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COMMITTEE ON BIOETHICS (DH-BIO)

Additional Protocol on the protection of the human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment

Compilation of comments received during the public consultation

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PACE

Jonas Gunnarsson, General Rapporteur on the Rights of LGBT people

Dear Ms Lwoff,

I refer to your letter of 22 June 2015 regarding the decision taken by the Committee on Bioethics to submit to public consultation the draft Additional Protocol to the Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment.

First, I would like to convey to you my appreciation of the possibility given to the public and relevant stakeholders to contribute to the drafting of an international treaty relating to fundamental human rights issues.

In my capacity as General Rapporteur on the Rights of LGBT people of the Parliamentary Assembly of the Council of Europe, I would like to share with you my concern as regards the definition given in the draft text to the term “mental disorder”.

Draft Article 2, paragraph 4, provides that: “For the purpose of this Protocol, the term (...) “mental disorder” is defined in accordance with internationally accepted medical standards” (lines 60-61). The draft explanatory report specifies that “an example of an internationally accepted medical standard is that provided by Chapter V of the World Health Organization’s International Statistical Classification of Diseases and Related Health Problems, which concerns Mental and Behavioural Disorders (ICD-10).”

I understand that the purpose of this provision is to ensure consistency in the implementation of the protocol by avoiding a situation in which each State Party defines at national level the term “mental disorder”. My concern is however that “gender identity disorders” are today still covered by the ICD-10 (F64). This implies that transgender persons are listed as having a mental illness and could therefore be included in the scope of application of this draft protocol on involuntary placement and treatment. In Ukraine, for example, Order No. 60 of 2011 of the Ministry of Health requires transgender persons seeking to change their legal gender to undergo 30 to 45 days of confinement in a psychiatric institution to be diagnosed with “transexualism”. This mandatory psychiatric treatment is denounced by human rights organisations, such as Human Rights Watch and Transgender Europe, as being unnecessary and not justified on medical grounds. I fully agree and I fear that the draft protocol in its current wording could be used to justify both the qualification of “mental disorder” for transgender persons and their placement in psychiatric institutions.

In Resolution 2048(2015) on Discrimination against transgender people in Europe, adopted by the Parliamentary Assembly in April this year, the Assembly stated that “transgender people are also at particular risk of multiple discrimination. The fact that the situation of transgender people is considered as a disease by international diagnosis manuals is disrespectful of their human dignity and an additional obstacle to social inclusion.”

There is a trend in Europe towards recognising that more needs to be done to ensure genuine equality of LGBT persons, and in particular the protection of transgender persons against discrimination and stigmatisation. This involves the depathologisation of transgender identity, in the same way as homosexuality was in the 70’s. The case-law of the European Court of Human Rights has greatly contributed to the recognition of the rights of transgender persons, notably by considering that sexual orientation and gender identity are covered by

Article 14 of the ECHR which prohibits discrimination (see among others P.V. v. Spain, 2010).

In addition, the International Day of Action for Trans Depathologisation is celebrated every 24 October since 2007.

At the level of the European Union, the European Parliament adopted as far back as September 2011 a resolution calling on “the Commission and the World Health Organisation to withdraw gender identity disorders from the list of mental and behavioural disorders, and to ensure a non-pathologising reclassification in the negotiations on the 11th version of the International Classification of Diseases (ICD-11)”.

The World Health Organisation is indeed working on the ICD-11, which is expected to be adopted in 2017. I have been informed that it is proposed to remove “gender identity disorders” from the international classification of diseases. This is a step in the right direction. Nevertheless, for the time being, ICD-10 continues to apply.

I would, therefore, like to suggest a complement to paragraph 10 of the draft explanatory report, which would reflect the abovementioned considerations. It could read as follows (proposals highlighted in grey and bold):

An example of an internationally accepted medical standard is that provided by Chapter V of the World Health Organization’s International Statistical Classification of Diseases and Related Health Problems, which concerns Mental and Behavioural Disorders (ICD-10). This method of defining mental disorder aims to prevent idiosyncratic approaches to diagnosis. **However, it should be kept in mind that ICD-10 is being revised and that “gender identity disorders” should no longer be included in ICD-11 as from 2018. Council of Europe member States should already refrain from applying this category from the classification of diseases.** It also follows the jurisprudence of the European Court of Human Rights, for example in its judgement in the Winterwerp case, that: “... Article 5.1e [of the European Convention on Human Rights] obviously cannot be taken as permitting the detention of a person simply because his views or behaviour deviate from the norms prevailing in a particular society.” **The same consideration applies to persons whose gender identity is different from the gender assigned at birth.**

In short, the explanatory report should make clear that “gender identity disorders” should never be considered to constitute grounds for involuntary placement or treatment.

Finally, I would like to emphasise that ceasing to classify “gender identity disorders” as mental or behavioural disorders must never be used as an excuse to deprive transgender people of the medical care that they need.

I would be grateful if you could transmit these proposals to the Committee on Bioethics.

COUNCIL OF EUROPE

The Commissioner for Human Rights

1. The Commissioner for Human Rights would like to thank the Committee on Biethics (DH-BIO) for having invited him to provide comments on the draft Additional Protocol to the Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment (hereinafter, “the draft Additional Protocol”).
2. The present comments are based on the Commissioner’s work, and in particular on two issue papers relating to the rights of persons with disabilities published by his Office, on the right to legal capacity¹ and the right to live in the community². The Commissioner also dealt with the issues falling under the scope of the draft Additional Protocol in a large number of country reports. In some recent reports, the Commissioner examined in more detail issues concerning the use of involuntary placement and treatment in psychiatry, for example in his latest reports on Denmark³ and Norway⁴.
3. The Commissioner was invited to comment on specific provisions in the draft Additional Protocol and to suggest drafting proposals, where possible. Having carefully examined the document and its draft explanatory report, however, the Commissioner came to the conclusion that he cannot subscribe to many of the basic assumptions underpinning the draft Additional Protocol and has serious misgivings about the compatibility of the draft’s approach with the UN Convention on the Rights of Persons with Disabilities (CRPD). The Commissioner finds that limited drafting proposals and amendments would not be sufficient to allay these fundamental concerns. The present document contains, instead of drafting proposals, a non-exhaustive description of the Commissioner’s main reservations about the draft Additional Protocol and his conclusions.

The aim of the draft Additional Protocol and its approach

4. The Commissioner would like to stress that he fully understands the concerns that prompted DH-BIO to work on this issue. Involuntary placement and involuntary treatment procedures give rise to a large number of human rights violations in many member states, as he himself witnesses first-hand in his various country visits.
5. As the Commissioner has already declared in 2014, human rights violations caused in the context of involuntary placements, and more generally in connection with the use of coercion in psychiatry:

“have their roots in outdated legal frameworks, but also assumptions the validity of which are being increasingly challenged. The premise so far has been that involuntary placement of persons with mental health problems was an inevitable

¹ See the Commissioner’s Issue Paper [“Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities”](#), 2012.

² See the Commissioner’s Issue Paper, [“The right of people with disabilities to live independently and be included in the community”](#), 2012.

³ Commissioner’s report following his visit to Denmark, [CommDH\(2014\)4](#), published on 24 March 2014.

⁴ Commissioner’s report following his visit to Norway, [CommDH\(2015\)9](#), published on 18 May 2015.

necessity, since they present a danger to themselves and others. The focus was very much on designing safeguards and controls, often judicial in nature. Well, very often these safeguards do not work. The case-law of the Strasbourg Court is now full of examples where national procedures have gone terribly wrong, where the person whose life is at stake has entirely lost his say in a process which has essentially been reduced to a dialogue between the judge and the psychiatrist. We need to shift the focus to how coercion can be avoided in the first place, and how the person can best be supported in making healthcare choices.”⁵

6. The Commissioner is therefore unable to share DH-BIO’s assessment of the main cause of the violation of the human rights and dignity of persons in the context of such coercive practices set out in the letter inviting the Commission to comment, i.e. “legal gaps in certain member states, in particular concerning legal provisions governing measures for involuntary placement and treatment of persons with mental disorders”. In the opinion of the Commissioner, the problem is not only the lack of adequate safeguards and legal frameworks for the use of involuntary measures. While violations due to such legal gaps do occur in some member states, many of these are clearly already illegal under the established case law of the European Court of Human Rights and represent the worst forms of a far larger phenomenon. In the Commissioner’s experience, the larger problem is rather that the legal safeguards prove often inadequate in practice, owing to the shortcomings of existing legal systems and their inherently discriminatory nature. The Commissioner considers that human rights of persons with psychosocial disabilities are routinely violated while respecting the letter of existing legal safeguards, including some that are very similar to those proposed in the draft Additional Protocol. In other cases, the persons lack any reasonable prospect of challenging the non-respect of the safeguards, because of numerous legal and practical impediments.
7. In the opinion of the Commissioner, a system which gives extensive powers to the medical professional, while the opinion of the person concerned is only “taken into account” and where the latter bears the burden of proving (despite often facing serious impediments, for example, in relation to legal capacity) that they do not constitute a “significant risk of serious harm” to themselves or others builds an inherent imbalance into the procedure. The medical authority will always enjoy a privileged position, since in practice the judge will need to rely on the professional expertise of the doctor in assessing the existence of the danger involved, there being no precise legal definition of and criteria for establishing “significant risk of serious harm”. The person concerned also must prove, against the doctor’s assessment, that her or his ability to decide on placement is not “severely impaired” (Article 10 of the draft Additional Protocol) – this would be a daunting challenge for anyone, with or without mental disorder. It should also be borne in mind that involuntary treatment in many cases involves the use of psychoactive substances which affect the mental state and decision-making capacity of the persons concerned, and could potentially interfere with their ability to challenge decisions affecting them.
8. The letter inviting the Commissioner to comment on the draft Additional Protocol states that the aim of the text is to protect the human rights and fundamental freedoms of all persons with mental disorder with regard to the use of involuntary measures, and that it does so by promoting the use of alternatives to involuntary measures and by ensuring that the latter are only used as a last resort. However, as far as the Commissioner can see, the only relevant provision in the draft Additional Protocol, apart from the preamble,

⁵ See the [keynote speech](#) on “Monitoring the Human Rights of Persons with Disabilities in Europe”, delivered by the Commissioner at the International Symposium “Human Rights and Disability” in Vienna on 10 April 2014.

is Article 5 which provides that “Parties to this Protocol shall promote the development and use of alternatives to involuntary placement and involuntary treatment”. Compared to the numerous, detailed provisions setting out a procedure for involuntary measures, this is a rather vague provision, programmatic in nature, the assessment of which is presumably left to the national authorities. The Commissioner has doubts therefore that the drafting choices serve the avowed aims.

Compatibility with the CRPD and the Commissioner’s approach

9. In his work on disability, the Commissioner consistently refers to the UN CRPD as the international benchmark and legal reference point in all matters pertaining to disability, including psychosocial disability. “Psychosocial disability” is a term which describes the experience of persons with impairments relating to mental health conditions and which puts the emphasis not on a medical diagnosis, but on the interaction between these impairments and society and the potential violation of the basic human rights of the persons concerned as a result of that interaction. In the opinion of the Commissioner, one can no more dissociate persons with psychosocial disabilities from persons with mental disorder than, for example, people with sensory disabilities from persons who have a disorder affecting their vision or hearing. The Commissioner therefore prefers to refer to “persons with mental disorders” as “persons with psychosocial disabilities”.
10. The Commissioner notes that the Committee on Social Affairs, Health and Sustainable Development of the Parliamentary Assembly of the Council of Europe considered at its meeting in Paris on 24 March 2015 an Introductory Memorandum entitled “Involuntary Placement and treatment of people with psychosocial disability: need for a new paradigm”. It decided to make this Introductory Memorandum available to DH-BIO and the Commissioner’s Office, in order to ensure that the Assembly’s views and concerns are heard at an early stage of the drafting process. The Rapporteur of this Introductory Memorandum, Ms Guguli Magradze, described the paradigm shift in the approach to disability which was enshrined in international law by the CRPD, and raised her concerns about the draft Additional Protocol.
11. The Commissioner fully shares the views of Ms Magradze, both in terms of her initial negative assessment as to whether the Council of Europe should be drawing up an Additional Protocol which will give legal sanction to involuntary measures imposed on people with “mental disorders”, as well as her concerns regarding its elaboration process with no involvement of the disability rights organisations beyond one consultation meeting. Both of these conclusions were, in the Commissioner’s opinion, based on a sound understanding of the CRPD and the paradigm shift it embodies. More specifically on the latter aspect, Ms Magradze rightly pointed out the requirement set out in the CRPD that disability rights organisations be involved as an integral part, rather than merely consulted, in all decision-making processes concerning issues relating to persons with disabilities. Council of Europe bodies are no exception, the drafting process of the Additional Protocol therefore raises certain concerns in view of Article 4, paragraph 3 of the CRPD.
12. The Commissioner finds that the current draft does not seem to have taken account of some of the legitimate concerns regarding the Protocol contained in this Introductory Memorandum. The Commissioner furthermore notes that DH-BIO took as its starting point the Recommendation(2004)10 concerning the protection of human rights and dignity of persons with mental disorder, and that the draft Additional Protocol remains remarkably close, both in letter and spirit, to this text. However, four years after the adoption of this Recommendation, the CRPD entered into force, challenging some of the basic assumptions underpinning the approach in the 2004 Recommendation.

13. One of these is the assumption, which seems to be corroborated by the actual title of the draft Additional Protocol, that the existence of a mental disorder is the determining pre-condition for the possibility to consider involuntary placement and treatment, although other subsidiary conditions relating to risk or impaired decision-making capacity are also required. This must, however, be contrasted with the absolute prohibition contained in the CRPD of discrimination on the basis of an impairment, such as a mental disorder. The draft explanatory report clearly sets out the view that involuntary measures imposed on persons with mental disorder pose no problem of discrimination, and hence compatibility with the CRPD, since it is not the existence of the mental disorder, in itself, which justifies the use of involuntary measures.
14. It is difficult to reconcile this view with either the letter and spirit of the CRPD, nor its authoritative interpretation by the Committee on the Rights of Persons with Disabilities, the Committee set up under the CRPD in order to examine periodic reports of the States Parties, as well as receive individual communications under the Optional Protocol to the CRPD. The Commissioner notes, in particular, the Guidelines on article 14 CRPD (the right to liberty and security of persons with disabilities) adopted by the Committee in September 2015, which state the following:

“6. [...] legislation of several States Parties, including mental health laws, still provide instances in which persons may be detained on the grounds of their actual or perceived impairment, provided there are other reasons for their detention, including that they are deemed dangerous to themselves or others. This practice is incompatible with article 14; it is discriminatory in nature and amounts to arbitrary deprivation of liberty.

7. During the negotiations of the Ad Hoc Committee leading up to the adoption of the Convention there were extensive discussions on the need to include a qualifier, such as “solely” or “exclusively”, in the prohibition of deprivation of liberty due to the existence of an actual or perceived impairment in the draft text of article 14(1)(b). States opposed it, arguing that it could lead to misinterpretation and allow deprivation of liberty on the basis of their actual or perceived impairment in conjunction with other conditions, like danger to self or others. Furthermore, discussions were held on whether to include a provision for periodic review of the deprivation of liberty in the text of draft article 14(2). Civil society also opposed the use of qualifiers and the periodic review approach. Consequently, article 14(1)(b) prohibits the deprivation of liberty on the basis of actual or perceived impairment even if additional factors or criteria are also used to justify the deprivation of liberty. The issue was settled in the seventh meeting of the Ad Hoc Committee.”⁶
15. The Commissioner observes that this interpretation clearly contradicts DH-BIO’s interpretation of the relevant articles of the CRPD.
16. DH-BIO’s position on this issue is also difficult to reconcile with the Commissioner’s own approach so far, who stressed on several occasions that there is a clear European trend towards reinforcing the rights and self-determination of patients and their participation in decisions about care, and that people with psychosocial disabilities should not be excluded from this development. All people with disabilities have the right to enjoy the highest attainable standard of health without discrimination and the care provided to them should be based on free and informed consent in line with Article 25 of the CRPD.

⁶ Committee on the Rights of Persons with Disabilities, Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities, adopted during the Committee’s 14th session, held in September 2015.

17. More specifically, in his report on Norway, for example, the Commissioner urged the authorities to “reform legislation on involuntary placements in a way that it applies objective and non-discriminatory criteria which are not specifically aimed at people with psychosocial disabilities, while ensuring adequate safeguards against abuse for the individuals concerned”.⁷ The Commissioner also stated that medical treatment should be based on free and fully informed consent with the exception of life-threatening emergencies when there is no disagreement about the absence of decision-making capacity.⁸
18. Another crucial matter is the restriction of the legal capacity of persons with intellectual and psychosocial disabilities, despite the fact that the right to legal capacity is guaranteed on an equal basis to persons with disabilities under Article 12 of the CRPD. Most Council of Europe member states clearly lag behind the CRPD standards in this area.⁹ Restriction of legal capacity, substitute decision-making and the non-provision of adequate supports for decision making are in the Commissioner’s opinion at the core of the issues covered by the draft Additional Protocol: not only are persons who are deprived of their legal capacity often unable to formulate or withhold their free and informed consent in the first place, in a way that is recognised by the legal system, but they are also frequently not in a position to challenge satisfactorily any involuntary measure affecting them.
19. In the opinion of the Commissioner, the draft Additional Protocol deals with this crucial question only peripherally, by requiring for example that courts “take into account” the opinion of the person concerned and by allowing for a person of trust. At the same time, the draft Additional Protocol takes substitute decision-making (the “representative”) and deprivation of legal capacity, including the capacity to consent, as a given, despite their clear incompatibility with Article 12 CRPD. Furthermore, it does not address the very serious problem the Commissioner observed in several countries of conflicts of interest between the person and the legal representative, for example when a staff member of the psychiatric institution assumes this role,¹⁰ or the impossibility for persons put in this position to contact a lawyer, let alone retain one through a valid legal act, or obtain legal aid. In addition, Article 10 of the draft Additional Protocol, while defining the condition that the person’s “ability to decide is severely impaired”, does not address the right of the person to supports which would reduce or neutralise such impairment.
20. The concept of “person of trust”, introduced with Article 6 of the draft Additional Protocol is admittedly a novelty. However, the Commissioner has misgivings as to whether this new entity would be sufficient to satisfy the requirements necessary to be considered as supported decision-making, in accordance with Article 12 of the CRPD. It seems, for example, that the person of trust, while chosen by the person whose placement is at stake, can act independently of the latter’s will. This is particularly apparent under Article 12, paragraph 2, of the draft Additional Protocol which provides that the court or other competent body shall “take into account” the opinion of the person concerned (iii) and consult, “according to law, his or her person of trust” (v). In a true supported decision-making system, the support must be there to help enable the person concerned to understand the stakes, reach a decision and communicate it to others; thus “taking into

⁷ Commissioner’s report following his visit to Norway, [CommDH\(2015\)9](#), published on 18 May 2015, paragraph 41.

