assistant Professor at Riga Stradins University, Department of Humanities

Liechtenstein -

Lithuania/Lituanie - Dr Asta ČEKANAUSKAITĖ, Director of Lithuanian Bioethics Committee

Luxembourg - Mr. Laurent JOME apologised/excusé

Malta/Malte - Prof. Pierre MALLIA, MD PhD, CBiol MPhil MA(Law) DipICGP MMCFD MRCP FRCGP, Professor of Family Medicine, Bioethics & Patients' Rights, Chairperson, National Health Ethics Committee, Dept. of Health, Chairperson, Bioethics Consultative Committee, Ministry of Health, Coordinator, Bioethics Research Programme, Univ. of Malta, President, Malta College of Family Doctors

Republic of Moldova/République de Moldova - Ms Rodica GRAMMA, Associate Professor, State University of Medicine and Pharmacy (USMF)

Mr. Andrei SVET, Ministry of Health, Labour and Social Protection, Head of the Legal Department

Monaco - M. Xavier RAUSCHER, Administrateur Juridique au Service du droit International, des droits de l'homme et des libertés fondamentales apologised/excusé

M. Gabriel REVEL

Mme Laura BENITA

Montenegro/Monténégro - Ms Olivera MILJANOVIC, Prim. doc., Director of the Centre for Medical Genetics and Immunology, Medical Centre of Montenegro

Netherlands/Pays-Bas - Ms Sanne VAN WEEZEL, Ministry of Health, Welfare and Sports

Mr Harrie STORMS, Ministry of Health, Welfare and Sports

North Macedonia/Macédoine du Nord - Ms Olgica VASILEVSKA, Senior Counselor, Directorate for Multilateral Relations and Security Cooperation, Sector for Council of Europe, OSCE and other European Organizations, Ministry of Foreign Affairs apologised/excusée

Norway/Norvège - Mrs Anne FORUS, Senior Adviser, ph.d, Biotechnology and health legislation department, Division of specialised health care services, Norwegian Directorate of Health

Ms Vårin HELLEVIK, Norwegian Directorate of Health, Department of Specialized Mental health care and Addiction Treatment

Ms Camilla Closs WALMANN, Senior Adviser, Department for Biotechnology and Health Law, Norwegian Directorate of Health

Poland/Pologne - Ms Mariola GROCHULSKA, Département des droits de l'homme, Ministère de la Justice

Portugal - Prof. Jorge SOARES, Président du Conseil National d'Ethique pour les Sciences de la Vie

Romania/Roumanie - Mrs Beatrice Gabriela IOAN, Associate Professor, President of the Bioethics Commission of the Romanian College of Physicians, Institutul de Medicina Legala

Mr. Gheorghe BORCEAN, President de L'Ordre des Medecins et Prof. Ass.a L'Universite de Medecine et Pharmacie " Victor Babes" de Timisoara, Vice-President of the Romanian College of Physicians, Spitalul Municipal Caransebes

Russian Federation/Fédération de Russie - Ms Lyalya GABBASOVA, Dr.MS, Assistant to the Minister, Ministry of Health of the Russian Federation

Ms Maria ORESHINA, 1st secretary of the Department of European cooperation, Ministry of Foreign Affairs
apologised/excusée

Ms Daria KHUKHREVA, Ministry of Health of the Russian Federation

Ms Olga OPANASENKO, Counsellor of the Department of the Humanitarian Cooperation and Human Rights of the Ministry of Foreign Affairs of the Russian Federation

San Marino/Saint-Marin - Dr Luisa BORGIA, Vice-President of the National Ethics Committee

Serbia/Serbie - Prof. Dr Zvonko MAGIC, Head of the Institute for Medical Research in the MMA (Military Medical Academy), professor of the human genetics at the Medical Faculty and Cochairmen of the National Committee for bioethics of UNESCO Commission of Serbia, Serbian Academy of Sciences and Arts

Slovakia/Slovaquie - Prof. Jozef GLASA, MD, PhD, PhD; Institute of Pharmacology and Clinical Pharmacology, Institute of Health Care Ethics, Slovak Medical University in Bratislava; Institute of Medical Ethics and Bioethics n.f.; Ethics Committee (NEC), Ministry of Health SR

Slovenia/Slovénie - Prof. Marjeta TERČELJ ZORMAN, Dr.Med.