⁸ See the [press release](#) on the aforementioned report.

⁹ For more details on the Commissioner’s approach to legal capacity, see the aforementioned Issue Paper.

¹⁰ See, for example, the Commissioner’s report on his visit to Romania, [CommDH\(2014\)14](#), published on 8 July 2014.

account” the opinion or wishes of the person should already imply the provision of support, for example by the person of trust. The fact that the consultation of the person of trust is considered a separate legal act within the proposed legal framework suggests to the Commissioner that the draft Additional Protocol is still operating under an implicit substitute decision-making paradigm, also when it comes to the person of trust.

21. The Commissioner considers that this approach is not only in conflict with the CRPD, but would also undermine the purported goal of the draft Additional Protocol to reduce involuntary placement and treatment. As the Commissioner observed in his aforementioned report on Norway, “the availability of supported decision-making alternatives and reasonable accommodation measures can contribute significantly towards the development of alternatives to coercion” and support the ultimate objective of “drastically reducing and progressively eliminating” coercive practices in psychiatry.¹¹

Potential contribution of the draft Additional Protocol to legal certainty concerning involuntary measures

22. Regardless of the observations made above, the Commissioner is of the view that one of the added values of the draft Additional Protocol could have consisted in creating more legal certainty for the use of coercive measures in psychiatry, thereby limiting cases of abuse. However, the Commissioner considers that the draft Additional Protocol leaves an unduly large margin of appreciation to national authorities, judges and medical professionals, by ruling out clearly only the most egregious forms of abuse, i.e. where involuntary measures are ordered without regard to due process and the minimum guarantees under Article 5 of the European Convention of Human Rights, or administered by unqualified personnel. The Commissioner is concerned that this margin of appreciation is so large that it could potentially appear to sanction in international law entirely unacceptable limitations of basic human rights.
23. One of the most worrying aspects in that regard is the extraordinarily large scope of the definition of “mental disorder” “in accordance with internationally accepted medical standards” (Article 2). The draft Additional Protocol does not define what these standards are, but its explanatory report cites as an example Chapter V of the World Health Organization’s *International Statistical Classification of Diseases and Related Health Problems*, which concerns *Mental and Behavioural Disorders* (ICD-10). The Commissioner observes that in its last iteration, ICD-10 covers a vast array of disorders such as, for example, mild depressive episode, various neurotic disorders, nonorganic insomnia, sexual dysfunction, or even abuse of non-dependence-producing substances such as vitamins or herbal remedies. Even more problematically, transsexualism and gender identity disorder of childhood are considered to be “mental disorders” according to this nomenclature. In short, the list is extremely open-ended and might potentially increase, rather than decrease, the risk of abuse.
24. The Commissioner finds that the definitions of a number of other legal concepts and the formulation of some of the Parties’ obligations are similarly vague or problematic. Thus, “therapeutic purpose” includes “management” of the disorder (Article 2) for example, which could be understood as sanctioning an open-ended placement. The draft Additional Protocol also provides that persons subject to involuntary placement and/or treatment (Article 4) shall be cared for in the “least restrictive environment available and with the least restrictive or intrusive treatment available”. The non-availability of less restrictive measures for whatever reason, for example owing to material shortcomings,

¹¹ Commissioner’s report following his visit to Norway, [CommDH\(2015\)9](#), published on 18 May 2015, paragraph 42.

would appear to justify the use of more restrictive measures if the text is interpreted literally.

25. The Commissioner already stated above that he considers that Article 5 on the promotion of alternative measures is too weak to contribute to a real improvement of the situation on the ground. Similarly, Article 8 provides that care should be delivered in accordance with “professional obligations and standards by staff having the requisite competence and experience” and Article 9 provides that involuntary measures take place in an “appropriate environment”. Both these articles appear overly broad and circular to the Commissioner, the precise content of what constitutes “requisite competence and experience” or “appropriate environment” being left entirely to the discretion of the Parties, with only very little guidance on the matter provided in the non-binding explanatory report.
26. As regards the provisions at the heart of the draft Additional Protocol, the Commissioner already expounded above on his concerns regarding the lack of certainty around the notions used in Article 10 of “significant risk of serious harm”, and impairment of the ability to decide on placement. In the absence of a clearer indication, for example a life-threatening situation, the assessment of the significance of the risk and the seriousness of the harm is entirely left to the discretion of the doctor, whose examination provides the basis on which the entire procedural system established under Articles 12 to 15 rests.
27. The Commissioner already addressed above the issue of why legal safeguards are not in themselves a sufficient guarantee against the violation of the human rights of persons with psychosocial disabilities owing to, *inter alia*, the presumption in favour of the medical professional, and the fact that the person is merely consulted in the process. In any case, the Commissioner considers that these guarantees, possibly with the exception of the person of trust (the consultation of whom is however qualified as being required only “according to law”), are already firmly established in the case-law of the European Court of Human Rights. Three aspects are, nonetheless, particularly worrying to the Commissioner:
 - that a decision of involuntary treatment of a person already subject to placement can be unilaterally taken by the doctor (Article 12, para. 3);
 - that the emergency procedure provided for under Article 13 allows for the bypassing of a court or even the prior consultation of the person;
 - that the draft Additional Protocol does not set a specific statutory limit, not even an indicative one in the explanatory report, as to the maximum time period beyond which the placement decision must be reviewed (while “48 or 72 hours” is mentioned as an example in the explanatory report in relation to the emergency procedure). The length of this period is thus entirely left to the Parties’ discretion.
28. In view of these elements, the Commissioner is not persuaded that the draft Additional Protocol would bring a significant added value in comparison to safeguards already clearly established in the case-law of the European Court of Human Rights and in the national legislation of the vast majority of member states. On the other hand, the Commissioner is concerned that its adoption would present a certain number of risks.

Potential risks in case of the adoption of the draft Additional Protocol

29. The Commissioner is concerned that, if the draft Additional Protocol is adopted, the broadness of some of the provisions examined above may lead to a situation in which a legally binding international treaty appears to sanction practices which were not intended by the drafters and which are indisputable violations of human rights. He is of

the view that, in the absence of clear and precise legal definitions, the draft Additional Protocol leaves a great deal of margin of appreciation to the national legislation, which will eventually be filled with the prevailing ethical standards and approaches of the psychiatric profession in the country in question, or failing that, the views and practices of doctors in individual cases.

30. Unfortunately, the history of psychiatry is riddled with examples which appear completely unethical today: to give a provocative example, in the not-too-distant past, electroconvulsive therapy was used to treat what was seen as “disorders” of sexual orientation or gender identity (the latter is still considered a mental disorder by WHO, as mentioned above). The Commissioner wonders if such practices would have necessarily been discouraged, had one applied the legal safeguards contained in the draft Additional Protocol, since the general consensus at the time was that these “disorders” constituted a “significant risk of serious harm”, thereby justifying involuntary placement (for an undefined maximum period) and involuntary treatments which appear barbaric today but which at the time were believed to serve a “therapeutic purpose”.
31. The Commissioner reiterates that severe violations of the human rights of persons with psychosocial disabilities occur today, in many countries in Europe, despite the existence of safeguards similar to the ones foreseen in the draft Additional Protocol. Today, thanks to the impetus given by the disability rights movement, which includes associations of users of psychiatry, as well as the paradigm shift embodied in the CRPD, such practices are being increasingly challenged by national and international human rights mechanisms, including the Commissioner himself. However, the adoption of the draft Additional Protocol now would send a mixed message and risk giving the semblance of legitimacy to such violations, including practices that the Commissioner severely criticised in the past, such as the use of non-consensual electroconvulsive therapy.¹² It would also render the awareness-raising work of the Commissioner on these issues considerably more difficult.
32. The Commissioner already pointed to the risk of an explicit conflict between international norms at the global and European levels, owing to the divergence of interpretation between the DH-BIO and the Committee on the Rights of Persons with Disabilities. He considers that such a situation would be detrimental both to the CRPD system, but also to the work of the Council of Europe. If the *only* binding legal instrument specifically targeting persons with disabilities of the Council of Europe were to be on such a controversial topic, seeking to regulate an exception to general principles of human rights, this would render it vulnerable to accusations of being discriminatory and reactionary *vis-à-vis* the CRPD system. This situation would be all the more striking since the key instrument of the Council of Europe on disability, the Council of Europe Disability Action Plan 2006-2015, is not legally binding. Furthermore, the explicit and implicit power accorded to the medical professionals in the procedures foreseen in the draft Additional Protocol, coupled with the insufficient involvement of concerned disability rights groups in its drafting process, may prompt criticism of bias in favour of the former over the latter.

Conclusion

33. For these reasons and based on his experience with country monitoring work on the subject, the Commissioner thinks that DH-BIO should not adopt the draft Additional Protocol: however well-intentioned the aim behind it, the Commissioner is not convinced that the draft is capable of fulfilling this aim, ensure compatibility with the CRPD, and

¹² See the Commissioner’s aforementioned report on Norway.

present sufficient added value to make it worthwhile taking a number of significant risks in terms of the protection of the human rights and dignity of persons with psychosocial disabilities, as well as the Council of Europe's and Commissioner's work on disability.

34. This is not to say, however, that DH-BIO could not fulfil an important gap in this field, and the Commissioner would like to make a suggestion in this respect. In his opinion, while it becomes increasingly clear what member states are not allowed to do under the CRPD, there is a great need for guidance for filling out their positive obligations and further awareness-raising. There are also extreme differences between member states: there are states which clearly operate under a medical paradigm where the individual has very little to no voice in decisions affecting her/him, including healthcare choices, and others which are much further advanced in terms of ensuring that treatment happens in the vast majority of cases with free and informed consent, with very narrowly defined exceptions limited to short periods of time. There is a clear need to promote an information exchange and sharing of best practices, and better guidance with a view to reducing the need for coercion in psychiatry in the first place and fighting against discrimination of persons with psychosocial disabilities.
35. Such guidance could include, *inter alia*, the views of the DH-BIO on the following issues, accompanied by examples of good practices from different member states:
 - How to develop non-discriminatory criteria for assessing risk to one's health or others, as well as impairment of decision-making capacity;
 - How to promote alternative measures and reduce recourse to coercion in psychiatry, as well as an excessive use of restraints or medication;
 - How to better involve patients in treatment decisions;
 - How to ensure access to adequate supports for decision-making over healthcare choices for persons with psychosocial disabilities;
 - How to involve persons with psychosocial disabilities and their representative organisations in policy-making and relevant procedures.
36. The explanatory report of the draft Additional Protocol already includes several valuable elements which could be expanded on through a comprehensive examination of practices in member states and thorough engagement with civil society. In the Commissioner's opinion, the resulting document, even if it is non-binding, would much better serve the DH-BIO's ultimate goal to protect the dignity of persons with psychosocial disabilities and promote alternatives to involuntary measures.
37. The Commissioner once more would like to emphasise his appreciation for the opportunity to comment on the draft Additional Protocol and remains at DH-BIO's disposal for any clarification of his views.

Committee of Experts on the Rights of Persons with Disabilities (DECS – RPD)

The Committee of Experts on the Rights of Persons with Disabilities (DECS-RPD) welcomes the opportunity to provide an opinion on the draft Additional Protocol to the Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment which is being prepared by the Committee on Bioethics (DH-BIO).

When preparing this draft Additional Protocol, account should be taken of the relevant international legal instruments, notably the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and the Council of Europe's Action Plan 2006-2015, and of the relevant case-law of the European Court of Human Rights. They should be considered as points of departure for any work of the Council of Europe in this area, notably as regards restrictive measures.

These texts reflect a “paradigm shift” to the rights of persons with disabilities: from the charitable and the medical approaches to disability to one which is firmly rooted in Human Rights and dignity. This implies highlighting the respect for human rights principles such as equality and non-discrimination, as well as participation of persons with disabilities in all decisions affecting their lives, both at individual level and through their organisations.

Chapter V of the World Health Organization’s International Statistical Classification of Diseases and Related Health Problems (ICD-10), entitled “Mental and Behavioural Disorders”, includes a series of developmental and learning disorders: thus certain persons with disabilities, for example autistic or with an intellectual deficiency, suffering from severe psychiatric disorders (case of dual diagnosis) could come under the Additional Protocol.

As such, the term ‘involuntary’ (lines 62-63: - “involuntary” refers to a placement or treatment measure applied to a person with mental disorder who objects to the measure) should be clarified. Indeed, certain persons with disabilities could undergo disproportionate or unsuitable placement and/or treatment, without understanding its possible consequences.

The term “involuntary” could usefully refer to persons with mental and behavioural disorders:

- i. who are capable of consenting to the placement and/or treatment concerned and of understanding the consequences thereof, but who refuse it; or
- ii. who are not capable of consenting to the placement and/or treatment concerned, or of understanding the consequences thereof, but who object to it.

Finally, double-diagnosed patients require a medical evaluation and complex care which can be administered only on a multidisciplinary basis and not on the advice of a single doctor only, as indicated in various points in the working document.

The DECS-RPD looks forward to continue working with the DH-BIO on this issue in the future.

UN

EUROPEAN UNION AGENCY FOR FUNDAMENTAL RIGHTS (FRA)

Thank you very much for the invitation to comment on the draft Additional Protocol to the Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment.

In June 2014, FRA provide comments, through the EU Delegation to the Council of Europe, on an earlier preliminary draft. This followed a request for comments by members of the CDDH. FRA's comments (please see Appendix) reflected concern about the overall approach of the draft Additional Protocol, and that adopting the draft Additional Protocol in its current form could raise issues for those EU Member States which have ratified the convention.

In particular, FRA's comments highlighted the authoritative interpretation provided by the Committee on the Rights of Persons with Disabilities' in its General comment No. 1 (2014). It states that "forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (Art. 17 of the CRPD), freedom from torture (Art. 15 of the CRPD), and freedom from violence, exploitation and abuse (Art. 16 of the CRPD)" (§38).

In addition, I would like to draw your attention to the [CRPD Committee's Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities](#) which were adopted in September 2015. The guidelines (attached) further elaborate the Committee's position with regard to involuntary placement and involuntary treatment. They reiterate the Committee's call for States parties to "repeal provisions which allow for involuntary commitment of persons with disabilities in mental health institutions based on actual or perceived impairments" (§10).

FRA will inform the other members of the EU Framework to promote, protect and monitor the implementation of the CRPD, established under Article 33(2) of the convention about the ongoing process.

FRA would be interested in continuing to follow the drafting process.

APPENDIX

Comments on Draft Additional Protocol to the Oviedo Convention

CDDH members were invited to comment on the form and substance of the draft Additional Protocol to the Convention on human rights and biomedicine concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment (Oviedo Convention). More particularly, CDDH members were invited to express their preferences on three questions concerning the definition of the scope of the protocol, minors and persons of trust.

The European Union Agency for Fundamental Rights' (FRA) comments do not respond to these specific questions but address the form of the draft as a whole, reflecting concern about the overall approach of the draft Additional Protocol.

The Oviedo Convention covers issues of great importance which FRA has addressed in the course of its report *Involuntary placement and involuntary treatment of persons with mental health problems*. This report examined current international legal standards and presented a comprehensive analysis of the EU Member States' legal frameworks in this area. The FRA results could be discussed in the CDDH if felt useful.

The UN Convention on the Rights of Persons with Disabilities (CRPD) was adopted in December 2006 and entered into force in May 2008, profoundly altering the legal framework concerning the rights of persons with disabilities, including persons with psychosocial disabilities. FRA's report on involuntary placement and treatment concludes that reconciling the non-discrimination principles of the CRPD with existing mental healthcare provisions represents a major challenge for EU Member States, as it would require a significant evolution in their current legal frameworks.

Since the entry into force of the UN Convention, the CRPD Committee has continued to elaborate its authoritative interpretation of the CRPD. It recently adopted General comment No 1 (2014) which states that "forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (Art. 17 of the CRPD), freedom from torture (Art. 15 of the CRPD), and freedom from violence, exploitation and abuse (Art. 16 of the CRPD)" (§38).

In relation to involuntary placement and treatment procedures, the General Comment underlines that "State parties have an obligation not to permit substitute decision-makers to provide consent on behalf of persons with disabilities" (§37). Additionally, the Committee recommends with regard to involuntary treatment "that State parties ensure that decisions relating to a person's physical or mental integrity can only be taken with the free and informed consent of the person concerned" (§38).

Furthermore, in its Concluding Observations, the CRPD Committee has called on State parties to take the "necessary legislative, administrative and judicial measures to ensure that no one is detained against their will in any medical facility on the basis of actual or perceived disability" (CRPD/C/SWE/CO/1, § 36).

One of the general obligations set out in Article 4 of the CRPD is to consult closely with and actively involve persons with disabilities, through their representative organisations, in decision-making processes concerning issues relating to persons with disabilities. The CDDH could therefore consider sharing the draft Additional Protocol with members of civil society for their comments.

Following the entry into force of the CRPD, national legislation in those countries that have ratified the convention will need to be harmonised with the CRPD and its interpretation by the CRPD Committee, including in the area of involuntary placement and involuntary treatment. The EU itself, as well as 25 of the 28 EU Member States and a large number of Council of Europe Member States, have ratified the CRPD as of May 2014. Adopting the draft Additional Protocol to the Oviedo Convention in its current form might raise issues for those EU Member States which have ratified the convention.

UNITED NATIONS

United Nations Committee on the Rights of persons with Disabilities (CRPD)

Maria Soledad Cisternas, Chairperson of the Committee on the Rights of Persons with Disabilities

On behalf of the United Nations Committee on the Rights of Persons with Disabilities, I present my compliments to the members of the Committee on Bioethics of the Council of Europe and would like to refer to the draft Additional Protocol to the Convention on Human Rights and Biomedicine purportedly aimed at protecting the human rights and fundamental freedoms of all persons with “mental disorder” with regard to the use of involuntary placement and involuntary treatment.

The United Nations Committee on the Rights of persons with Disabilities (hereinafter, the Committee) is the international monitoring body of the United Nations Convention on the Rights of Persons with Disabilities (hereinafter, the Convention), the first human rights treaty of the XXI century, which has been ratified by 159 Member States of the United Nations and 1 regional integration organization, the European Union.

The Committee is appreciative that the Committee on Bioethics of the Council of Europe has decided to conduct and open consultation process in relation to the draft Additional Protocol.

The Committee provides this opinion, based in its jurisprudence, with the aim of further assisting Member States of the Council of Europe that are parties or signatories to the Convention on the Rights of Persons with Disabilities, in fulfilling their international obligations under the Convention. Out of the current 47 Member States of the Council of Europe, 41 are also parties to the Convention on the Rights of Persons with Disabilities, and another five have signed the Convention. The Convention is legally binding on ratifying parties, while signatories, according to customary international law, are required to behave in manner consistent with the object and purpose of the treaty.

The Committee would like to highlight that involuntary placement or institutionalization of all persons with disabilities, and particularly of persons with intellectual or psychosocial disabilities, including persons with “mental disorders”, is outlawed in international law by virtue of article 14 of the Convention, and constitutes arbitrary and discriminatory deprivation of liberty of persons with disabilities as it is carried out on the basis of actual or perceived impairment.

The Committee would like to recall that involuntary institutionalization and involuntary treatment, which are grounded on therapeutic or medical necessity, do not constitute measures for protecting the human rights of persons with disabilities, but they are an infringement of persons with disabilities’ rights to liberty and security and their right to physical and mental integrity.

Furthermore the Committee would like to recall that in order to ensure that medical treatment is compliant with the right of persons with disabilities to their physical and mental integrity, and pursuant to article 15 (freedom from torture or cruel, inhumane or degrading treatment or punishment), 17 (protecting the integrity of the person) and 25 of the Convention (right to health), States parties to the Convention have an obligation to require all health and medical professionals (including psychiatric professionals) to obtain the free and informed consent of persons with disabilities prior to any treatment, so that persons with

disabilities' rights, autonomy, will and preferences are duly respected. States parties have an obligation not to permit substitute decision-makers to provide consent on behalf of persons with disabilities. States parties must also abolish policies, legislative and administrative provisions that allow or perpetrate forced treatment, as it is an ongoing violation found in mental health laws across the globe, despite empirical evidence indicating its lack of effectiveness and the views of people using mental health systems who have experienced deep pain and trauma as a result of forced treatment.

In order to further provide guidance on the afore-mentioned issues to States parties to the Convention, regional bodies, international cooperation mechanisms, national monitoring mechanisms, organizations of persons with disabilities and civil society organizations, the Committee has developed Guidelines on the right of persons with disabilities to liberty and security, which are attached as an annex to this letter.

The Committee would like to recall that, pursuant to article 4.1.d) of the Convention, Member States of the Council of Europe that are parties to the Convention, should refrain from engaging in any act or practice that is inconsistent with the Convention, including by engaging in the negotiation of regional standards that are not in line with the human rights approach to disability enshrined in the Convention.

The Committee reiterates its willingness and commitment to further engage with regional bodies so that international efforts, both at the universal and regional level, for the promotion and protection of the rights of persons with disabilities are consistent with the international human rights standards set forth in the Convention.

ANNEX

Committee on the Rights of Persons with Disabilities

Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities

The right to liberty and security of persons with disabilities

Adopted during the Committee's 14th session, held in September 2015

I. Introduction

1. Since the Committee on the Rights of Persons with Disabilities (hereinafter, the Committee) adopted a statement on article 14 of the United Nations Convention on the Rights of Persons with Disabilities (hereinafter, the Convention), in September 2014, (CRPD/C/12/2, Annex IV), some United Nations bodies as well as inter-governmental processes have developed guidelines on the right to liberty and security as well as on the treatment of prisoners, which make reference to the deprivation of liberty of persons with disabilities. Some regional bodies have also considered adopting additional binding instruments which would allow for involuntary internment and forced treatment of persons with intellectual and psychosocial disabilities. The Committee, on the other hand, has further developed its understanding of article 14 while engaging in constructive dialogues with several States parties to the Convention.

2. The Committee, being the international monitoring body of the Convention, has adopted these guidelines to provide further clarification to States parties, regional integration organizations, National Human Rights Institutions and national monitoring mechanisms, organizations of persons with disabilities, civil society organizations as well as United Nations agencies, bodies, and independent experts about the obligation of States parties pursuant to the Convention on the Rights of Persons with Disabilities to respect, protect and

guarantee the right of persons with disabilities to liberty and security. These guidelines replace the statement adopted by the Committee on article 14 of the Convention.

II. The right to liberty and security of persons with disabilities

3. The Committee reaffirms that liberty and security of the person is one of the most precious rights to which everyone is entitled. In particular, all persons with disabilities, and especially persons with intellectual disabilities and psychosocial disabilities are entitled to liberty pursuant to article 14 of the Convention.

4. Article 14 of the Convention is, in essence, a non-discrimination provision. It specifies the scope of the right to liberty and security of the person in relation to persons with disabilities, prohibiting all discrimination based on disability in its exercise. Thereby, article 14 relates directly to the purpose of the Convention, which is to ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect of their inherent dignity.

5. This non-discrimination nature of article 14 provides evidence of the close interrelation with the right to equality and non-discrimination (article 5). Article 5(1) recognizes that all persons are equal before and under the law and are entitled to equal protection of the law. Article 5(2) prohibits all forms of discrimination on the basis of disability and guarantees to persons with disabilities equal and effective legal protection against discrimination on all grounds.

III. The absolute prohibition of detention on the basis of impairment

6. There are still practices in which States parties allow for the deprivation of liberty on the grounds of actual or perceived impairment.¹³ In this regard the Committee has established that article 14 does not permit any exceptions whereby persons may be detained on the grounds of their actual or perceived impairment. However, legislation of several States parties, including mental health laws, still provide instances in which persons may be detained on the grounds of their actual or perceived impairment, provided there are other reasons for their detention, including that they are deemed dangerous to themselves or others. This practice is incompatible with article 14; it is discriminatory in nature and amounts to arbitrary deprivation of liberty.

7. During the negotiations of the Ad Hoc Committee leading up to the adoption of the Convention there were extensive discussions on the need to include a qualifier, such as “solely” or “exclusively”, in the prohibition of deprivation of liberty due to the existence of an actual or perceived impairment in the draft text of article 14(1)(b). States opposed it, arguing that it could lead to misinterpretation¹⁴ and allow deprivation of liberty on the basis of their actual or perceived impairment in conjunction with other conditions, like danger to self or others.¹⁵ Furthermore, discussions were held on whether to include a provision for periodic review of the deprivation of liberty in the text of draft article 14(2).¹⁶ Civil society also opposed the use of qualifiers and the periodic review approach.^{17, 18} Consequently, article

¹³ Impairment in these guidelines is understood as a physical, psycho-social, intellectual or sensory personal condition which may or may not come with functional limitations of the body, mind or senses. Impairment differs from what is usually considered the norm. Disability is understood as the social effect of the interaction between individual impairment and social and material environment as described in Art. 1 UNCRPD

¹⁴ Ad Hoc Committee, Third Session, Daily summary of discussions, May 26, 2004; Fifth Session, Daily summary of discussions, January 26, 2005

¹⁵ Ibid. Fifth Session, Daily summary of discussions, January 26, 2005

¹⁶ Originally, the provision was in article was 10(2)(c)(ii) of the draft.

¹⁷ Ad Hoc Committee, Fifth Session, Daily summary of discussions, January 27, 2005

14(1)(b) prohibits the deprivation of liberty on the basis of actual or perceived impairment even if additional factors or criteria are also used to justify the deprivation of liberty. The issue was settled in the seventh meeting of the Ad Hoc Committee.

8. The absolute ban of deprivation of liberty on the basis of actual or perceived impairment has strong links with article 12 of the Convention (equal recognition before the law). In its General Comment No. 1, this Committee has clarified that States parties should refrain from the practice of denying legal capacity of persons with disabilities and detaining them in institutions against their will, either without the free and informed consent of the persons concerned or with the consent of a substitute decision-maker, as this practice constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention.¹⁹

9. Enjoyment of the right to liberty and security of the person is central to the implementation of article 19 on the right to live independently and be included in the community. This Committee has stressed this relationship with article 19. It has expressed its concern about the institutionalization of persons with disabilities and the lack of support services in the community,²⁰ and it has recommended implementing support services and effective deinstitutionalization strategies in consultation with organizations of persons with disabilities.²¹ In addition, it has called for the allocation of more financial resources to ensure sufficient community-based services.²²

IV. Involuntary or non-consensual commitment in mental health institutions

10. Involuntary commitment of persons with disabilities on health care grounds contradicts the absolute ban on deprivation of liberty on the basis of impairments (article 14(1)(b)) and the principle of free and informed consent of the person concerned for health care (article 25). The Committee has repeatedly stated that States parties should repeal provisions which allow for involuntary commitment of persons with disabilities in mental health institutions based on actual or perceived impairments.²³ Involuntary commitment in mental health facilities carries with it the denial of the person's legal capacity to decide about care, treatment, and admission to a hospital or institution, and therefore violates article 12 in conjunction with article 14.

V. Non-consensual treatment during deprivation of liberty

11. The Committee has emphasized that States parties should ensure that the provision of health services, including mental health services, are based on free and informed consent of the person concerned.²⁴ In its General Comment No. 1, the Committee stated that States parties have an obligation to require all health and medical professionals (including psychiatric professionals) to obtain the free and informed consent of persons with disabilities prior to any treatment. The Committee stated that, "in conjunction with the right to legal capacity on an equal basis with others, States parties have an obligation not to permit

¹⁸ Ad Hoc Committee, Third Session, Daily summary of discussions, May 26, 2004

¹⁹ CRPD/C/GC/1, para.40

²⁰ CRPD/C/ESP/CO/1, paras. 35-36; CRPD/C/CHN/CO/1, para. 26; CRPD/C/ARG/CO/1, para. 24; CRPD/C/PRY/CO/1, para. 36; CRPD/C/AUT/CO/1, para. 30; CRPD/C/SWE/CO/1, para. 36; CRPD/C/CRI/CO/1, para. 30; CRPD/C/AZE/CO/1, para. 29; CRPD/C/ECU/CO/1, para. 29; CRPD/C/MEX/CO/1, para. 30.

²¹ Ibid.

²² CRPD/C/CHN/CO/1, para. 26; CRPD/C/AUT/CO/1, para. 31; CRPD/C/SWE/CO/1, para. 36.

²³ CRPD/C/KOR/CO/1, para. 29, CRPD/C/DOM/CO/1, para. 27, CRPD/C/AUT/CO/1, para. 30

²⁴ CRPD/C/ECU/CO/1, para. 29 d), CRPD/C/NZL/CO/1, para. 30, CRPD/C/SWE/CO/1, para. 36

substitute decision-makers to provide consent on behalf of persons with disabilities. All health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities.”²⁵

VI. Protection of persons with disabilities deprived of their liberty from violence, abuse and ill-treatment

12. The Committee has called on States parties to protect the security and personal integrity of persons with disabilities who are deprived of their liberty, including by eliminating the use of forced treatment²⁶, seclusion and various methods of restraint in medical facilities, including physical, chemical and mechanic restrains.²⁷ The Committee has found that these practices are not consistent with the prohibition of torture and other cruel, inhumane or degrading treatment or punishment against persons with disabilities pursuant to article 15 of the Convention.

VII. Deprivation of liberty on the basis of perceived dangerousness of persons with disabilities, alleged need for care or treatment, or any other reasons.²⁸

13. Throughout all the reviews of State party reports, the Committee has established that it is contrary to article 14 to allow for the detention of persons with disabilities based on the perceived danger of persons to themselves or to others. The involuntary detention of persons with disabilities based on risk or dangerousness, alleged need of care or treatment or other reasons tied to impairment or health diagnosis is contrary to the right to liberty, and amounts to arbitrary deprivation of liberty.

14. Persons with intellectual or psychosocial impairments are frequently considered dangerous to themselves and others when they do not consent to and/or resist medical or therapeutic treatment. All persons, including those with disabilities, have a duty to do no harm. Legal systems based on the rule of law have criminal and other laws in place to deal with the breach of this obligation. Persons with disabilities are frequently denied equal protection under these laws by being diverted to a separate track of law, including through mental health laws. These laws and procedures commonly have a lower standard when it comes to human rights protection, particularly the right to due process and fair trial, and are incompatible with article 13 in conjunction with article 14 of the Convention.

15. The freedom to make one’s own choices established as a principle in article 3(a) of the Convention includes the freedom to take risks and make mistakes on an equal basis with others. In its General Comment No. 1, the Committee stated that decisions about medical and psychiatric treatment must be based on the free and informed consent of the person concerned and respect the person’s autonomy, will and preferences.²⁹ Deprivation of liberty on the basis of actual or perceived impairment or health conditions in mental health institutions which deprives persons with disabilities of their legal capacity also amounts to a violation of article 12 of the Convention.

²⁵ CRPD/C/GC/1, para. 41

²⁶ CRPD/C/PER/CO/1, paras. 30 and 31; CRPD/C/HRV/CO/1, para. 24; CRPD/C/TKM/CO/, para. 32; CRPD/C/DOM/CO/1, para. 31; CRPD/C/SLV/CO/1, paras. 33-34; CRPD/C/SWE/CO/1, paras. 37-38.

²⁷ CRPD/C/NZL/1, para. 32, CRPD/C/AUS/CO/1, para. 36.

²⁸ For example, severity of impairment, observation, or prevention as a form of long-term detention

²⁹ CRPD/C/GC/1, para. 21 and 42

VIII. Detention of persons unfit to stand trial in criminal justice systems and/or incapable of criminal liability

16. The Committee has established that declarations of unfitness to stand trial or incapacity to be found criminally responsible in criminal justice systems and the detention of persons based on those declarations, are contrary to article 14 of the Convention since it deprives the person of his or her right to due process and safeguards that are applicable to every defendant. The Committee has also called for States parties to remove those declarations from the criminal justice system. The Committee has recommended that “all persons with disabilities who have been accused of crimes and... detained in jails and institutions, without trial, are allowed to defend themselves against criminal charges, and are provided with required support and accommodation to facilitate their effective participation”³⁰, as well as procedural accommodations to ensure fair trial and due process.³¹

IX. Conditions of detention of persons with disabilities

17. The Committee has expressed its concerns for the poor living conditions in places of detention, particularly prisons, and has recommended that States parties ensure that places of detention are accessible and provide humane living conditions. More recently, it recommended “that immediate steps are [to be] taken to address the poor living conditions in institutions.”³² This Committee has recommended that States parties establish legal frameworks for the provision of reasonable accommodation that preserve the dignity of persons with disabilities, and guarantee this right for those detained in prisons.³³ It has also addressed the need to “[p]romote training mechanisms for justice and prison officials in accordance with the Convention’s legal paradigm”.³⁴

18. While developing its jurisprudence under the Optional Protocol to the Convention³⁵, the Committee has affirmed that, under article 14(2) of the Convention, persons with disabilities deprived of their liberty have the right to be treated in compliance with the objectives and principles of the Convention, including conditions of accessibility and reasonable accommodation. The Committee has recalled that States parties must take all relevant measures to ensure that persons with disabilities who are detained may live independently and participate fully in all aspects of daily life in their place of detention, including ensuring their access, on an equal basis with others, to the various areas and services, such as bathrooms, yards, libraries, study areas, workshops and medical, psychological, social and legal services. The Committee has stressed that a lack of accessibility and reasonable accommodation places persons with disabilities in sub-standard conditions of detention that are incompatible with article 17 of the Convention and may constitute a breach of article 15(2).

X. Monitoring of detention facilities and review of detentions

³⁰ CRPD/C/AUS/CO/1, para. 30.

³¹ CRPD/C/MNG/CO/1, para. 25, CRPD/C/DOM/CO/1, para. 29 a), CRPD/C/CZE/CO/1, para. 28, CRPD/C/HRV/CO/1, para. 22, CRPD/C/DEU/CO/1, para. 32, CRPD/C/DNK/CO/1, para. 34 and 35, CRPD/C/ECU/CO/1, para. 29 b), CRPD/C/KOR/CO/1, para. 28, CRPD/C/MEX/CO/1, para. 27, CRPD/C/NZL/CO/1, para. 34

³² CRPD/C/HRV/CO/1, para. 24

³³ CRPD/C/COK/CO/1, para. 28 b), CRPD/C/MNG/CO/1, para. 25, CRPD/C/TKM/CO/1 para. 26 b), CRPD/C/CZE/CO/1, para. 28, CRPD/C/DEU/CO/1, para. 32 c), CRPD/C/KOR/CO/1, para. 29, CRPD/C/NZL/CO/1, para. 34, CRPD/C/AZE/CO/1, para. 31, CRPD/C/AUS/CO/1, para. 32 b), CRPD/C/SLV/CO/1, para. 32

³⁴ CRPD/C/MEX/CO/1, para. 28

³⁵ CRPD/C/11/D/8/2012

19. The Committee has stressed the necessity to implement monitoring and review mechanisms in relation to persons with disabilities deprived of their liberty. Monitoring existing institutions and review of detentions do not entail the acceptance of the practice of forced institutionalization. Article 16(3) of the Convention explicitly requires monitoring of all facilities and programmes that serve persons with disabilities in order to prevent all forms of exploitation, violence and abuse, and article 33 requires that States parties establish a national independent monitoring mechanism and ensure civil society participation in monitoring (paras. 2 and 3). Review of detentions must have the purpose of challenging the arbitrary detention and obtain immediate release, in no case it should allow for the extension of the arbitrary detention.³⁶

XI. Security measures

20. This Committee has addressed security measures imposed on persons found not responsible due to “insanity” and incapacity to be held criminally responsible. This Committee has also recommended eliminating security measures,³⁷ including those which involve forced medical and psychiatric treatment in institutions.³⁸ It has also expressed concern about security measures that involve indefinite deprivation of liberty and absence of regular guarantees in the criminal justice system.³⁹

XII. Diversion mechanisms and restorative justice schemes

21. The Committee has stated that deprivation of liberty in criminal proceedings should only apply as a matter of last resort and when other diversion programmes, including restorative justice, are insufficient to deter future crime.⁴⁰ Diversion programmes must not involve a transfer to mental health commitment regimes or require an individual to participate in mental health services; such services should be provided on the basis of the individual's free and informed consent.⁴¹

XIII. Free and informed consent in emergency and crisis situations

22. In its General Comment No. 1, the Committee states that States parties must respect and support the legal capacity of persons with disabilities to make decisions at all times, including in emergency and crisis situations. States parties must ensure that support is provided to persons with disabilities, including in emergency and crisis situations, and “accurate and accessible information is provided about service options and that non-medical approaches are made available”.⁴² The Committee also states that, “States parties must abolish policies and legislative provisions that allow or perpetrate forced treatment”, and that “decisions relating to a person’s physical or mental integrity can only be taken with the free and informed consent of the persons concerned.”⁴³ In paragraph 41 of its General Comment No. 1, the Committee states that, “in conjunction with the right to legal capacity on an equal

³⁶ CRPD/C/KOR/CO/1, para. 26

³⁷ CRPD/C/BEL/CO/1, para. 28.