Spain/Espagne - M^a Concepción MARTIN ARRIBAS, Subdirección General de Investigación en Terapia Celular y Medicina Regenerativa – Instituto de Salud Carlos III – ISCIII

Prof. Carlos M. ROMEO – CASABONA, Professor of Penal Law, Head, Inter-University Chair in Law and the Human Genome

Mme Leonor RUIZ SICILIA, Coordinatrice de la Stratégie de Bioéthique du Système de Santé Publique, Andalousie, Département Ministériel de la Santé et de la Famille - Membre du Comité de Bioéthique de l'Espagne
apologised/excusée

Sweden/Suède - Mrs Tesi ASCHAN, Legal Adviser, The National Board of Health and Welfare, Socialstyrelsen

Ms Kerstin CARLSSON, political scientist and international relations officer, National Board of Health and Welfare, Socialstyrelsen

Switzerland/Suisse – Prof. Dr. Rodrigo RODRIGUEZ, Département fédéral de justice et police DFJP, Office fédéral de la Justice OFJ, Domaine de direction Droit privé

Ms Nina SCHERRER, Wissenschaftliche Mitarbeiterin, Sektion Forschung am Menschen, Eidgenössisches Departement des Innern EDI, Bundesamt für Gesundheit BAG, DB Öffentliche Gesundheit, Abteilung Biomediz
apologised/excusée

Turkey/Turquie - Prof. Ergun ÖZSUNAY, Professor of Civil, Comparative Law and EU Private law, Istanbul Culture University, Faculty of Law
apologised/excusée

Ukraine - Ms Iuliia DAVYDOVA, Professor, Head of High-Risk Pregnancy Department, Institute of Pediatrics, Obstetrics and Gynecology, member of Local Bioethics Committee

Prof. Olesya HULCHIIY, Vice-Rector, Shupyk National Medical Academy of Postgraduate Education

United Kingdom/Royaume-Uni - Dr Mark BALE, Deputy Director, Health Science & Bioethics Division, Department of Health

Dr Pete MILLS, Assistant Director, Nuffield Council on Bioethics

INVITED GUESTS

Dr. Annagrazia ALTAVILLA, Consultant to collect good practices, Italy

Prof. Ina WAGNER, Vienna University of Technology, Austria

Dr Kristof VAN ASSCHE, Postdoctoral researcher, Bioethics Institute Ghent, Ghent University, Belgium

PARTICIPANTS

PARLIAMENTARY ASSEMBLY/ASSEMBLÉE PARLEMENTAIRE - Ms Tanja KLEINSORGE, Head of Secretariat, Committee on Social Affairs, Health and Sustainable Development

Ms de BRUIJN WEZEMAN, Rapporteur on the deinstitutionalisation of people with disabilities

Ms Jennifer DE TEMMERMAN, Rapporteur, Committee on Social Affairs, Health and Sustainable Development

Ms Anita GHOLAMI, Committee on Social Affairs, Health and Sustainable Development

Mr Benny BORGHEI, Committee on Social Affairs, Health and Sustainable Development

Ms Dana KARANJAC, Committee on Culture, Science, Education and Media

OFFICE OF THE COMMISSIONER FOR HUMAN RIGHTS/BUREAU DU COMMISSAIRE AUX DROITS DE L'HOMME – Mr Hasan BERMEK, Adviser

CDCJ - Prof. Dr. Rodrigo RODRIGUEZ, Département fédéral de justice et police DFJP, Office fédéral de la Justice OFJ, Domaine de direction Droit privé

CPT – Mr Michael NEURAUTER, Head of Division of the Secretariat of CPT

T-PD – Ms Sophie KWASNY apologised/excusée

CDENF – Ms Livia STOICA apologised/excusée

Permanent représentation of Turkey/Représentation permanente de la Turquie - Ayşen EMÜLER

OTHER PARTICIPANTS / AUTRES PARTICIPANTS

Canada -

Holy See/Saint-Siège - Mgr Jacques SUAUDEAU excusé/apologised

Japan/Japon -

Mexico/Mexique – Mme Berenice CRUZ MAYA, Directrice du Développement Institutionnel à la Commission Nationale de Bioéthique

M. Gustavo Fernando OLAIZ BARRAGAN, Sous-directeur des Politiques Publiques et de Bioéthique à la Commission Nationale de Bioéthique