³⁸ CRPD/C/ECU/CO/1, para. 29 c)

³⁹ CRPD/C/DEU/CO/1, para. 31

⁴⁰ CRPD/C/NZL/CO/1, para. 34

⁴¹ CRPD/C/AUS/CO/para.29

⁴² CRPD/C/GC/1, para. 42

⁴³ Ibid, para. 42

basis with others, States parties have an obligation not to permit substitute decision-makers to provide consent on behalf of persons with disabilities".⁴⁴

23. The Committee has also called for States parties to ensure that persons with disabilities are not denied the right to exercise their legal capacity on the basis of a third party's analysis of their "best interests", and that when after significant efforts have been made it is impracticable to determine a person's will and preferences, practices associated with "best interests" determinations should be replaced by the standard of "best interpretation of the will and preferences" of the person.⁴⁵

XIV. Access to justice, reparation and redress to persons with disabilities deprived of their liberty in infringement of article 14 taken alone, and taken in conjunction with article 12 and/or article 15 of the Convention.

24. Persons with disabilities arbitrarily or unlawfully deprived of their liberty are entitled to have access to justice to review the lawfulness of their detention, and to obtain appropriate redress and reparation. The Committee calls States parties' attention to Guideline 20 of the "United Nations Basic Principles and Guidelines on remedies and procedures on the right of anyone deprived of their liberty to bring proceedings before a court", adopted by the Working Group on Arbitrary Detention on 29 April 2015, during its 72th session. Guideline 20 contains specific measures for persons with disabilities, including the following:⁴⁶

"126. The following measures shall be taken to ensure procedural accommodation and the provision of accessibility and reasonable accommodation for the exercise of the substantive rights of access to justice and equal recognition before the law:

(a) Persons with disabilities shall be informed about, and provided access to, promptly and as required, appropriate support to exercise their legal capacity with respect to proceedings related to the detention and in the detention setting itself.ⁱ Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substituted decision-making;ⁱⁱ

(b) Persons with psychosocial disabilities must be given the opportunity to promptly stand trial, with support and accommodations as may be needed, rather than declaring such persons incompetent;

(c) Persons with disabilities can access, on an equal basis with other persons subject to detention, buildings in which law-enforcement agencies and the judiciary are located. The jurisdictional entities must ensure that their services include information and communication that is accessible to persons with disabilities.ⁱⁱⁱ Appropriate measures shall be taken to provide signage in Braille and in easy to read and understand forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to communication in the facilities of jurisdictional entities;^{iv}

(d) Individuals who are currently detained in a psychiatric hospital or similar institution and/or subjected to forced treatment, or who may be so detained or forcibly treated in the future, must be informed about ways in which they can effectively and promptly secure their release including injunctive relief;

(e) Such relief should consist of an order requiring the facility to release the person immediately and/or to immediately cease any forced treatment, as well as systemic measures such as requiring mental health facilities to unlock their doors and inform persons of their right to leave, and establishing a public authority to provide for access to housing, means of subsistence and other forms of economic and social

⁴⁴ Ibid, para. 41

⁴⁵ Ibid, para. 21

⁴⁶ A/HRC/30/36

support in order to facilitate de-institutionalization and the right to live independently and be included in the community. Such assistance programs should not be centred on the provision of mental health services or treatment, but free or affordable community-based services, including alternatives that are free from medical diagnosis and interventions. Access to medications and assistance in withdrawing from medications should be made available for those who so decide;^v

(f) Persons with disabilities are provided with compensation, as well as other forms of reparations, in the case of arbitrary or unlawful deprivation of liberty.^{vi} This compensation must also consider the damage caused by the lack of accessibility, denial of reasonable accommodation, lack of health care and rehabilitation, which have affected the person with disability deprived of liberty.”

United Nations Special Rapporteur on the Rights of Persons with Disabilities

As United Nations Special Rapporteur on the Rights of Persons with Disabilities, I welcome the opportunity to submit my comments on the draft Additional Protocol to the Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment, prepared by the Committee of Bioethics’ (DH-BIO)

The comments made in the present submission take as their basis the UN Convention on the Rights of Persons with Disabilities (CRPD). To date, there are 160 States Parties to the CRPD, including 41 members of the Council of Europe.⁴⁷ As the most recently adopted international human rights treaty focusing on the rights of persons with disabilities, the CRPD stands as the most authoritative instrument to guide the formulation of any standards, laws or guidelines related to the rights of persons with disabilities, which includes persons with intellectual and persons with psychosocial disabilities, and fully covers the scope of the draft Additional Protocol.

My principal concern with the draft Additional Protocol is that it neglects both the letter and spirit of the CRPD. Although the CRPD is explicitly referred to in the Protocol’s preamble, the draft provisions fall short of, or are expressly in conflict with the human rights standards of persons with disabilities enshrined within the CRPD and developed by the CRPD Committee.

Similarly, the statement adopted in 2011 by the Steering Committee on Bioethics (CDBI) on the Convention on the Rights of Persons with Disabilities⁴⁸ which appears to declare a compatibility between the Protocol and the CRPD, is inconsistent with the CRPD and the CRPD Committee’s jurisprudence, including the most recently elaborated Guidelines on Article 14⁴⁹ adopted in September 2015.

DH-BIO is encouraged to align its work with CRPD standards as expressed by the CRPD Committee, which are increasingly used by other United Nations human rights mechanisms. The overall approach must be founded in human rights, ensuring non-discrimination in the

⁴⁷ The following six Council of Europe member states have not yet ratified the CRPD - all, with the exception of Liechtenstein, have signed the CRPD: Netherlands, Ireland, Finland, Iceland, Monaco & Liechtenstein.

⁴⁸ Statement on the United Nations Convention on the Rights of Persons with Disabilities adopted by the Steering Committee on Bioethics, Appendix II to Abridged report of the 41st plenary meeting (2-4 November 2011), CM(2011)172, 9 December 2011 available at <https://wcd.coe.int/ViewDoc.jsp?id=1885295&Site=CM>

⁴⁹ See www.ohchr.org/Documents/HRBodies/CRPD/GC/GuidelinesArticle14.doc

enjoyment and exercise of rights and engagement in meaningful consultation and participation of persons with disabilities.

Human rights based approach

The draft Additional Protocol purports to protect the dignity, respect for integrity and fundamental rights and freedoms of “all persons with mental disorders”. However, there is a stark disparity between this and the overall purpose of the text, which is *involuntary* placement and *involuntary* treatment which targets “persons with mental disorder”. By the very nature of “involuntary”, the draft Additional Protocol necessarily denies individual dignity and integrity in violation of a series of human rights. The draft Additional Protocol justifies these practices on the basis of treatment and therapeutic purpose (defined as including “management or cure of the disorder and rehabilitation”) or for the protection from harm of self or others. This approach continues to uphold and sustain the medical model of disability which views disability as residing within the individual and thus renders them objects of treatment; permitting their decision-making and views to be dismissed and displaced on the basis of a medical opinion.

The history of psychiatry demonstrates that the good intentions of service providers can turn into violations of the human rights of service users. The traditional arguments that restrict the human rights of persons diagnosed with psychosocial and intellectual disabilities, which are based on the medical necessity to provide those persons with necessary treatment and/or to protect his/her or public safety, are now seriously being questioned as they are not in conformity with the CRPD.

The human rights standards set forth by the CRPD provide a call to rethink the historical legacy of previous models and to move away from those health-care practices which are against human rights and the modern public health approach. There is a unique and historic opportunity to end the legacy of the overuse and misuse of the biomedical model.

There needs to be a departure from the medical model of disability toward the human rights based model which places the individual at the centre of the enjoyment and exercise of rights and decision-making. Selective approaches to human rights reinforce inequalities, social exclusion, discrimination and violence and are detrimental to the full enjoyment of rights. Adoption of a human rights based approach must be all-encompassing and prioritise human dignity and integrity and individuals as subjects of their rights, with full exercise of rights, including with the provision of support where requested.

Non-discrimination

Non-discrimination as a principle and a right must be a central feature of any human rights instrument. The CRPD enshrines the rights of persons with disabilities and elaborates upon how they must be upheld on an equal basis with others. Given the historical marginalisation of persons with disabilities, it was necessary to articulate these rights and make clear that restrictions or denials based on disability constitute human rights violations.

Non-discrimination applies across the enjoyment and exercise of all rights including: the right to liberty and security of person, equal recognition before the law, freedom from torture, cruel, inhuman and degrading treatment or punishment, protection of personal integrity, right to live independently and be included in the community, and the right to health. Regardless of intent, any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of compromising the enjoyment and exercise of rights on an equal basis with others constitutes discrimination.

Right to liberty and security of the person – prohibition of involuntary/forced detention, hospitalisation, institutionalisation

The CRPD Committee’s jurisprudence and recently adopted Guidelines on Article 14 set out that there is an absolute prohibition of detention on the basis of actual or perceived impairment. The draft Protocol states that “the existence of a mental disorder *in itself* shall in no case justify an involuntary measure”.⁵⁰ Proposals made during the drafting of the CRPD to qualify the criteria for involuntary measures by the addition of terms such as “in itself” or “solely” were strongly rejected given that they would permit and result in the deprivation of liberty on the basis of actual or perceived impairment in conjunction with other conditions, such as harm/danger to self or others, or alleged therapeutic purpose of need for treatment.⁵¹ As explained and recognised by the OHCHR, “since such measures are partly justified by the person’s disability, they are to be considered discriminatory and in violation of the prohibition of deprivation of liberty on the grounds of disability, and the right to liberty on an equal basis with others prescribed by Article 14.”⁵² Hence, while the criteria purport to be objective and reasonable, in practice they have the effect of targeting persons with disabilities, in particular persons with psychosocial and persons with intellectual disabilities who are commonly considered as being a danger to self or others and in need of treatment or care.

Regarding the criteria of dangerousness, legal systems are already equipped to deal with persons established as dangerous through general criminal law and procedure. Yet persons with disabilities are frequently denied equal protection under these laws; as a category, they may -without act or cause- be pre-determined as dangerous and diverted to a separate system for treatment (under mental health laws or related provisions within criminal law). The fact that persons with disabilities are subjected to an alternative system, distinct from what is applied to everyone else and in which the standard of rights protection is inferior to that applied to others in terms of due process, fair trial and deprivation of liberty, infringes the right to non-discrimination, access to justice, and the right to liberty under Articles 5, 13 and 14 of the CRPD. Involuntary placement, whether in hospitals or institutions, also breaches the right to live in the community under Article 19 of the CRPD.⁵³

Recently, in September 2015, the UN Working Group on Arbitrary Detention presented to the Human Rights Council its Basic Principles and Guidelines on remedies and procedures on the right of anyone deprived of their liberty to bring proceedings before a court. Following CRPD standards, this instrument calls on States to:

“comply with the obligation to prohibit involuntary committal or internment on the ground of the existence of an impairment or perceived impairment, particularly on the basis of psychosocial or intellectual disability or perceived psychosocial or intellectual disability, as well as with their obligation

⁵⁰ Preamble, lines 28 and 29.

⁵¹ In the course of the third session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, proposals were made to add the word “solely” to then draft article 10, paragraph 1 (b), so it would read “any deprivation of liberty shall be in conformity with the law and in no case shall be based solely on disability”.

⁵² OHCHR, Thematic Study on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities, A/HRC/10/48, 26 January 2009, para 48.

⁵³ See Action Line no 8 on Community Living of Council of Europe Disability Action Plan 2006-2015 and Recommendations of Issue Paper of Commissioner for Human Rights, “The right of people with disabilities to live independently and be included in the community”, Council of Europe, June 2012, pp. 7-8.

to design and implement de-institutionalization strategies based on the human rights model of disability.”⁵⁴

Like the Working Group, other human rights mechanisms should be vigilant to respect and align themselves with CRPD standards when addressing the human rights of persons with disabilities.

Protection of integrity of the person, right to health, freedom from torture, cruel, inhuman degrading or punishment- prohibition of involuntary/forced treatment

Regarding the draft Protocol’s criteria of need for treatment/care, therapeutic purpose or medical necessity, this is yet another example of a departure from a standard of rights that is applicable to all, on the grounds of disability. Whilst the general standard is the right to free and informed consent, this right has been systematically derogated when it comes to persons with disabilities considered to be incapable of making decisions or incapable of making decisions according to their ‘best interest’. The general standard permits that even measures which are considered to be life saving or in one’s ‘best interest’ can be rejected based on an individual’s decision and that treatment imposed against one’s will is prohibited and must be punished as an infringement of human dignity and the right to physical and mental integrity. The long standing practice within psychiatry and which the present draft Protocol foresees to perpetuate is a derogation of this standard -a derogation which the CRPD rejects as discriminatory. Forced treatment, whether imposed on persons with or without disabilities, is always a violation of one’s dignity and integrity because it acts against one’s will and autonomy.

Arguments which advance treatment for therapeutic purpose or medical necessity based on health grounds cannot and should never override freedom of consent to accept or reject treatment. The right to free and informed consent is an inherent element of the right to health. Article 25 of the CRPD on the right to health explicitly stipulates that health care is provided on the basis of free and informed consent without discrimination. The UN Committee on Economic, Social and Cultural Rights (CESCR Committee) also sets out in its General Comment on the right to the highest attainable standard of health that:

“The right to health is not to be understood as a right to be *healthy*. The right to health contains both freedoms and entitlements. The freedoms include the right to control one’s health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, *non-consensual medical treatment* and experimentation. By contrast, the entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.”⁵⁵

It is clear that health is not an end in itself that can be pursued independent of the will of the individual, but enjoyment of the right to health requires respect for each individual’s will and autonomy over their own physical and mental integrity. Any argument which permits supplanting individual consent on the basis of ‘therapeutic purpose’ or ‘medical necessity’ is in conflict with international human rights standards on the right to health.

Further, the concept of ‘therapeutic purpose’ or ‘medical necessity’ behind non-consensual placement and treatment falls short of scientific evidence and sound criteria. The legacy of

⁵⁴ Report of the Working Group on Arbitrary Detention, United Nations Basic Principles and Guidelines on the right of anyone deprived of their liberty to bring proceedings before a court, WGAD/CRP.1/2015, May 2015, para 56.

⁵⁵ General Comment No. 14 (2000), The right to the highest attainable standard of health (Article 12, International Covenant on Economic, Social and Cultural Rights), E/C.12/2000/4, 11 August 2000, para 8.

the use of force in psychiatry is against the principle '*primum non nocere*' (first do no harm) and should no longer be accepted. Moreover, there is a growing body of evidence concerning the damaging impact and ineffectiveness of forced psychiatric treatment.

As recognised by the CRPD Committee, all non-consensual treatments, such as forced medication, chemical or physical restraints, isolation/seclusion as well as electroconvulsive therapy (ECT- with or without anaesthetics or muscle relaxants) and psychosurgery, amount to violations of physical and mental integrity and freedom from cruel, inhuman and degrading treatment and may constitute torture.

Equal recognition before the law- exercise of legal capacity

The overarching premise of the present submission is that decisions, and decision making processes, of persons with disabilities be respected on an equal basis with others at all times. Equal recognition before the law and equal exercise of legal capacity lies at the heart of the CRPD and embodies the paradigm shift from the medical model of substitution of individual autonomy, will and preferences of persons with disabilities to the human rights based approach which recognises, supports and respects individual autonomy, will and preferences. General Comment no 1 of the CRPD Committee on equal recognition before the law sets out the obligation for States to respect and support the legal capacity of persons with disabilities with right to support, including in emergency and crisis situations.⁵⁶

As elaborated above, legal and policy provisions that allow or perpetrate forced treatment must be prohibited and decisions relating to one's physical or mental integrity and health can only be taken with the individual's free and informed consent. General Comment no 1 sets out the obligation of all health and medical professionals (including those from psychiatry) to obtain the free and informed consent of persons with disabilities prior to any treatment. It makes it explicit that there must be direct engagement with the individual and that consent cannot be substituted by third parties. Support may be provided to individuals to understand and come to their decisions and attention must be taken to ensure that support persons do not substitute or have undue influence over individual's decisions. And where it is not practicable to determine the will and preferences of an individual, it is not the 'best interest' principle which will prevail, but the "best interpretation of the will and preferences". The "will and preferences" paradigm must replace the dominance of "best interests" for full respect of one's legal capacity on an equal basis with others which is intimately linked with protection from non-discrimination, right to liberty and security of person, protection of integrity of person, freedom from torture, cruel, inhuman and degrading treatment, right to live in the community and right to health.

Coherence of international human rights law

The draft text of the Additional Protocol and its draft explanatory report necessarily take as their primary basis the Oviedo Convention, the Convention on Human Rights and Biomedicine. Certain provisions of the Oviedo Convention, while claiming to be a human rights instrument, do not align themselves with the latest international human rights standards as embodied in the CRPD. In particular, as discussed above, those provisions which permit for substitution of consent which essentially authorise forced treatment of persons with psychosocial disabilities and persons with intellectual disabilities, as inscribed in Articles 6, 7, 8, 17 and 20 of the Oviedo Convention, present departures from international human rights law. The departure can be explained by the fact that the Oviedo Convention was adopted in 1997, i.e. roughly ten years before the adoption of the CRPD, at a time when

⁵⁶ CRPD/C/GC/1

the rights of persons with disabilities had not fully evolved within the framework of international human rights law.

It is also recognised that the draft text refers heavily to the jurisprudence of the European Court of Human Rights as an institution of the Council of Europe. In the same manner as the Oviedo Convention, it must be acknowledged that the European Convention on Human Rights (ECHR) is an instrument which dates from 1950 and the text of the ECHR reflects a neglect and outdated approach concerning the rights of persons with disabilities.

First, Article 14, the non-discrimination provision, does not include disability in its list of prohibited grounds of discrimination, albeit leaves open the list by insertion of “or other status”, and with the entry of Protocol no 12, there is generally more flexibility to bring complaints of discrimination on any ground. Nonetheless, the first and single time that the Court has found a violation on the grounds of disability based discrimination (under Article 14) was in 2009.⁵⁷ Moreover, in matters concerning mental health detention, the 1950 text explicitly permits deprivation of liberty on the basis of “unsound mind” (Article 5(1)(e)). Even though the ECHR is considered to be a “living instrument...which must be interpreted in the light of present day conditions,”⁵⁸ the Court has faced limits in progressing towards the full recognition of the human rights of persons with disabilities, in particular concerning persons with psychosocial and intellectual disabilities as it relates to these very issues.

All new human rights instruments should seek to uphold the coherence of the corpus of international human rights law as it is developing and to take as a model those instruments which have been most recently adopted by the international community and are specialised on the very group of rights holders concerned. For example, the Committee on the Elimination of Discrimination against Women (CEDAW Committee), a sister treaty body of the CRPD Committee, aligns itself with CRPD standards on this issue, among others, by calling on States “to repeal laws and prohibit disability-based detention of women, including involuntary hospitalization and forced institutionalization”;⁵⁹ and to guarantee that “all medical interventions are based on informed consent”.⁶⁰

Similarly, a harmonised approach was taken by the UN Working Group on Arbitrary Detention which was guided by the CRPD in articulating its standards on the right to liberty of persons with disabilities and embraces a holistic view including measures to guarantee that:

“All health and support services, including all mental health-care services, are provided based on the free and informed consent of the person concerned. The denial of legal capacity of persons with disabilities and detention in institutions against their will, without their consent or with the consent of a substituted decision-maker, constitutes arbitrary deprivation of liberty in violation of international law. Perceived or actual deficits in mental capacity, that is, the decision-making skills of a person that naturally vary from one to another, must not be used as justification for denying legal capacity, understood as the

⁵⁷ *Glor v Switzerland*, Application no 13444/04, 30 April 2009

⁵⁸ *Tyrer v UK*, Application no 5856/72, 25 April 1978, para 31

⁵⁹ CEDAW Committee Concluding Observations on India, [CEDAW/C/IND/CO/4-5](#), 2014, para 37

⁶⁰ CEDAW Committee Concluding Observations on Moldova, [CEDAW/C/MDA/CO/4-5](#), 2013, para 38

ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency).”⁶¹

In the same vein, in 2011, the Inter-American Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities of the Organization of American States (OAS) adopted a resolution concerning a provision of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities. The resolution called for re-interpretation of legal capacity in light of Article 12 of the CRPD.⁶² The provision in question, which stated that a declaration of incompetence was not discrimination, was found to be contrary to the CRPD, which most states in the region had ratified. The Inter-American Committee resolved to seek conformity of the legal mandate with the more progressive standards in the CRPD, and to urge States Parties to take concrete measures to apply the new paradigm inscribed in Article 12, by phasing out declarations of incompetence and fostering the development of supported decision-making.

Way forward

DH-BIO is strongly urged to align its instruments with the corpus of international human rights law by adopting a human rights-based approach which guarantees non-discrimination of persons with disabilities before the law and upholds individual dignity, integrity and human rights.

Departing from the outdated model, the opportunity should be taken to promote the latest international human rights standards and to engage in reflection to learn from existing innovative practices which do not employ force and which respect the individual’s autonomy, will and preferences. In practical terms, this could mean refraining from adopting the draft Additional Protocol and considering how to move ahead to develop the Oviedo Convention to be true to its human rights objective and how the work of DH-BIO could evolve to support the coherence of international human rights law. It is good timing to take stock and to open a dialogue amongst stakeholders to work on human rights based solutions, including direct engagement with the CRPD Committee itself. In particular, DH-BIO is strongly encouraged to reach out to the community of users and survivors of psychiatry to proactively seek their views and expertise as they comprise the group of rights holders concerned.

I remain at your disposal should further information or clarifications be required by the Committee on Bioethics (DH-BIO) with respect to the following comments. Please do not hesitate to contact my office at: sr.disability@ohchr.org.

Catalina Devandas-Aguilar
UN Special Rapporteur on the rights of persons with disabilities

⁶¹ Report of the Working Group on Arbitrary Detention, United Nations Basic Principles and Guidelines on the right of anyone deprived of their liberty to bring proceedings before a court, WGAD/CRP.1/2015, May 2015, Guideline 20: Specific measures for persons with disabilities, para 125(b)

⁶² Resolution OEA/ Ser.L/XXIV.3.1, CEDDIS/RES.1(I-E/11), 4 May 2011; General Observation of the Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities on the need to interpret Article I.2(b) in fine of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities in the context of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, OEA/ Ser.L/XXIV.3.1CEDDIS/doc.12(I-E/11) rev.1, 28 April 2011, available at <http://bit.ly/XVallq>

Ms **Catalina Devandas-Aguilar** (Costa Rica) was designated as the first Special Rapporteur on the rights of persons with disabilities in June 2014 by the UN Human Rights Council. Ms Devandas Aguilar has worked extensively on disability issues at the national, regional and international level with the Strategic Partnerships with the Disability Rights Advocacy Fund, the UN unit responsible for the Convention on the Rights of Persons with Disabilities and the World Bank. Her work has focused on the rights of women with disabilities and the rights of indigenous peoples with disabilities. For more information on the Special Rapporteur and her mandate, please visit: <http://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/SRDisabilitiesIndex.aspx>.

The UN Special Rapporteurs are part of what is known as the ‘Special Procedures’ of the Human Rights Council. Special Procedures, the largest body of independent experts in the UN Human Rights system, is the general name of the Council’s independent fact-finding and monitoring mechanisms that address either specific country situations or thematic issues in all parts of the world. Special Procedures’ experts work on a voluntary basis; they are not UN staff and do not receive a salary for their work. They are independent from any government or organization and serve in their individual capacity.

UN Special Rapporteur on the question of torture and other cruel, inhuman or degrading treatment or punishment

Juan E. Méndez, Special Rapporteur on the question of torture and other cruel, inhuman or degrading treatment or punishment

Dear Laurence Lwoff,

I have the honour to address you in my capacity as the UN Special Rapporteur on the question of torture and other cruel, inhuman or degrading treatment or punishment in accordance with Human Rights Council resolution 25/13.

In that connection, please accept this letter to the Council of Europe Committee on Bioethics on the draft of the Additional Protocol to the Convention on Human Rights and Biomedicine (DH-BIO/INF (2015) 7).

I am aware that the UN Special Rapporteur on the Rights of Persons with Disabilities, Ms Catalina Devandas, has provided comments on the Committee of Bioethics’ (DH-BIO) draft version of the Working Document concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment (DH-BIO/INF (2015) 7) and while I concur with most of her submission, I take this opportunity to make a separate submission, in my capacity as Special Rapporteur on torture, on non-consensual treatment of persons with mental disabilities in the current framework on international human rights law on this issue.

I agree with the Special Rapporteur on Disabilities that the Convention on the Rights of Persons with Disabilities (CRPD) has altered the normative landscape on this matter in important ways and should be considered the starting point for the Protocol.

I also agree that, as drafted, the Oviedo Protocol pays lip service to the need to uphold and implement the CRPD but, in practice, does not. By and large, the Protocol continues to implement the pre-CRPD paradigm by which health care professionals make all the decisions about treatment and about restraints, as long as in their considered professional opinion such measures are medically necessary and in the best interest of the patient.

Instead, the new normative landscape establishes that a person with a mental disability does not lose autonomy to decide on what is the best treatment for him or her, and that such treatment can only be imposed with his or her fully informed and free consent.

It is for that reason that in my 2013 thematic report (A/HRC/22/53) to the Human Rights Council, I alluded to the need to bring domestic legislation in line with the CRPD, especially in the area of capacity to make decisions affecting the patient's rights. Domestic standards about capacity, guardianship and medical necessity, as well as about the duties and responsibilities of health care professionals, must be adapted and modified to give full effect to the autonomy that persons with mental disabilities retain at all times, and to the need to seek and obtain their free, full and informed consent for any therapy.

Nevertheless, my report did allow for some restraints and treatment against the will of the patient. As explained in the passages of a follow up publication on "Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture's 2013 Thematic Report" (attached to this letter) the very limited circumstances when non-consensual treatment can be legitimate must be strictly confined to when absence of such treatment represents a serious danger of harm to the patient or to other hers.

At the same time, as my report explains, even in those circumstances, the non-consensual treatment must be limited -- in specific measures as well as in time -- to the exigencies of preventing such harm to self or to others, and should cease as soon as that risk is over.

I take this opportunity to thank the Committee on Bioethics (DH-BIO) for holding consultations and eliciting comments on this working document. I hope my comments will be of assistance in the finalisation of the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment.

I remain at your disposal and should further information or clarifications be required by the Committee on Bioethics (DH-BIO) with respect to my comments, I can be contacted through Ms. Sonia Cronin (Tel.: + 41 22 917 91 60; e-mail: scronin@ohchr.org) at the Office of the High Commissioner for Human Rights.

UN Special Rapporteurs are part of what is known as the 'Special Procedures' of the Human Rights Council. Special Procedures, the largest body of independent experts in the UN Human Rights system, is the general name of the Council's independent fact-finding and monitoring mechanisms that address either specific country situations or thematic issues in all parts of the world. Special Procedures' experts work on a voluntary basis; they are not UN staff and do not receive a salary for their work. They are independent from any government or organization and serve in their individual capacity.

Mr. Juan E. Méndez (Argentina) was appointed by the UN Human Rights Council as the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment in November 2010. Mr. Méndez has dedicated his legal career to the defense of human rights, and has a long and distinguished record of advocacy throughout the Americas. He is currently a Professor of Law at the American University – Washington College of Law and was Co-Chair of the Human Rights Institute of the International Bar Association in 2010-11. To learn more, visit:

<http://www.ohchr.org/EN/Issues/Torture/SRTorture/Pages/SRTortureIndex.aspx>

Office of the United Nations High Commissioner for Human Rights – Regional Office for Europe (OHCHR-ROE)

The Office of the United Nations High Commissioner for Human Rights – Regional Office for Europe (OHCHR-ROE) – welcomes the opportunity to provide comments on the draft Additional Protocol to the Oviedo Convention concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment. We also welcome the fact that the draft Additional Protocol has been opened for public consultation.

In preparing these comments, we have consulted with a variety of civil society stakeholders, including disabled persons' organizations, human rights experts, and others. The comments below set out OHCHR-ROE's concerns with the current draft, in particular as regards alignment with the UN Convention on the Rights of Persons with Disabilities.

Departure from international standards

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) represents a paradigm shift away from the charitable and medical approach to disability. The CRPD brings a human rights-based approach to disability: it challenges paternalistic views by emphasizing the person as a rights-holder and an active subject of rights, rather than a passive object of care.

The CRPD applies to situations that the draft Additional Protocol seeks to regulate. Nevertheless, while the draft Additional Protocol refers to the CRPD in its preamble, it does not appear to take its spirit nor its provisions into account in a meaningful way, let alone to use it as a basis of the standard-setting effort. OHCHR-ROE is concerned that the draft Additional Protocol remains apparently based on the medical model of disability, i.e., as if reflecting the situation prior to adoption of the CRPD.

In our view, it is problematic for the Council of Europe to draft standards, one decade after the CRPD adoption, which do not take the aforementioned paradigm shift fully into account. Indeed, as a general rule, regional bodies such as the Council of Europe should take full account of those international standards which most of its Member States are bound by. Currently, 41 out of 47 Member States of the Council of Europe have ratified the CRPD and are thus legally bound by its provisions. Further, all States parties to the Oviedo Convention have either signed or ratified the CRPD. We are convinced that in no case should regional initiatives set standards lower than international ones when it comes to human rights protection. On the contrary, such bodies should, in their work, aim to contribute to the full implementation of those international standards.

The aim of the CRPD is the full and equal enjoyment of all human rights by persons with disabilities. According to the CRPD, persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. This definition includes persons with psychosocial disabilities. However, use of the term "mental disorder" in the draft considers persons with disabilities as patients rather than rights-holders, reflecting the medical model. According to the draft Explanatory Report the term "mental disorder" is defined broadly in accordance with internationally accepted medical standards – but that reinforces the medical perspective, rather than taking the notion of disability as enshrined in the CRPD as a starting point.

Capacity to consent and liberty and security of the person

The draft Additional Protocol as a whole concerns non-consensual treatment or placement and applies to persons who have not expressed consent to being placed or treated. Article 2 of the draft Protocol defines involuntary as: “*a placement or a treatment measure applied to a person with mental disorder who objects to the measure*”¹.

The entire approach of the draft Additional Protocol thus appears to be starting from very different premises than Article 14 of the CRPD, according to which State parties shall ensure that persons with disabilities “*shall not be deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law and that the existence of a disability shall in no case justify a deprivation of liberty*”. If persons with disabilities are deprived of their liberty “*through any process, they are entitled to guarantees in accordance with international human rights law*”. Article 14 of the Convention is, in essence, a non-discrimination provision, prohibiting all discrimination based on disability in its exercise.

Working document concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment, DH-BIO/INF (2015) 7, article 2(4).

In addition, the notion of “representative” applies in the draft Additional Protocol to cases in which a person does not have, according to law, the capacity to consent. This again contrary to Article 12(2) CRPD, which provides that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. The CRPD Committee has insisted that a person’s status as a person with disability or the existence of an impairment must never be grounds for denying legal capacity.² While some national laws currently deny legal capacity to persons with disabilities in particular cases, the CRPD Committee has specifically called on such States parties to reform these laws. In this regard, setting standards for substitute decision-making (Articles 2, 10, 11 and 12 of the draft Additional Protocol read together) instead of supported decision-making (Article 12 UN CRPD) also runs contrary to the principles of non-discrimination, of individual autonomy, which includes the freedom to make one’s own decisions, and the right to inclusion in society.

Consent and Prohibition of torture

Article 15(1) of the CRPD provides that no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

Further, the CRPD Committee has called on States parties to protect the security and personal integrity of persons with disabilities who are deprived of their liberty, including by eliminating the use of forced treatment, seclusion and various methods of restraint in medical facilities, including physical, chemical and mechanic restraints. The Committee has found that these practices are not consistent with the prohibition of torture and other cruel, inhumane or degrading treatment or punishment against persons with disabilities pursuant to article 15 of the Convention. In relation to Article 7 of the International Covenant on Civil and Political Rights (prohibition of torture), the United Nations Special Rapporteur on torture has remarked on the issue of treatment without consent: “*Whereas a fully justified medical treatment may lead to severe pain or suffering, medical treatments of an intrusive and irreversible nature, when they lack a therapeutic purpose, or aim at correcting or alleviating a disability, may constitute torture and ill-treatment if*”² General Comment No. 1. Article 12: Equal recognition before the law, CRPD/C/GC/1, para. 40 Committee on the Rights of Persons with Disabilities: Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities, para. 12. *enforced or administered without the free and informed consent of the person concerned.*”

Conclusion

We would like to recall that, pursuant to article 4.1.d) of the CRPD, Member States of the Council of Europe that are parties to the CRPD should refrain from engaging in any act or practice that is inconsistent with the CRPD. This includes engaging in the negotiation of regional standards that are not in line with the human rights approach to disability enshrined in the Convention.

We are of the view that the draft Additional Protocol risks not only lowering the level of protection of persons with disabilities (in particular persons with psychosocial disabilities), but also undermining the progressive shift in national laws and policies in the field of disability law that is currently under way as States seek to modernize their approach in the light of the obligations stemming from the CRPD. Due to the aforementioned paradigm shift, this process is often challenging for States parties to the CRPD, including Council of Europe Member States; but it is nonetheless going on, as shown (for instance) by the recent reforms in the area of legal capacity in several Council of Europe Member States. Therefore, we are concerned that the adoption of the proposed regional standard would merely reinforce conservative tendencies and slow down the process of CRPD-induced change of legislation and policy in Council of Europe Member States.

Therefore, OHCHR-ROE would like to encourage you to withdraw this proposal while pursuing – in cooperation with a wide range of stakeholders including disabled persons' organizations – other initiatives that would enhance the protection of rights of persons with disabilities and help to bring national legislation in line with the UN CRPD.

A letter from relevant stakeholders under the OHCHR-ROE

The undersigned organizations thank you for the opportunity to provide comments to the draft Additional Protocol concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment.

We have each prepared our respective comments, in line with the mandates of our organizations, which set out concerns regarding the compatibility of the draft Additional Protocol with the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). In addition, we have prepared this joint letter as we have some common, overall issues to raise regarding the draft. Our main concerns arise in relation to non-discrimination, equal recognition before the law, liberty and security of a person, right to health and prohibition of torture and ill-treatment. Furthermore, we are concerned about the lack of meaningful involvement and consultation of disabled persons' organizations in the elaboration and drafting of this document, contrary to article 4(3) of the UN CRPD.

It is important to recall at the outset that 41 out of 47 Member States of the Council of Europe (CoE) have ratified the UN CRPD. In addition, 5 CoE Member States have signed but not yet ratified the UN CRPD, and are therefore bound, in the period between signing and ratification or consent to be bound, to refrain from acts that would defeat the object and purpose of the treaty.

The UN CRPD is based on the recognition of persons with disabilities, including those with psychosocial disabilities, as rights holders, not objects of care. However, both the overall approach of, and the language used in the draft Additional Protocol reflect the old, medical model of disability which constitutes a step back from the developments that led to the adoption of the UN CRPD. The stated aim of the draft Additional Protocol is to clarify the "standards of protection applicable to the use of involuntary placement and of involuntary treatment". It is our view that the *raison d'être* and the provisions contained in the

document (as detailed further in our comments) demonstrate that the guiding principles of the UN CRPD, namely non-discrimination and equality, autonomy, participation and inclusion in society, are not incorporated in a meaningful way in the draft.

We also have concerns with the draft viewing involuntary treatment and placement as a form of “therapy” or “care”. There is a growing and convincing body of evidence of involuntary interventions violating human rights and in some cases, even amounting to torture. The CRPD Committee has stated in several concluding observations, as well as in their General Comment No. 1 and in their Guidelines on CRPD Art. 14, that forced treatment by psychiatric or other health and medical professionals is a violation of the right to equal recognition before the law and not consistent with the prohibition of torture and other cruel, inhuman or degrading treatment or punishment pursuant to article 15 of the CRPD.