USA/Etats-Unis d'Amérique -

Republic of Belarus - Ms Valerya SOKOLCHIK, Dean of the Department of Public Health and Healthcare Management, Belarusian Medical Academy of Post-Graduate Education

Mr Andrei BABCHANOK, Head of Legal Department, Ministry of Health

UNESCO - Mrs. Dafna FEINHOLZ KLIP, Section de la bioéthique, Division de l'éthique des sciences et des technologies, UNESCO

OECD/OCDE - Mr David WINICKOFF, STI/STP excusé/apologised

World Health Organisation/Organisation Mondiale de la Santé (WHO/OMS) - Dr Andreas REIS, Technical Officer, HIS/KER, Cluster of Health Systems and Innovation, World Health Organization excusé/apologised

OBSERVERS / OBSERVATEURS

KEK - Conference of European Churches/Conférence des Eglises Européennes - Rev. Sören LENZ, Executive Secretary, Conference of European Churches

INGOs

Rehabilitation International (RI) - Dr Régine ERNST - Project Manager on Rehabilitation and Foreign Affairs, Bundesarbeitsgemeinschaft für Rehabilitation e.V./Rehabilitation International (RI) apologised/excusée

European Association of Service Providers for Persons with Disabilities (EASPD) - Mr Josep Maria SOLÉ CHAVERO, Board member of EASPD

European Disability Forum (EDF) - Pat CLARKE

Marine ULDRY

Kristijan GRDJAN (MHE)

Jonas BULL (MHE)

Helen PORTAL (Inclusion Europe) apologised/excusée

Gerlinde SCHMIDT (Inclusion Europe)

Stephanie WOOLEY (ENUSP)

Jolijn SANTEGOEDS (ENUSP)

SECRETARIAT

**DIRECTORATE GENERAL HUMAN RIGHTS AND RULE OF LAW
HUMAN RIGHTS DIRECTORATE/ DIRECTION DES DROITS DE L'HOMME**

Mr Christophe POIREL, Director/Directeur

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Ms Valeriia DYMBRYLOVA, Trainee / Stagiaire

INTERPRETERS / INTERPRETES





Jean-Jacques PEDUSSAUD
Amanda BEDDOWS
Barbara GRUT

**Appendix II
Agenda/order of business**

Tuesday 3 November 2020 (9.30-12.30)	
09.30	1. Adoption of the draft agenda
09.35-10.00	2. Opening – Introduction <ul style="list-style-type: none"> a. New DH-BIO members invited to introduce themselves b. Opening address by Mr Christophe Poirel, Council of Europe Human Rights Director, and exchange with delegations
10.00-10.45	3. Strategic Action Plan implementation in the light of new priorities <ul style="list-style-type: none"> ○ <i>Objectives:</i> <ul style="list-style-type: none"> ▪ <i>Brief presentation of the actions initiated (e.g. dissemination of the Guide to public debate...)</i> ▪ <i>Agreement on the necessary changes to address the new priorities defined taking into account the COVID-19 pandemic</i>
10.45-11.30	4. Examination of draft Working method document <ul style="list-style-type: none"> ○ <i>Objective: Discussion on the document with a view to its revision and finalisation in June 2021</i>
11.30-12.30	5. Gender equality <ul style="list-style-type: none"> ○ <i>Presentation and exchange with Prof. Ina Wagner on the basis of a report on “Human rights in biomedicine: integrating a gender equity/equality perspective”</i>
Wednesday 4 November 2020 (9.00-12.30)	
09.00-09.30	6. Information on progress in the collection of examples of practices aiming at promoting voluntary measures in mental health care
09.30-12.30	7. Additional Protocol concerning the protection of human rights and dignity of person with regard to involuntary placement and involuntary treatment within mental health care services <p><i>Objectives: With a view to the finalisation of the work in 2021</i></p> <ul style="list-style-type: none"> ○ <i>Comments on the revised draft Protocol</i> ○ <i>Comments on the revised draft Explanatory Report</i> ○ <i>Delegations invited to indicate whether they are ready to vote on the draft Protocol in June 2021</i>