Finally, we take this opportunity to recall that regional human rights standards should not aim lower than nor undermine international human rights standards. The standards in this draft Additional Protocol appear to reflect provisions contained in national laws currently in force in some CoE Member States, for instance related to legal capacity and to involuntary placement and treatment. However, in its reviews of State Party reports to date, the UN Committee on the Rights of Persons with Disabilities has identified some such national laws as requiring reform in order to be in line with the UN CRPD. While it is understood that some legislative reforms may take time, the State Parties’ obligation to abolish discriminatory regimes of detention and practices amounting to torture or other ill-treatment is of immediate application.

States Parties to the UN CRPD have undertaken to put in place systems that respect persons with disabilities as rights holders, and not objects of care. However, the document in question does not promote nor encourage the principles underlying the UN CRPD. Rather, it sets out standards that step away from those contained in the UN CRPD.

Given the nature of our concerns, we have come to the conclusion that they cannot meaningfully be addressed by partial changes to some of its provisions. Therefore, we would like to encourage you to withdraw this proposal while pursuing – in cooperation with a wide range of stakeholders including disabled persons’ organizations (DPOs) – other initiatives that would enhance the protection of rights of persons with disabilities and help to bring national legislation in line with the UN CRPD.

MINISTRIES

Ministry of Health (Denmark)

The Danish Ministry of Health would like to put forward the following comments:

Article 1, line 46

According to article 1.1: “Parties to this Protocol shall protect the dignity and identity of all persons with mental disorder and guarantee, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to involuntary placement and involuntary treatment”.

The definition “mental disorder” has not been clarified in the explanatory report and there seems to be some uncertainty about what the term implies. In Denmark involuntary treatment and involuntary placement can take place on the ground of “insanity/psychosis” and not on the grounds on mental disorder.

Instead of mental disorder we recommend that the term “mental” is changed to a “severe and significant” disorder.

Article 6, line 93-95

According to article 6: “Persons who are or may be subject to involuntary placement or involuntary treatment shall have the right to choose a person of trust”.

We recommend, that it is taken into consideration what measures must be taken if a patient is unable to find a person of trust. Should it have any legal effect.

Furthermore we recommend that it is taken into consideration what kind of confidential information the person of trust can receive concerning the patient.

Article 10, line 111 and 119

According to article 10: “Involuntary placement of a person with mental disorder may only be used if the following criteria are met: i. a) the person’s mental health condition represents a significant risk of serious harm to his or her health and his or her ability to decide on placement is severely impaired or b) the person’s mental health condition represents a significant risk of serious harm to others; ii. the placement has a therapeutic purpose; and iii. no less restrictive means of addressing the risk are available.

We recommend that the condition under indent i. a) also comprises the risk of significant deterioration of the prospect of a cure or an improvement of the conditions or the risk of danger to the mentally ill person or others. This comment also applies to article 11.

Article 13, line 154 and 161

According to article 13: “Procedures for taking decisions in emergency situations

1. When there is insufficient time to follow the procedures set out in Article 12 because of the imminent risk of serious harm, either to the health of the individual concerned, or to others, the decision to subject a person to involuntary placement and/or to involuntary treatment may be taken by a competent body, under the following conditions:

- i. involuntary placement and/or involuntary treatment shall only take place for a short period of time on the basis of a medical examination appropriate to the measure concerned;
- ii. the criteria set out in Articles 10 and/or 11, as appropriate to the measure(s) concerned, are met;
- iii. paragraph 2 iii, iv and v of Article 12 shall be complied with as far as possible;
- iv. decisions to subject a person to involuntary placement or to involuntary treatment shall be documented.

2. The law shall specify the maximum period for which the emergency measure may be applied.

3. If the measure is to be continued beyond the emergency situation, or the maximum period referred to in paragraph 2, the decisions on the relevant measure shall be taken in accordance with Article 12 promptly. ”

We find that there might be a need an explanation of the differences between 1 i and 2.

Article 16, line 183

According to article 16, 1. i: “Member states shall ensure that persons subject to involuntary placement and/or involuntary treatment can effectively exercise the right: i. to appeal to a court against the decision to subject them to measures...”

We recommend that it is clarified if the appeal is solely to a court or also a competent body.

Article 17, line 209

According to article 17: "Appropriate information about their rights in respect to the involuntary measure(s) and of the remedies open to them shall be promptly given to persons subject to involuntary placement and/or treatment, and their lawyers and representatives, if any. They shall be informed regularly and appropriately of the reasons for the decision and the criteria for its potential extension or termination. The law may provide that the person of trust also receives this information."

It ought to be clarified whether the information of the person of trust cover otherwise confidential information of the patient. We recommend that these circumstances are developed at national level.

Ministry of Foreign Affairs (Finland)

According to Article, 2 paragraph 2, the provisions of the draft Additional Protocol do not apply to minors. According to paragraph 3 the Additional Protocol does not apply to placement and treatment ordered in the context of a criminal law procedure. According to paragraph 9 of the Draft Explanatory Report to the Additional Protocol the term "mental disorder" is defined broadly in accordance with internationally accepted medical standards. According to paragraph 3 of the Draft Explanatory Report the Additional Protocol does not apply to involuntary treatment given to persons with dementia.

The Government considers that the scope of application of the Additional Protocol should be made more precise. It is of paramount importance that the scope of the Additional Protocol regarding all covered patient groups appears clearly from text of the Additional Protocol itself. The text of the Additional Protocol should indicate whether the mental disorders falling within its scope of application also include e.g. intellectual disability, substance abuse, different memory illnesses or autism. The Additional Protocol should guarantee all patients equal rights related to involuntary treatment, regardless of disability or illness. Paragraph 10 of the Draft Explanatory Report refers to the World Health Organization's *International Statistical Classification of Diseases and Related Health Problems (ICD-10)*. The Additional Protocol should, as mentioned above, indicate clearly how extensively the ICD-10 is to be applied. The Government considers that the reference in the Draft Explanatory Report does not alone sufficiently clearly delimit the scope of the commitments of the States Parties.

The Government notes that the Additional Protocol would often be applied simultaneously with the United Nations Convention on the Rights of Persons with Disabilities in the States Parties. Although Article 1 of the Draft Additional Protocol and paragraph 1 of the Draft Explanatory Report refer to respect for the rights of persons with mental disorder, and although paragraph 46 of the Draft Explanatory Report also mentions the Convention on the Rights of Persons with Disabilities, it might be appropriate to express more clearly in the Draft Explanatory Report that the Additional Protocol and the Convention are intended to be based on the same perspective emphasising the inclusion and rights of persons with disabilities. Regarding the practical measures of the future States Parties, it is of vital importance to try to guarantee, already when drafting the Additional Protocol, that the Additional Protocol and the Convention be applied consistently.

Regarding paragraphs 30 and 31 of the Draft Explanatory Report, the Government points out that, in order to clarify the scope of application of the Additional Protocol, it should be mentioned in the Draft Explanatory Report whether the treatment covered by the Additional Protocol is considered to include all restrictive measures taken during involuntary treatment

that are not part of the involuntary treatment. The Draft Explanatory Report could explain more clearly whether the scope of application of the Additional Protocol in all situations includes all restrictive measures (restraint, seclusion, tying up, seizure of property, restrictions on contacts and on freedom of movement etc.). In the same context, it should explain more clearly whether a patient should always be guaranteed the right of appeal regarding such measures and whether a decision on restrictive measures should always be taken by a doctor. Such an explanation would clarify the situation especially regarding those domestic practices where medical staff may decide on urgent restrictive measures.

According to the detailed reasoning for Article 12 of the Additional Protocol (para. 69 of the Draft Explanatory Report), the body taking a decision on involuntary placement should be independent of the person or body proposing the measure. It might be appropriate to supplement the text with the mentioning that if the decision-maker is not independent, the patient should be given an opportunity to obtain an opinion of an external doctor on their involuntary placement.

Chapter 4 of the Additional Protocol contains provisions on decision-making procedure concerning involuntary placement and treatment. The Government considers it warranted to emphasise that a decision-making procedure that makes it possible to restrict personal freedom must also as such provide sufficient legal safeguards in situations where it is basically impossible for the person subject of the decision to use procedural legal remedies. In this respect, in the Government's view, the relation between the proposal and Article 5 of the European Convention on Human Rights, and especially the case-law of the European Court of Human Rights on Article 5, remains unclear (see Art. 12 paras. 1 and 3; Art. 15 paras. 2 and 3; Art. 2 para. 4; and Art. 12, para. 12). The Government notes that if the meaning of Article 16 paragraph 3 is that a person should have an oral hearing held concerning their matter before an administrative court whenever they request it, this requirement may in some cases be unreasonable in terms of the effective functioning of the administrative court. Such a situation may arise when a person requests an oral hearing so often that holding such a hearing cannot in fact add any new evidence to the proceedings. This should be taken into account at least in the Draft Explanatory Report.

The Draft Explanatory Report lists examples of situations envisaged to fall within the scope of application of Article 18, paragraph 2. These examples are rather open to different interpretations. The Government notes that the right to respect for private and family life under Article 8 of the European Convention on Human Rights means that any restrictions imposed on contacts must be based on law and given a narrow interpretation.

The Government observes that according to Article 20, paragraph 1 the Contracting States shall ensure that compliance with the provisions of the Protocol is subject to appropriate independent monitoring. According to Article 16 paragraph 7 if the national court identifies any violations of the relevant national legislation it shall report these in the framework of the monitoring referred to in Article 20. In the Government's view the draft Additional Protocol leaves it unclear what the requirement of ensuring independent monitoring, on one hand, and the reporting obligation of courts in the proposed context, on the other hand, mean. Courts established as independent from the State administration are not monitoring authorities and cannot be assigned tasks of such authorities.

Finally, the Government considers it positive that the terminology used corresponds to the terms used by the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID): "intellectual disability" / "people with intellectual disability". Alternatively, the term "intellectual and developmental disability", used by the American Association on Intellectual and Developmental Disabilities, AAIDD, could be used.

Department of Social Affairs, Health and Environment (Finland)

The Government of Åland kindly thanks for the opportunity to comment on the draft. Human rights and the importance of respect in mental health services, where the patient often is in a sensitive and vulnerable position, is an important issue.

We find the document deals with what seems to be (almost) all the relevant issues in a very, detailed, sensible and clinically adequate way.

Concerning the lines 99-102 dealing with **Professional standards** we suggest an additional line: *The importance of an enough number of well trained staff members is stressed and a preconception for providing the important therapeutic measures in order to avoid unnecessary use of physical force and physical restrictions as well as involuntary treatment or placement.*

Health and Social Care Inspectorate (Sweden)

Given the opportunity to comment the above titled document the Health and Social Care Inspectorate will hereby give the following comments.

After reading the working document DH-BIO/INF (2015) 7 concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment the Inspectorate understands that article 2 paragraph 3 (page 2 line 57) excludes the application of the protocol on placement and treatment for mental disorder imposed in the context of a criminal law procedure.

It is the Inspectorates opinion that Swedish legislation is in conformity with the requirements and considerations that emerges in the above mentioned document

What appears somewhat strange to the Inspectorate however, is that role a person of trust might be given in connection with involuntary placement and treatment of a person with mental disorder and in connection with appeals (Line 140-141 and 186-187). As this role is not a requirement the Inspectorate sees nothing that prevents that the regulation is given the proposed form.

Ministry of Foreign and European Affairs (Slovakia)

Following you call for consultation of a draft Additional Protocol to the Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment, I would like to inform you that Slovak authorities (particularly Ministry of Justice and Ministry of Health) have studied relevant texts and we would like to present the following comments and suggestions to the draft Protocol:

To add in the Preamble the reference to the relevant standards of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) concerning the involuntary placement in psychiatric establishments and the relevant provisions of the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment.

Reference should also be made to the psychiatric care for prisoners, as well as on additional safeguards for children following the principle of the „best interests of the child“ formulated in Art. 3 of the UN Convention on the Rights of the Child (in special Articles, if appropriate).

In addition, the CPT’s own on-site observations and reports received from other sources indicate that the deliberate ill-treatment of patients in psychiatric establishments does occur from time to time. A number of questions are closely-linked to the issue of the prevention of ill-treatment (e.g. means of restraint, complaints procedures, contact with the outside world, choice of staff and staff supervision, training of the staff, external supervision).

In the Draft Explanatory Report concerning Articles 17 and 18 “Information and Communication” we would like to add that a patient shall be informed about his/her rights “regularly, properly and comprehensibly”.

Concerning para 52 of the Draft Explanatory Report we do not agree that “merely financial risk” is not sufficient to apply involuntary measures. For example, patient in acute mania may face a risk of economic bankruptcy. This suggestion may be further discussed during the next DH-BIO meeting.

NATIONAL INSTITUTIONS

Equality and Anti-Discrimination Ombud (Norway)

The Norwegian Equality and Anti-Discrimination Ombud refer to the letter from the Committee on Bioethics dated 22 June 2015. The Ombud appreciates the opportunity to give our remarks to the draft Protocol on the Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment.

About the Equality and Anti-Discrimination Ombud

The Equality and Anti-Discrimination Ombud is an independent public body that operates free from the instruction of the Norwegian Government. The main task of the Ombud is to promote equality and fight discrimination based on gender, ethnicity, religion, disability, sexual orientation, gender identity, gender expression and age.

The Ombud has a legal mandate to monitor the implementation of the UN’s Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), Convention on Racial Discrimination (CERD) and Convention on Rights of Persons with Disabilities (CRPD) in Norway.

General remarks to the draft Protocol

The Ombud welcomes the intention behind the draft Protocol, namely to limit the use of involuntary treatment and involuntary placement of people with mental or psychosocial disabilities. The Ombud agrees that there is a pressing need to reduce the use of involuntary placements and involuntary treatment in this field. However, in its current form, the Ombud can not support the draft Protocol.

In line with the United Nations Convention on the Rights of Persons with Disabilities, the Ombud is of the opinion that the very essence in strengthening the rights and freedoms of people with disabilities is to ensure that international and domestic legislation is non-discriminatory. This includes a zero-tolerance for legislation where mental or psychosocial disabilities are a criterion for use of coercion. The draft Protocol, on the other hand, is as a

whole based on the idea that “mental disorder” is a legitimate criterion for use of involuntary treatment and involuntary placement.

Involuntary placement

According to CRPD article 14, the existence of disability can not, in any case, justify a deprivation of liberty. In a statement from the CRPD-committee from September 2014, the Committee elaborates its view on the interpretation of this article as an *absolute prohibition of detention on the basis of disability*.⁶³ The Committee establishes that article 14 does not permit people with mental or psychosocial disabilities to be detained on the grounds of their disability. This prohibition includes legislation where the disability is one of more criterions for deprivation, for example where the other criterion is that a person is dangerous to himself/herself or to others.

In the view of the Ombud the draft Protocol, in its current form, is not compatible with article 14 as interpreted by the CRPD committee.

Involuntary treatment

CRPD article 25 states that people with disabilities have a right to health care on the basis of free and informed consent. The article must be read in conjunction with article 15 and 17 of the CRPD. Article 15 protects the freedom from torture or cruel, inhuman or degrading treatment or punishment, and article 17 protects the right to integrity of person.

Involuntary treatment is a serious interference with the right to integrity of person, and in gross cases involuntary treatment can be defined as inhumane or degrading treatment in breach with article 15 of the Convention.

In light of the CRPD committee’s clear and unequivocal interpretation of the Convention when it comes to using disabilities as a criterion for use of coercion, the Ombud finds that mental disability can not be a criterion for use of involuntary treatment.

In the view of the Ombud the draft Protocol, in its current form, is not compatible with CRPD article 25 read in conjunction with article 15 and 17 as interpreted by the CRPD committee.

Conclusion

The Ombud finds the draft Protocol is not in conformity with CRPD and the fundamental idea of non-discriminatory legislation. In worst case, the draft Protocol its current form can weaken the implementation of CRPD in the member States.

On these grounds, the Ombud can not support the further work of the Committee on Bioethics on the draft Protocol to the Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment.

In the view of the Ombud, this draft Protocol is not the tool that is necessary to end discriminatory practice against people with disabilities. We recommend that the draft Protocol is re-written to be in line with the United Nations Convention on the Rights of Persons with Disabilities, or that the work is discontinued.

⁶³ Statement on article 14 of the Convention on the Rights of Persons with Disabilities
<http://www.ohchr.org/RU/NewsEvents/Pages/DisplayNews.aspx?NewsID=15183&LangID=E>

Pavel Doubek, Office of the Public Defender of Rights (Czech Republic)

My name is Pavel Doubek and I come from Brno, beautiful city in the Moravia region in the Czech Republic. I work for the Office of The Public Defender of Rights, specifically for the department which plays a role as a National Preventive Mechanism (NPM). I am a PhD. candidate at Faculty of Law Masaryk University in Brno and my field of study is Constitutional Law and Political Science. The theme of my dissertation thesis is „Medical intervention without consent of the patient“ and within the thesis I deal with issues of human rights, medical law, ethics and coercion.

With regard to my profession as an NPM member and my field of study, I welcome the opportunity to add my contribution and comments to the public consultation. I very appreciate effort of the The Committee on Bioethics of the Council of Europe (hereinafter referred to as „The Committee“) to adopt Additional Protocol in order to strengthen protection of human rights and dignity of persons with mental disorder.

I have read the Additional Protocol and its Explanatory Report carefully and I found out five problematic issues, which I would like to discuss. It was my goal to write down very short theoretical background and also propose some amendments of certain provisions of the Additional Protocol. The structure of each range of issues is as follows:

1. Theoretical background of the issue discussed,
2. wording of the certain provision of the Additional Protocol and
3. the proposed amendment to the Additional Protocol.

It was not my intention to write down a comprehensive analysis of the studied issues, but rather to point out some problematic features of the concrete articles of Additional Protocol and to provoke a discussion.

Proposed Material

ISSUE N. 1

1. Principles of necessity and proportionality

1.1 Theoretical background

Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (hereinafter referred to as „the Convention“) in Article 5 states, that *„an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it“*. The Convention makes the exceptions from this general rule. According Article 26 of the Convention it is possible to make a restriction of Article 5 (it is possible to interfere into the bodily integrity of person without his consent), only if this measure is *„prescribed by law and is necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others.“*

Article 26 of the Convention seeks balance between two conflicting values – patient’s right to protect his health and bodily integrity on one side and right of other people to protect their health and bodily integrity on the other side. To weigh these conflicting values, the courts use so called „test of proportionality“ and „principle of necessity“.