Thursday 5 November 2020 (9.00-12.30)	
09.00-11.00	<p>8. Genome editing technologies</p> <ul style="list-style-type: none"> ○ <i>Objective: Agreement on the way forward i.e. whether clarification or revision of Article 13 is needed</i>
11.00-12.30	<p>9. Children’s participation in decision-making on matters relevant to their health</p> <ul style="list-style-type: none"> ○ <i>Objective: Presentation of and discussion on a concept document and questionnaire prepared by Dr Annagrazia Altavilla, Consultant to collect good practices</i>
Friday 6 November 2020 (9.00-12.30)	
09.00-10.30	<p>10. Equity of access to vaccines</p> <p><i>Objectives:</i></p> <ul style="list-style-type: none"> ○ <i>Examination of outlines for a draft instrument on equity in access to vaccines in the context of a public health crisis</i> ○ <i>Subject to the outcome of the examination of the outlines, proposal on the way forward with a view to finalise the work</i>
10.30-10.45	<p>11. Election to the Bureau</p> <ul style="list-style-type: none"> ○ <i>Election of the Chair and Vice-Chair of the Committee for a one-year term</i> ○ <i>Subject to the outcome of the election of the Chair and Vice-Chair, the election of at least 3 Bureau members for a two years term:</i> <ul style="list-style-type: none"> ▪ <i>replacement of Sarah Rueda (France) who left the DH-BIO,</i> ▪ <i>end of term for Rodica Gramma (Moldova) and Pierre Mallia (Malta) (both re-eligible)</i>
10.45-11.15	<p>12. Decisions taken by the DH-BIO at its 17th meeting</p> <ul style="list-style-type: none"> ○ <i>Approval of the list of decisions</i>
11.15-12.00	<p>13. Dates of the next meetings</p> <p><i>Dates proposed:</i></p> <ul style="list-style-type: none"> ○ <i>18th meeting of the DH-BIO: 1-4 or 8-11 June 2021</i> ○ <i>19th meeting of the DH-BIO: 2-5 November 2021</i>
12.00-12.30	<p>14. Other business</p> <p>a. Opinion of DH-BIO on PACE recommendation 2176(2020) “Ethics in science and technology: a new culture of public dialogue”</p> <ul style="list-style-type: none"> ○ <i>Objective: Examination of a draft opinion based on comments sent by delegations with a view to its approval</i> <p>b. Questions put to the ECHR under Article 29 of the Oviedo Convention</p> <ul style="list-style-type: none"> ○ <i>Information on the advances in the process</i>

POINTS TO BE DEALT WITH IN WRITING

	<p>15. Developments in the field of bioethics</p> <p>Delegations, including observers, are invited to send information in writing.</p> <ol style="list-style-type: none"> a. Developments in member states and other states b. Developments in the field of bioethics in international organisations c. Relations with other international organisations: list of meetings d. Developments in other Council of Europe bodies e. Developments at the European Court of Human Rights
	<p>16. Chart of signatures and ratifications of the Convention on Human Rights and Biomedicine, the Protocol on the Prohibition of Cloning Human Beings, the Protocol concerning Transplantation of Organs and Tissues of Human Origin, the Protocol concerning Biomedical Research and the Protocol concerning Genetic Testing for Health Purpose</p>
	<p>44. Cooperation with other committees</p> <ol style="list-style-type: none"> a. European Committee on Organ Transplantation (CD-P-TO) b. European Committee on Blood Transfusion (CD-P-TS) c. Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD) d. Steering Committee for the Rights of the Child (CDENF)
	<p>18. Cooperation activities</p> <ul style="list-style-type: none"> - Information on relevant activities foreseen under the Armenia Action Plan.

Appendix III Intervention of Ms De Bruijn-Wezeman

Ladies and gentlemen,

It is an honour for me to address you today at the 17th meeting of the Committee on Bioethics (DH-BIO) on behalf of the Committee on Social Affairs, Health and Sustainable Development of the Parliamentary Assembly of the Council of Europe.

Our Committee considers issues relating to, inter alia, social rights and policies and public health, having special regard to the situation of the more vulnerable groups in society.

Involuntary placement and involuntary treatment within mental health care services can affect the most fundamental rights of a human being, including the right to integrity and the right to liberty.

I am the rapporteur for the report on deinstitutionalisation of persons with disabilities, which is foreseen to be debated by the Parliamentary Assembly at the end of next year. This report is a follow-up to my last report on “ending coercion in mental health: the need for a human rights-based approach”, which led to the unanimous adoption of Resolution 2158 last year, and which was also supported by our organisation’s Commissioner on Human Rights.

We are currently working on finalising the introductory memorandum for this report and in this regard I would like to share with you some of our first findings. These findings are in line with the position of the Assembly, now expressed on two occasions in the Plenary Assembly in the last years, that invites you to redirect your efforts from the drafting of the additional protocol to the drafting of guidelines on ending coercion in mental health. Deinstitutionalisation is a key stepping stone to ending coercion in mental health, and I thus hope that you can integrate some of my findings into your work today.

Deinstitutionalisation is the transition from institutional to community-based services. Whereas institutions were once seen as the best way of taking care of and treating persons with additional support needs, it is now widely agreed upon that institutional care provides a poorer outcome, especially in terms of quality of life.

Furthermore, institutionalisation is increasingly acknowledged as poor policy and a potential violation of human rights. The UN Convention on the Rights of Persons with Disabilities (as well as other human rights instruments) have enabled a shift to a human rights-based approach to this issue which I would invite you to make your own.

The process of deinstitutionalisation requires a long-term strategy that ensures that good quality care is available in community settings. As institutionalised persons are being reintegrated into society, there is need for comprehensive social services and individualised support in the deinstitutionalisation process in order to support these persons, and in many cases their families or other carers. Such support must be accompanied by specific access to services outside institutions, enabling people to obtain care, work, social assistance, housing, etc., thus also addressing the social determinants of health.

If the process of deinstitutionalisation is not managed properly, and without due consideration of the special needs of each person concerned, this can have unfortunate consequences. The lack of support and monitoring can lead to abuse and violence, or a return to institutions.

Persons with disabilities in institutions have special needs, but the same rights as you and me. I believe it is important to have in mind also that these persons are some of the most vulnerable

in our society, as was highlighted by the Covid-19 pandemic in which they are disproportionately affected.

In this regard, allow me to reference my colleague Sevinj Fataliyeva's report on supporting people with autism and their families, which she will be presenting to the Assembly's Standing Committee in two weeks' time. Three of her observations really struck me: First, that misassessment of persons with autism by medical personnel can lead to unwarranted sectioning and involuntary psychiatric placement and treatment. Second, that the impact on people with autism living in care homes who have been separated from their families and subject to blanket visiting bans can be devastating, and affect both their mental health and their emotional wellbeing in a particularly acute manner. Third, that the closure of mental health hospitals to the outside world during the pandemic also increases the risk of people's human rights being breached.

I look forward to continue working on this issue and to ensure that the human rights and dignity of the persons concerned are upheld. Thank you for your attention.

Appendix IV

Intervention of Pat Clarke, EDF Vice President

Dear members of the Committee on Bioethics, dear participants to this meeting,

My name is Pat Clarke and I am the vice-president of the European Disability Forum, the umbrella organisation of persons with disabilities that defends the interests of over 100 million of persons with disabilities in Europe.

The disability movement is appalled that members of Committee of Bioethics continue to go ahead with this draft additional protocol. We are appalled by the fact that 6 years have passed and that we continue to have the same conversation, despite a strong and clear opposition to this draft protocol by a multitude of actors and experts.

In this discussion, we welcome the leadership of Finland in questioning the purpose of this draft protocol, reminding States of the UN Convention on the Rights of Persons with Disabilities, and proposing an impact assessment of the potential impact of this draft. It also seems that Finland is the only country that have been involving civil society and users or ex-users of mental health services in the discussion.

This Committee has ignored on several occasions the fact that a number of States have questioned the purpose of this protocol. This include comments (once raised by Belgium and Switzerland for instance) that non-legally binding instruments may be more appropriate.

EDF read closely the comments sent by States to the most recent version of the draft protocol. It has become clear that most of the States are not aiming at defending the rights of persons in mental healthcare settings but at making the draft protocol fit their existing national legislation.

On 15th of September, together with 14 other organisations, we sent an Open letter to the Council of Europe's Committee of Ministers and Committee on Bioethics regarding the draft additional protocol to the Oviedo Convention. We hope you received it. In that open letter, we highlighted the growing consensus against coercion within the medical community. A growing number of practitioners in the medical and scientific community are questioning the use of coercive measures in mental healthcare. Some have reached the conclusion that all forms of coercive practices are inconsistent with human rights-based mental health care. The lack of evidence of their effectiveness is accompanied by the evidence that coercive practices such as seclusion and restraint actively cause harm to physical and mental health. Evidence that contests coercive treatment also points to poor health outcomes and drastically shorter life-expectancy of those involuntary treated.