Proportionality test

The proportionality test should be applied for all limitation of fundamental rights⁶⁴, therefore the limitation of the right to personal integrity must be also subjected to this test. The proportionality test is consisted of three steps (test of suitability, test of need and test of proportionality in the narrow sense). The limitation of the fundamental right will be consistent with the constitutional order only, if successfully pass all three steps required.

Within the first step the court (usually the Constitutional Court) considers, whether the measure limiting a fundamental right pursues a legitimate aim (legitimate aim is usually protection of another fundamental right)⁶⁵. It is likely that involuntary treatment of patient with mental health disability who poses threat to others will pursues the legitimate aim. The legitimate aim in this context is the protection of others against the dangerous mentally ill patient.

The second step of the proportionality test is the criterion of need, „*consisting in comparing the legislative measures which restricts a fundamental right, respectively freedom, with other measures which are able to achieve the same aim, but not affect the fundamental rights and freedoms.*“⁶⁶ In this step, it is necessary to examine whether there exist alternatives to involuntary treatment (help of psychologist for example).

The purpose of the third step of the proportionality test is to weigh the conflicting fundamental rights, or the conflicting fundamental rights and public interest. „*This step is necessary to ascertain whether the sacrifice brought by limitation of (interference into) fundamental right did not get into a disproportion with the benefit to the public, which was achieved by limiting the fundamental right.*“⁶⁷. When analysing this step, the Constitutional Court regularly takes into account so called „argument of value“, which can be explained as „*the consideration of benefits of the conflicting fundamental rights with respect to the accepted hierarchy of values.*“⁶⁸

Right to health and right to bodily integrity occupy the exclusive position in the system of fundamental rights and freedoms. Serious breach of these rights can attack the human dignity and achieve degrading and inhuman treatment.⁶⁹

Involuntary intervention into the bodily integrity of a patient can be carried out only in very exceptional cases. Generally accepted rule is that „*the more intensive intervention ... into the more important interests of the individual, the more important must be he pursuing legitimate aim for the society.*“⁷⁰ The threat to the health of the others must be so severe and so

⁶⁴ WAGNEROVÁ, Eliška, ŠIMÍČEK, Vojtěch, LANGÁŠEK, Tomáš, POSPÍŠIL, Ivo a kol. Charter of Fundamental Rights and Freedoms. Commentary. Praha: Wolters Kluwer ČR, a. s. 2012, p. 931. p. 26.

⁶⁵ The Constitutional Court judgement Pl. ÚS 4/94.

⁶⁶ The Constitutional Court judgement Pl. ÚS 4/94.

⁶⁷ WAGNEROVÁ, Eliška, ŠIMÍČEK, Vojtěch, LANGÁŠEK, Tomáš, POSPÍŠIL, Ivo a kol. Charter of Fundamental Rights and Freedoms. Commentary. Praha: Wolters Kluwer ČR, a. s. 2012, p. 931. p. 27.

⁶⁸ The Constitutional Court judgement Pl. ÚS 4/94.

⁶⁹ Medical intervention which can reach the level of degrading treatment is for example castration. See the CPT Report on the visit to the Czech Republic conducted from 25 March to 2 April 2008. [online]. p. 18. Available from: http://www.vlada.cz/assets/ppov/rlp/dokumenty/zpravy-plneni-mezin-umluv/report-cpt-czech-rep-2008-czech_.pdf.

⁷⁰ Kmec, J., Kosař, D., Kratochvíl, J., Bobek, M. European convention on human rights. Commentary. 1. ed. Praha: C. H. Beck, 2012, p. 885.

imminent, that the only way to face this threat, is to sacrifice the health of the individual. The human sacrifice may for example consists in pharmacological intervention. When the threat is gone, it is possible to continue with the treatment only with patient's consent.

Necessity criterion

The ECHR deals with the question of the necessity in the case *Dudgeon v United Kingdom*, when ECHR stated as follows: "*Firstly, "necessary" in this context does not have the flexibility of such expressions as "useful", "reasonable", or "desirable", but implies the existence of a "pressing social need" for the interference in question.*"⁷¹ In the judgement *Olsson v. Sweden*, ECHR stated, that *„the notion of necessity implies that the interference corresponds to a pressing social need and, in particular, that it is proportionate to the legitimate aim pursued.“*⁷²

At this point, I wish to repeat what was already said. Involuntary intervention into bodily integrity of patient must respond to the actual threat to health of the patient or others, in words of ECHR, it must *corresponds to a pressing social need*. The intervention must be also proportionate to the *„legitimate aim pursued“*. When there is no sufficient evidence, that the necessity criterion is fulfilled, it is not possible to prefer public interest over the interest of patient. In case of doubt, what interest should prevail, it is necessary to apply the principle "in favorem libertatis" and give preference to the fundamental rights and freedoms of the individual.⁷³

1.2 The regulation in the Additional Protocol. Article 4 – Necessity and proportionality:

Article 4 states, that *„measures for involuntary placement and involuntary treatment shall only be used in accordance with the principles of necessity and proportionality.“* The article further states, that *„persons subject to involuntary placement and/or involuntary treatment shall be cared for in the least restrictive environment available and with the least restrictive or intrusive treatment available, taking into account their health needs and the need to protect other persons from harm.“*

This provision contains two different issues. The provision firstly deals with the principles of necessity and proportionality of the measure for involuntary placement and treatment, and secondly, it considers the quality of the environment (it is usually the environment of the facility, where patient should be detained) and the quality of the treatment itself (the provision uses wording "*the least restrictive environment available*" and *„the least restrictive or intrusive treatment available“*). The term „available“ relates to the quality of care and also to the quality of environment of care. The term „available“ does not refer to the highest standards of care and environment, but to the standards, which are currently available.

International human rights standard requires, that patient has a right to live in the community and if he is placed into the facility, the environment must be the least restrictive.⁷⁴ CPT recognises that *“in times of grave economic difficulties, sacrifices may have to be made,*

⁷¹ Kmec, J., Kosař, D., Kratochvíl, J., Bobek, M. *European convention on human rights. Commentary.* 1. ed. Praha: C. H. Beck, 2012, p. 884.

⁷² See ECHR judgement in case of *Olsson v. Sweden*. In: Kmec, J., Kosař, D., Kratochvíl, J., Bobek, M. *European convention on human rights. Commentary.* 1. ed. Praha: C. H. Beck, 2012, p. 885.

⁷³ WAGNEROVÁ, Eliška, ŠIMÍČEK, Vojtěch, LANGÁŠEK, Tomáš, POSPÍŠIL, Ivo a kol. *Charter of Fundamental Rights and Freedoms. Commentary.* Praha: Wolters Kluwer ČR, a. s. 2012, p. 931. p. 193.

⁷⁴ This human right arises for example from Article 19 of Convention on the Rights of Persons with Disabilities.

including in health establishments”⁷⁵. CPT however states, that “the provision of certain basic necessities of life must always be guaranteed.”⁷⁶ CPT furthermore extensively defines the minimum standard of these “basic necessities”. The principle 9(1) of the United Nations Resolution A/RES/46/119 concerning “The protection of persons with mental illness and the improvement of mental health care” (hereinafter referred to as “UN Resolution”) stress, that “every patient shall have the right to be treated in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others.”

My point of view is, that the wording “the least restrictive environment available” decrease the human rights standard, because the word „available“ enable to provide health care even in the restrictive environment, if the least restrictive environment is not available. Due to word „available“, the requirement of the least restrictive environment is relativized.

The above mentioned is applied also to the wording „the least restrictive or intrusive treatment available“. The international conventions grant the right to receive treatment at the appropriate level of expertise in accordance with the available scientific knowledge (treatment lege artis). It should be also the standard of this Additional Protocol, to provide health care always in accordance with the available scientific knowledge, not to provide only available care. This rule is included also in Article 4 of the Convention: “Any intervention in the health field, including research, must be carried out in accordance with relevant professional obligations and standards.” Also the principle 1(1) of the UN Resolution contains a rule, that “all persons have the right to the best available mental health care, which shall be part of the health and social care system.”

1.3 Proposed amendment

With respect to above mentioned, I propose to remove the word “available”. New provision would be as follows:

Measures for involuntary placement and involuntary treatment shall only be used in accordance with the principles of necessity and proportionality. Persons subject to involuntary placement and/or involuntary treatment shall be cared for in the least restrictive environment ~~available~~ and with the least restrictive or intrusive treatment ~~available~~, taking into account their health needs and the need to protect other persons from harm.

ISSUE N. 2

2. Involuntary treatment of the patient in order to protect health of the others

2.1 Theoretical background

The first part of this paper was devoted to the concept of necessity and proportionality. I said, that involuntary treatment can be done only if it is proportionate and necessary in a democratic society for the protection of the rights of others.

It's very difficult for me to find out an example of involuntary medical intervention that can be done to protect the rights of others and still meet the requirements of necessity and proportionality. The example of that medical intervention should be maybe the compulsory vaccination, which patient must undergo in the event of an outbreak of transmissible disease, if the vaccination is only way to face immediate threat to the life and health of others.

People with mental disorder can represent serious threat to others if they are under the influence of their illness. In the newspapers we can read many articles showing the cases,

⁷⁵ CPT standards (point 33). In: <http://www.cpt.coe.int/en/documents/eng-standards.pdf>

⁷⁶ CPT standards (point 33). In: <http://www.cpt.coe.int/en/documents/eng-standards.pdf>

when person with mental disorder murdered, raped or hurt someone. However, the statistics shows, that persons with mental disorder are rather victims than perpetrators.

At this point I have to repeat, that involuntary medical intervention requires, that the patient must pose a threat to health or life of others and this threat must be serious and immediate (requirement of proportionality and necessity). In such an emergency situation, it is acceptable to calm the aggressor via psychiatric medication, if it is impossible to use less intrusive measures. The purpose of this medical intervention is to restrain the patient. CPT continuously reiterates, that *“patient should only be restrained as a measure of last resort; an extreme action applied in order to prevent imminent injury or to reduce acute agitation and/or violence.”*⁷⁷

When the person poses no longer threat to others, it is not acceptable to provide him a treatment without his consent. If the patient is involuntarily placed to the hospital, the doctors can provide only emergency care to treat his mental disorder in order to protect his own health.

On these principles the Convention on Human Rights and Biomedicine is based. Article 6 states, that *“an intervention may only be carried out on a person who does not have the capacity to consent”*.

This rule is concretized in Article 7, which states, that *“a person who has a mental disorder of a serious nature may be subjected, without his or her consent, to an intervention aimed at treating his or her mental disorder only where, without such treatment, serious harm is likely to result to his or her health.”*

Czech legal regulation of involuntary placement and treatment draws from above mentioned principles. Act No. 372/2011 Coll., on health services and the terms and conditions for the providing of such services, as last amended (*hereinafter referred to as „Act No. 372/2011 Coll.”*) in paragraph 39 states, that *“the patient should be administered only emergency care without his/her consent, if a) the patient’s state of health does not allow him/her to express the consent or b) the treatment of serious mental disorder, if it should lead with all probability to serious injury of patient.”* According to the czech law, the treatment of persons with mental disorder is always carry out with the intention to protect the health of the patient, not the health of the others.

I can summarize, that the contemporary international and national law stands on the principle, that it is not possible to interfere into the patient's bodily integrity solely in order to protect others. If we look back into the history, it is obvious, that denial of this principle usually led to the massive violation of fundamental human rights and freedoms of patients⁷⁸. Also from this reason the Article 2 of the Convention contained the principle that *“the interests and welfare of the human being shall prevail over the sole interest of society or science”*.

2.2 The regulation in the Additional Protocol. Article 11 paragraph i) letter b) – Criteria for involuntary treatment:

This provision regulates the criteria for involuntary treatment. This provision regulates an involuntary medical treatment in order to protect both - the health of the patient and the

⁷⁷ CPT standards (point 43). In: <http://www.cpt.coe.int/en/documents/eng-standards.pdf>

⁷⁸ I can mention the forced sterilisation, castration and euthanasia in Nazi Germany, involuntary placement and treatment of people with mental disorder during the eugenic period in USA, involuntary sterilisation in Czechoslovakia, etc.

health of others. Paragraph i) letter b) states as follows: **„Involuntary treatment of a person with a mental disorder may only be used if ... the person's mental health condition represents a significant risk of serious harm to others“.**

With the view of the above mentioned, it seems unacceptable to me, to legalize the involuntary treatment of patient in order to protect other people. I am of the view, that this provision decrease the standard of protection of the rights of persons with disabilities, as is regulated in the Convention, and even in the Act No. 372/2011 Coll.

Moreover, the Additional Protocol does not specify what does the term „harm“ mean. Although the The Draft Explanatory Report (point 52) states that *„involuntary measures designed to address mental disorder are not appropriate for addressing economic risk to others“*, from the text of the Additional Protocol itself it is not clear, if the term „harm“ means only personal injury or it may be interpreted broadly as any loss (for example, economical harm). My point of view is, that Additional Protocol should use unambiguous terms. In this context it will be better to use term „bodily harm“.

The proposal of the Additional Protocol does not specify what kind of treatment should be done without patient's consent. At this point, I would like to make an observation on castration. In Czech Republic, the so called „therapeutical castration“ is still accepted lege artis treatment of patient with mental disorder. The professional community (The Sexological Society) defends this medical intervention and argues, that it has therapeutical benefits for patient. Despite the CPT states, that *„the castration in the context of treatment of sex offenders was a degrading treatment“*⁷⁹. Current regulatuon in czech law is, that the castration should can be done only with the consent of patient (plus other strict requirements). My point is as follows: If castration is accepted as treatment and the Additional Protocol allows involuntary treatment, should it be legal to carry out involuntary castration of the patient with mental disorder? I would like to point out that, if we accept even very trivial medical intervention, which purpose is not to cure patient but to protect the health of the others, then we can accept more invasive intervention in order to protect other goals („slippery slope“ argument).

With regard to our own history of forced sterilization of Roma women during the Communist regime and persisting paternal attitude to patients, lack of individualised care and understanding of patient's needs, I will be very afraid of accepting the involuntary treatment of patient with mental disorder.

2.3 Proposed amendment

With respect to above mentioned, I propose to remove Article 11 par. i letter b). Amended provisoin should be as follows:

⁷⁹ CPT Report on the visit to the Czech Republic carried out from 7 to 16 September 2010 (point 121). In: <http://www.cpt.coe.int/documents/cze/2014-03-inf-eng.pdf>.

Article 11 – Criteria for involuntary treatment

Involuntary treatment of a person with a mental disorder may only be used if the following criteria are met:

- i. a) the person's mental health condition represents a significant risk of serious harm to his or her health and his or her ability to decide on treatment is severely impaired*~~*or*~~
b) the person's mental health condition represents a significant risk of serious harm to others;

and no less intrusive means of addressing this risk are available.

ISSUE N. 3

3. The scope of treatment provided within the regime of involuntary placement; decision making of a doctor

3.1. The regulation in the protocol. Article 12 paragraph 2) and 3) – Standard procedures for taking decisions on involuntary placement and on involuntary treatment

Another question arose from the Additional Protocol. This question is, whether the decision on involuntary placement itself can be ground for involuntary treatment, or whether there must be separate decision on involuntary treatment. Art. 12 par. 2 states, that „***the decision to subject a person to involuntary placement or to involuntary treatment shall, subject to paragraph 3, be taken by a court or another competent body.***“ The paragraph 3 states, that „***the law may provide that when a person is subject to involuntary placement the decision to subject that person to involuntary treatment may be taken by a doctor having the requisite competence and experience, after examination of the person concerned, and in accordance with the requirements set out in paragraph 2 ii, iii, iv and v.***“

Draft Explanatory Report states, that „*these measures shall be considered separately.*“ The Draft Explanatory Report however further states, that „*if the person is subject to involuntary placement, paragraph 3 of this Article provides an alternative means of taking a decision on the use of involuntary treatment. If the national legal system requires the decision to be taken by a court or competent body the provision does not require the court or other competent body to approve, for example, each individual dose of medication to be given.*“

I understand the purpose of paragraph 2 in that way, that every slightest medical intervention should not be decided by the court, but it should be let to the doctor. It would be really inappropriate and impossible for the court to decide on each individual dose of medication to be given.

However, the Additional Protocol defines neither the scope of the treatment, nor under what circumstances the treatment should be done. Does the Additional Protocol allows doctors to make decisions on any treatment? Does the Additional Protocol entitles doctors to carry out even invasive involuntary treatment (for example invasive surgery)? CPT states similary, that „*the admission of a person to a psychiatric establishment on an involuntary basis should not be construed as authorising treatment without his consent.*“ CPT furthermore states, that involuntary treatment within the regime of involuntary placement must „*only relate to clearly and strictly defined exceptional circumstances.*“⁸⁰

According the Act No. 372/2011 Coll., when patient is involuntary placed into the hospital, only emergency care should be given to him without his consent. The patient will be usually

⁸⁰ CPT standards (point 41). In: <http://www.cpt.coe.int/en/documents/eng-standards.pdf>

given a treatment, which directly relates to the reason for hospitalization. For example, if a patient is involuntarily placed on the ground that he, under the influence of his mental disorder, injured himself or attempted suicide, he must undergo such a medical intervention (usually psychiatric medication) which prevent further harm or risk of harm. When the mental disorder is sufficiently stabilized and patient does not pose the imminent threat to himself, it is possible to provide additional treatment only with his consent.

There is very narrow boundary between what is emergency care and what is not. To recognize what is and what is not an emergency care, the doctors must strictly apply the above mentioned principle of proportionality and necessity. In any case, the Article 3 of the Additional Protocol should contain a clear rule, that the doctor can decide on involuntary treatment on his own, only when necessary and only, if the proposed treatment closely relates to the ground of involuntary placement.