In addition, many practitioners and UN experts agreed that forms of coercion, including ECT amount to torture or ill-treatment (despite comments from States arguing that such barbaric practices have a therapeutic purpose).

Today, Human Rights Watch publicly asked "What Does the Council of Europe Have Against People with Disabilities?" and called you to oppose the draft protocol.

To conclude my statement, I would like to read you a paragraph coming from a report of the former UN Special Rapporteur on the rights to health – who is a Lithuanian psychiatrist – from April of this year:

"The combination of a dominant biomedical model, power asymmetries and the wide use of coercive practices together keep not only people with mental health conditions, but also the entire field of mental health, hostage to outdated and ineffective systems. States and other stakeholders, specifically the professional group of psychiatry, should

critically reflect on this situation and join forces already on the way towards abandoning the legacy of systems based on discrimination, exclusion and coercion.” (end of quote)

We have one message for this Committee and Member States of the Council of Europe: it is okay to be wrong. You can stop this protocol, and we remain ready to support you in working on guidelines on ending coercion. This is what countries and its people truly need. Thank you.

Comments submitted by Mental Health Europe (MHE)

Mental Health Europe welcomes the efforts of the Committee already invested into the study of good practices. We would like to draw the attention of the Committee that the definition of criteria and the final selection of practices need to be done in partnership with civil society, in particular persons with lived experience and persons with psychosocial disabilities. Good practices are not only those which can be solely scientifically validated. Good practices must show that they have a positive impact and can improve life of people concerned and those people must be listened and their position respected in any policy-making process that aims their well-being.

While this work is a promising effort of the Committee and has a historical importance, Mental Health Europe is disappointed to see the continuation of work of the Committee on the draft Additional Protocol. This Protocol disregards international human rights law, stands in the opposition to international bodies and promotes violation of human rights. In this process, we are glad to see that Finland requires that this Protocol be aligned with international human rights standards, in particular UN Convention on Rights of People with Disabilities. We also commend the position of Belgium that this document should be rather a recommendation than a binding legal instrument. These reflections call upon member states to consider the draft additional protocol in light of their commitments towards UN Convention on Rights of Persons with Disabilities because eventual ratification of this Protocol would put them into breach with international standards they are obliged to respect.

We would like to recall that even within the psychiatric profession there is no consensus on the use of involuntary measures, for example underlined by the position paper from the World Psychiatric Association recently published in October 2020 and titled *Call to Action: Implementing Alternatives to Coercion: A Key Component of Improving Mental Health Care*. Among others it recommends to consider the evidence base relating to alternatives to coercion (such as 'Safewards', 'Six Core Strategies', 'open door policies', and the WHO Quality Rights Initiative), learn from the experiences of those who have generated change, identify alternatives that are feasible to implement and take active steps to work with partners to develop and implement evidence-based alternatives to coercion in the delivery of mental healthcare.

Instead of comparing the draft to existing national mental health laws, we encourage member states to take a proactive and visionary stance to making the UNCRPD a reality, and in particular that mental health care systems should not rely on involuntary measures and harmful practices. We have growing knowledge of policies and practices that work towards this end and which require the attention they deserve which can and should be an inspiration to the work of the Committee.

The Committee of Bioethics is one of the most important bodies of the Council of Europe when it comes to health and human rights. Ladies and gentlemen, it is not only about your personal and expert views, the work you do today here can have significant consequences for your countries and people in Europe for decades to come. Therefore, we urge you to be aware of this significance, your political responsibility and stop the work on the draft Protocol.

Thank you.

Kristijan Grdjan, MHE Board Member
Jonas Bull, MHE Research and Policy Officer

Intervention by Inclusion Europe

On behalf of Inclusion Europe, the European movement of 20 million people with intellectual disabilities and their families, I would like to explain **why this Additional Protocol should not see the light**.

The involuntary placement and treatment within mental health care services goes against the human rights enshrined in the UN Convention on the Rights of Persons with Disabilities; these are not new but simply existing rights applied to people with disabilities.

Across Europe people with intellectual disabilities are disproportionately placed in institutional care settings, are stripped of their legal capacity and are constantly being denied their right to be included in the community.

Exclusion of people with intellectual disabilities is not new.

The Covid-19 pandemic highlights this ongoing segregation of and discrimination against people with intellectual disabilities, as residential institutions were hotbeds for infections and people living there - without much choice for most of them - were abandoned.

Therefore, we are strongly opposed to this draft additional protocol, as it goes against this very philosophy of the CRPD aiming to include people with disabilities as equal citizens.

The protocol **would create a leeway for even more exclusion** of persons with intellectual disabilities from their community.

Instead, efforts should be redirected into support measures that respect the rights of people with disabilities.

We would like the committee to listen to disability organisations, and especially people first concerned by those measures, like people with intellectual and psychosocial disabilities, and to be guided by the binding principles of the UN CRPD.

Thank you.

**Comments submitted by ENUSP
(European Network of (Ex-)Users and Survivors of Psychiatry)**

The compendium of good practices and the call for examples of good practices are welcome initiatives, in addition to the work already done on this level by NGOs, the European Union, the report commissioned by the Special Rapporteur on the Rights of Persons with Disabilities and the soon to be published collection of good practices and guidance from the WHO.

We regret that the Committee did not accept our suggestion that ENUSP, representing current and former users of mental health services directly, along with the organizations present here and other relevant members of civil society, be involved in an advisory role, to determine and weigh criteria and select practices.

In our opinion, the Committee's ongoing work on the draft Additional Protocol to the Oviedo Convention is contradictory to this compendium of good practices. This can be seen in the very title of the draft protocol. As a binding instrument, the protocol would lead States in the wrong direction. Having a binding protocol on the one hand and having nice practices on the other will certainly not "guide" States – we know from experience that "the last resort" approach does not work and inevitably is overused for many reasons, including economic, and becomes mainstream.

The idea that the protocol "prohibits discrimination on the grounds of mental health problems" is simply not true because it is exactly what this protocol does – discriminates against persons with mental health problems or psychosocial disabilities who are a separate group of the population being targeted and treated without the same human rights as others.

We, who have experienced the type of coercive "treatment" provided for in the draft protocol, express our continued opposition to this draft protocol as a violation of our human rights. Involuntary measures do not work and are counterproductive. This is particularly unwelcome just at a time when we see the winds are changing.

The representative organizations here, the many UN bodies involved in this area, and the Council of Europe's own Commissioner for Human Rights and the Parliamentary Assembly understand this change of paradigm now needed in the name of our common humanity and equality. The DH Bio Committee knows that the Parliamentary Assembly unanimously called on member states to immediately start the transition to the abolition of coercive practices in mental health settings in its Resolution in June 2019 on ending coercion in mental healthcare.

In terms of history, the Council of Europe was founded in the wake of World War II to uphold the highest standard of human rights, democracy and the rule of law in Europe. Ethics are supposed to shield us from what is morally a bad practice. And despite a variety of opinions on what this exactly means in various contexts, there is consensus across Europe that human rights must be respected at all times.

This universal respect for human rights is exactly why the European Convention on Human Rights was established on this very day (4 Nov) exactly 70 years ago with the aim of bringing us closer to the European dream of human rights, democracy and justice for all.

This was in close coherence with the establishment of the United Nations and its human rights system just five years earlier in 1945. The United Nations form the highest body authorized to interpret human rights, whereas the Council of Europe gives the European interpretation tailored to the European situation. Logically, the European interpretation of human rights should not be of lower standard or offer lower protection than the human rights standards defined in the relevant UN treaties.

Regarding the rights of persons with disabilities, the binding interpretation of human rights standards are set out by the UN CRPD Committee which is democratically elected by UN Member States. It would only be logical if the Council of Europe Bioethics Committee were to follow the human rights interpretation and guidance as provided for by the UN CRPD Committee, including their clear call to drop the draft protocol and ban forced treatments and institutionalization.

How is it possible to talk here about forced measures and institutionalization in Europe, when the UN CRPD Committee in September 2020 announced the establishment of a UN Working Group to support deinstitutionalization? When we hear the announcement at this meeting today by the Representative of the PACE that the Council of Europe is also undertaking an initiative on deinstitutionalization? On top of that, the European Union does not support institutionalization any longer as can be seen with the European social funds that are not allowed to fund segregation and human rights violations. Finally, the Covid 19 pandemic clearly shows that institutions are not safe places. On the contrary, they are places of isolation, loneliness and risk where approximately 1.3 percent of the European population currently lives, i.e., far over 9 million people. The call for deinstitutionalization is real.

Regarding the comments from the DH-Bio members from Malta and Hungary on the “right to health” prevailing over the “right to liberty” and the “right to be protected against harm from oneself or others” requiring coercion, we disagree. Of course, people in crisis deserve care and support. But the protocol is not about providing care and support, not oriented towards recovery or well-being. It is about coercive measures that are more of a criminal law nature, including deprivation of liberty, exclusion and control. In fact, it does not ensure safety or solve the problems a person faces. When you isolate a person against their will, the problems and risks only increase. This does not provide support, nor a new chance to find ways to deal with the situation. There is also no therapeutic necessity or benefit to coercion, which is why it is called a last resort, because it is undesirable and should be avoided and is in no way therapeutic.

The draft protocol conflates the concepts involved, as can be seen right from the beginning in its very title. The discussion today of “therapeutic purposes” of the use of coercion and “respecting persons wishes during coercion” demonstrates this conflation throughout, as it is impossible to respect a person’s human rights and at the same time treat and institutionalize them by force. You cannot respect a person’s wishes when subjecting them to coercion and involuntary measures.

The patients referred to earlier by the DH-Bio member from Malta, who do not find a solution in the current mental health care and support system that does not meet our needs will continue to be subject to coercion and this will not move us forward with innovative, up-to-date practices compliant with human rights. The real meaning of care and support is not imprisonment in an under-resourced setting as we experience everywhere today. In a global comparison, the deprivation of liberty of persons with disabilities in institutions is in fact a very European practice, which is still being copied in other countries. This proliferation of exclusion, confinement and even restraint practices is not something to be proud of as a European. As one of the most resourced continents, Europe must be the first to realize the call to the full extent under the UN CRPD for the abolition of forced treatment and institutionalization, to provide support in line with the will and preferences of persons with psychosocial disabilities, and ensure they enjoy rights and freedom on an equal basis with others.

Initiatives, alternatives and reforms are underway with the involvement of mental health service users, enlightened professionals in mental health care, policy and legislation throughout the world. The system will not change overnight as stated in her introduction by Reina de Bruijn-Wezeman from the PACE Committee on Social Affairs, Health and Sustainable Development. But now is not the time to backtrack by developing new instruments

facilitating involuntary placement and treatment. All states should be moving forward and investing in alternatives to eliminate coercion and developing forms of mental health care based on informed consent, the will and preferences of those concerned and ensuring that people with psychosocial disabilities live and have the services which correspond in their community. Harmful practices, such as those allowed under the draft protocol, should be banned, not permitted.

What is needed is a moratorium on forced admissions, on the use of seclusion and restraint, the administration of forced medication and other forced interventions, to be instituted with due urgency and for the work on this draft protocol to be put aside after so many years of dispute and opposition from civil society and disability organizations representing person directly concerned, as well as from the international human rights community.

The Council of Europe should stop isolating themselves from the global discourse on this topic, by which they are losing credibility as an up-to-date authoritative body. Banning coercion and active deinstitutionalization is the new norm. Therefore, we continue to strongly oppose continuing work on the draft Additional Protocol by the DH-Bio Committee.

You, the members of the Bioethics Committee could make a difference in the lives of millions of persons and their families, by making a turn, making a real change happen. Rather than striving for simple confirmation or vindication of states' current mental health legislation through this draft protocol – leaving us with the status quo and leveling down standards – ENUSP would be very happy to work on changing the paradigm together with the Council of Europe in harmony with other international organizations, in the form of a recommendation to eliminate coercive practices, implement good practices and set up mechanisms to share them between states. The Council of Europe should lead the way for its member states. We would like to see the current study of good practices be used as a basis for such a recommendation to eliminate coercive practices.

Human rights have been fought for, and people have stood up for their rights even when it was dangerous to speak. And it is now up to us all to take this further, and push to realize the goals we have set for ourselves: a Europe that is truly upholding the highest standard of human rights.

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