3.2 Proposed amendment

With respect to above mentioned, I propose to add new Article 12 into the Chapter III. New article should be as follows:

***„Article 12- The scope of treatment provided within the involuntary placement
Within the involuntary placement, the patient should be administered involuntary treatment only if it is necessary for the protection of his/her health and only, if the treatment closely relates to the ground of involuntary placement.“***

Furthermore, I propose to change present Article 12 paragraph 3 as follows:

*The law may provide that when a person is subject to involuntary placement the decision to subject that person to **necessary** involuntary treatment **according Article 12** may be taken by a doctor having the requisite competence and experience, after examination of the person concerned, and in accordance with the requirements set out in paragraph 2 ii, iii, iv and v.*

ISSUE N. 4

4. Right to be heard

4.1 Theoretical background

The patient should always be given the opportunity to be heard in person and to express his opinions, wishes and ideas. The same should be given also to the patient's deputy, relatives and other close persons, unless their interests are not in conflict with the interests of the patient. Also the way of life of the patient, his preferences and previously expressed wishes should be taken into account. Even if the patient does not have the capacity to express his opinions and wished, he should be given the opportunity to do so. In such a case, the medical records and court files should always contain sufficient evidences, that the doctor, court or other authorized person attempted so.

4.2. The regulation in the protocol: Article 12 paragraph 2 letter iii:

„... The court or other competent body shall take into account the opinion of the person concerned and, where appropriate, any relevant previously expressed wishes made by that person“

From the wording of this provision is clear, that previously expressed wishes made by patient will be taken into account only if it is „appropriate“. I am of the opinion, that previously expressed wished should be always taken into account (see above).

4.3 Proposed amendment

With respect to above mentioned, I propose to remove the collocation „where appropriate“. New Article 12 paragraph 2 letter iii should be as follows:

„... The court or other competent body shall take into account the opinion of the person concerned and, ~~where appropriate,~~ any relevant previously expressed wishes made by that person“

ISSUE N. 5

5. Right to communication of persons subject to involuntary placement

5.1 Theoretical background

The patient should have a right to communicate with the outside world, to ask and receive help and support, as well as he should have a right to lodge a complaint⁸¹. The patient should have a right to communicate not only with the official state authorities, but also with non-governmental organizations and other informal organisations providing help and support. I have to stress however, that the right to seek information, help and support is the right of the patient, not the right of the NGOs and other organisations. Therefore it is necessary to ensure both: the patient's right to communicate with these organisations, as well as it is necessary to protect the patient against unsolicited visits of these organisation, who can bother him or obstruct the treatment.

5.2. The regulation in the Additional Protocol. Article 18 paragraph 1:

„Persons subject to involuntary placement have the right to communicate with their lawyers, representatives, or any official body charged with the protection of the rights of persons subject to involuntary measures, without restriction.“

From the wording of the provision, it is clear, that the protocol allows patient to contact only lawyers, representatives, or any official body. Beyond this, I am of a view, that patient should have a right to contact also other providers of help and support (see above).

5.3. Proposed amendment

With respect to above mentioned, I propose to change this provision as follows:

Article 18 – Right to communication of persons subject to involuntary placement

*1. Persons subject to involuntary placement have the right to communicate with their lawyers, representatives, any official body charged with the protection of the rights of persons subject to involuntary measures, **or other persons providing help and support, without restriction.***

Conclusion

With respect to above mentioned, I am of a view, that the analysed provisions of the Additional Protocol should be amended or be more specific.

As I said in the introduction, it was not my intention to write down a comprehensive analysis, so if the Committee will need specification of some of my idea or proposal, I am prepare to answer the questions. The line which is stretching within the whole material is the idea of Article 2 of the Convention, which states, that *„the interests and welfare of the human being shall prevail over the sole interest of society or science.“* I used this idea as an interpretative tool of all provisions in the Additional Protocol and via the sense of this idea, I also formulated the proposed amendments. I have no objections to the provisions regarding involuntary placement. I think that conditions and criteria of involuntary placement are regulated properly.

I firmly believe that the this material will be useful for the next work of the Committee and it will be my pleasure to participate on the next development of the Additional Protocol.

⁸¹ CPT states, that *„effective complaints procedure is a basic safeguard against ill-treatment in psychiatric establishments“*. In: CPT standards (point 53). In: <http://www.cpt.coe.int/en/documents/eng-standards.pdf>

ACADEMIC

Marie BAUDEL, Doctorante en Droit International Public, Université de Nantes

General comments:

The draft Additional Protocol adopts a different approach to that of the Convention on the Rights of Persons with Disabilities (CRPD) with regard to the involuntary placement and treatment of persons suffering from mental disorders. It is based on the assumption that “the existence of a mental disorder in itself shall in no case justify an involuntary measure” (lines 28 and 29). However, it is clear from the Additional Protocol that, when it is combined with other criteria, a mental disorder is considered to justify such measures.

Commentators on the CRPD tend to interpret this Convention, particularly Article 14 thereof, to mean that all involuntary placement or treatment measures are prohibited. It is worth pointing out that the United Nations High Commissioner for Human Rights considers that “unlawful detention encompasses situations where the deprivation of liberty is grounded in the combination between a mental or intellectual disability and other elements such as dangerousness, or care and treatment. Since such measures are partly justified by the person’s disability, they are to be considered discriminatory and in violation of the prohibition of deprivation of liberty on the grounds of disability, and the right to liberty on an equal basis with others prescribed by article 14”⁸².

In the interests of the consistency of international law but also of better protection for the rights and autonomy of persons suffering from mental disorders, it would be desirable for the Additional Protocol to align its approach with that of the CRPD.

Furthermore, the draft Additional Protocol does not include any specific guarantee concerning seclusion and restraint although this question is raised in the draft explanatory report (paragraphs 30 and 31).

Lastly, the possibility of persons suffering from mental disorders using advance directives is not mentioned although this mechanism is one possible means for them to preserve their rights and autonomy.

Specific comments:

- Lines 46-48: In its current wording the description of the object validates in principle a form of discrimination vis-à-vis persons suffering from mental disorders with regard to involuntary placement and treatment measures. The notion of autonomy could also be added here.

Proposal:

⁸² UN High Commissioner for Human Rights, Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary-General, Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities, A/HRC/10/48, 2009, paragraph 48.

Parties to this Protocol shall protect the dignity, identity and autonomy of all persons with mental disorder and guarantee, without discrimination, respect for their integrity and their rights and fundamental freedoms, particularly with regard to involuntary placement and involuntary treatment.

- Lines 66 and 67: For the sake of accuracy the purposes of placement could be spelt out.
Proposal:

*“placement” refers to placing a person in a specific environment for a **social and/or therapeutic purpose.***

- In lines 93 and 94 [of the French]*, the word “disponible” does not seem necessary. It can be considered to be encompassed by the word “possible”.
In line 96 [of the French], the word “dommage” could refer to material damage to property. As a rule, persons should not be subject to an involuntary treatment or placement measure because they pose a risk of damaging property. The expression “la protection d’autrui” (protection of other persons) should suffice in itself as it implies the protection of persons’ physical and mental integrity.

Proposal:

The French text should read as follows:

Les personnes faisant l’objet d’un placement ou d’un traitement involontaires sont soignées dans l’environnement le moins restrictif possible et bénéficient du traitement le moins restrictif possible ou impliquant la moindre intrusion, tout en tenant compte des exigences liées à leur santé et à la protection d’autrui.

* Words in square brackets added by translator

- Line 94: The scope of this article could be extended.
Proposal:

All persons suffering from mental disorder, including those who are or may be subject to involuntary placement or involuntary treatment shall have the right to choose a person of trust.

- Line 111: The wording is unclear.
Proposal:

a) if he or she is not placed, there is a significant risk of serious harm to his or health ...

- Line 121 [of the French]: same comment as above concerning the use of the word “dommage” in the French.

Proposal:

[Amend the French as follows:]

b) l’état de santé mentale de la personne pose un risque avéré à l’intégrité physique ou mentale d’autrui.

- Line 115: States should, in so far as is possible and their resources allow, ensure that less restrictive options are available. The use of the word “available” here implies that States may escape this obligation. It also happens that less restrictive options are available but have been tried without success. It would be more appropriate to use the word “possible”.

Proposal:

*no less restrictive means of addressing the risk are **possible**.*

- Lines 128, 131 and 132 [of the French and 123 of the English]: Same comments as for lines 118 and 121 [of the French and 115 of the English].
- Lines 131 and 142 to 145 (English): The court or the relevant authority should be in a position to authorise an involuntary treatment measure as this is a serious breach of a person's physical and mental integrity. Authorisation for placement cannot be equated to a blank cheque authorising any form of treatment. Therefore, it would be advisable to delete paragraph 3.
- Lines 176-177: The purpose of the second part of this paragraph is unclear. The doctor, other health personnel and the responsible authority should all be able to take action to terminate the measure in all circumstances.

Proposal:

The doctor in charge of the person's care or other health personnel designated by law, and the responsible authority, shall be able to take action on the basis of the assessment referred to in paragraph 2, in order to terminate that measure.

- Line 122 [of the French]: There is a drafting error.

*D'exercer un recours devant un tribunal contre une décision de **les** soumettre à la mesure,*

- Lines 191 and 192: The expression "where necessary through his or her representative" could result in persons who do not have legal capacity and are subject to a measure such as guardianship being deprived of the right to be heard in person. If the term "representative" is used here to mean individuals chosen by persons subject to measures to help them express their wishes and defend their interests (such as a mental health advocate or a member of a users' organisation), this should be specified in the text.
- Lines 194 and 195: The materials before the court will often include all or part of the person's medical file. Therefore, it seems necessary that persons should be able to give their consent for their representative, lawyer or person of trust to have access to them.

Proposal:

*The person concerned **and, with his or her consent**, his or her representative and lawyer, and, according to law, his or her person of trust shall have access to all the materials before the court subject to the protection of the confidentiality and safety of others according to law.*

Elodie Canut

19 Considering that placement and treatment of persons with mental disorder form an integral

20 part of the health services offered to the population;

(new line) Recalling the importance of taking **necessary** appropriate measures, taking into

21 ~~account health needs and available resources~~, with a view to providing
22 equitable access to mental health services of appropriate quality;
23 Recalling that any intervention in the health field must be carried out in accordance with
24 relevant professional obligations and standards;
25 Emphasising that respect for dignity entails the need to support people to exercise their
autonomy;
26 Stressing that respect for dignity raises the importance of the principle of free and
27 informed consent to interventions in the health field;

(...)

30 Recognising that restrictions on the rights set out in the Convention on Human Rights and
31 Biomedicine are permissible only if prescribed by law and are necessary and
proportionate in a democratic society
32 in the interests of public safety, crime prevention, protection of public health or the
protection
33 of the rights and freedoms of others;

(...)

62 “involuntary” refers to a placement or treatment measure applied to a person with mental
63 disorder who does not consent or objects to the measure;

The distinction between involuntary measure and forced measure is not apparent in the draft protocol and is taken up in a manner lacking clarity in para. 11 of the draft explanatory report on the protocol.

Nor does the protocol address a recurrent problem in psychiatry, whether involuntary placement justifies recourse to involuntary treatment during placement. This distinction is absent in certain legislations including that of France, which has not really settled the problem. It draws an unfortunate parallel between the two, with the result that anyone hospitalised without their consent in an institution may have care administered to them without their consent.

This protocol could be the occasion to dispel the confusions. In para. 13 of the draft explanatory report on the protocol, this difference is partially dealt with: ***“A person might object to a proposed placement, but agree to the proposed treatment, or vice-versa.”*** Thus the following might be added to line 63 **“Consent to treatment must be sought in connection with the involuntary placement of any person”**.

(...)

73 – “court” refers to a judicial body within the meaning of Article 6 para. 1 of the European Convention on Human Rights

(...)

85 In order to respect human rights and fundamental freedoms, measures for involuntary placement and involuntary treatment shall only be used in accordance with the principles of necessity and proportionality. Persons subject to involuntary placement
87 and/or involuntary treatment shall be cared for in the least restrictive environment available and
88 with the least restrictive or intrusive treatment available, taking into account their health needs and
89 the need to protect other persons from harm.

(...)

103 Article 9 – Appropriate environment

104 Parties to this Protocol shall take measures to ensure that any involuntary placement and

105 involuntary treatment takes place in an appropriate environment.

It might be specified whether “appropriate environment” pertains to respect for the principle of dignity or comes within the ambit of the prohibition of inhuman and degrading treatment as construed in the European Court’s judgment in the case of *Stanev v. Bulgaria* on 17 January 2012 (Application No. 36760/06). Indeed, the title of the protocol implies that an infringement to the principle of dignity may be at stake, whereas hitherto the Court found a “*violation of Article 3 (prohibition of inhuman or degrading treatment) owing to the conditions under which the applicant was compelled to live*”. It is also possible to accept a dual legal foundation.

Cornelia Hagl, PhD, MD, MME, Assistant Professor at the Medical Faculty Mannheim of the Heidelberg University

Dear Madam,

Dear Sir,

With reference to the consultation of the Committee on Bioethics (DH-BIO) of the Council of Europe I like to contribute my comments to the Additional Protocol to the Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and in voluntary treatment, reference DH-BIO/INF (2015) 7.

As physician, specialized in paediatric surgery and training instructor for medical students at the medical faculty Mannheim of the Heidelberg University I agree, that the protection of patients and especially of those that can not speak for themselves is one of the most important considerations that has to be made within a society.

Because of the German history and the enmeshment of medical professionals and psychiatrists in the degrading sterilization legislative process and the recorded murder of 70,273 mental patients at six extermination centres located at psychiatric hospitals in Germany and Austria⁸³, and the mass murder of a total of approximately 300,000 mental patients who fell victim to the psychiatric “*euthanasia*” program⁸⁴ legal regulations to protect human rights of mental patients have to prohibit specifically each action that has the potential to endanger human dignity and fundamental rights and freedoms.

That means involuntary treatment and/or detainment without consent for mentally disturbed patients should in general not be enforced. Especially as compulsory treatment has no

⁸³ Proctor, Robert N. (1988). *Racial Hygiene: Medicine under the Nazis*. Library of Congress: Harvard College. See: 414 (Postwar Legacies). ISBN 0-674-74578-7

⁸⁴ Exhibition Catalogue “Registered, persecuted, annihilated” published by German Association of Psychiatry, Psychotherapy, Psychosomatics and Neurology 2014,

proven scientific beneficial therapeutic effect⁸⁵ and the German Federal Supreme Court has banned involuntary treatment⁸⁶.

Mr Juan Mendez member of the Steering Committee of The Crimes Against Humanity Initiative, launched by the Whitney R. Harris World Law Institute to study the need for a comprehensive convention on the prevention and punishment of crimes against humanity, analysed the necessary elements of such a convention, and draft a proposed treaty, which is now being debated before the UN International Law Commission⁸⁷. Mr Mendez wrote, "My main report focuses on certain forms of abuse in health care settings that may cross a threshold of mistreatment that is tantamount to torture or cruel, inhuman or degrading treatment or punishment. The report sheds light on often-undetected forms of abusive practices that occur under the auspices of healthcare policies, and emphasizes how certain treatments run afoul of the prohibition on torture and ill treatment. It identifies the scope of the State's obligation to regulate, control and supervise health-care practices with a view to preventing mistreatment under any pretext and the policies that promote these practices and existing protection gaps."⁸⁸

The initiative to protect the human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment is in this light urgently required. As a concerned citizen, recognizing that deprivation of liberty for psychiatric reasons occurs currently in each European country I will contribute my comments in detail for peruse at the Committee on Bioethics.

For further questions please do not hesitate to contact me, phone +49 (0) 172 8904020 or cornelia@haql.net.

Specific comments to the

Working document concerning the protection of human rights and dignity of persons with mental disorder with regard to in voluntary placement and involuntary treatment.

The line number is indicated; the existing unchanged text is cited in black.

Blue indicates a new text; red indicates deletion of the existing text.

Explanations and reasoning are in black italic. If no appropriate new text is available, but there is a concern about the original text, the unchanged text is cited and the reasoning about the pitfalls is attached in black italic.

61 "mental disorder" is defined in accordance with internationally accepted medical standards; **they have to be demonstrated by physical or other tests.**

Rationale: There is no valid medical standard to define "mental disorder". The fifth Diagnostic and Statistical Manual has on-going issues concerning the validity and reliability of its diagnostic categories^{89,90}. It is no suitable scaffold for the definition of mental disorders.

⁸⁵ Peter C. Gøtzsche: Deadly Psychiatry and Organised Denial. Kindle Edition, 2015

⁸⁶ <http://juris.bundesgerichtshof.de/cgi-bin/rechtsprechung/document.py?Gericht=bgh&Art=pm&Datum=2012&Sort=3&Seite=1&anz=151&pos=37&nr=60970&linked=bes&Blank=1&file=dokument.pdf>

⁸⁷ <http://ilg2.org/2014/08/06/un-international-law-commission-to-elaborate-new-global-convention-on-crimes-against-humanity/>

⁸⁸ http://mdac.info/sites/mdac.info/files/march_4_torture.pdf; page1

⁸⁹ Kendell R, Jablensky A. Am J Psychiatry. 2003 Jan;160(1):4-12. Distinguishing between the validity and utility of psychiatric diagnoses. PMID 12505793.

⁹⁰ Frances A. The new crisis of confidence in psychiatric diagnosis. Ann Intern Med. 2013 Nov 19;159(10):720. PMID 24247686.

65 “treatment” means an intervention (physical or psychological) on a person with mental disorder that has a therapeutic purpose in relation to that mental disorder, and which does not have secondary effects that may harm in excess of a reasonable risk/benefit ratio;

62 “involuntary” refers to a placement or treatment measure applied to a person with mental disorder who has not agreed to the measure.

Rationale: Patients with severe physical or mental issues may not be able to express their opinion. To accept a measure as involuntary only when the patient objects to the measure is not qualified to protect the patient’s fundamental rights.

68 “therapeutic purpose” includes **management** cure of the disorder and rehabilitation; Treatments opposed to the patients fundamental rights or his/her right for physical integrity, including administration of unknown or experimental medications, mind-altering psychiatric drugs with severe risks and side effects, non-consensual administration of psychosurgery, electroshock and mind altering drugs, for both long and short-term application are not accepted as „therapeutic purpose“.

Rationale: Mr Juan Mendez recommends in his Special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment to ban these treatments as torture⁹¹. Article 3, of the European Convention on Human Rights prohibits torture⁹².

73 “court” refers to a judicial body, assisted by an independent body comprising four members of which one is a medical doctor, one a representative of a patient advocacy organization and completed by two layers, which could be selected based on the same principles as for lay judges or jury members.

Article 4 - Necessity and proportionality

85 Measures for involuntary placement and treatment shall only be used in accordance with the principles of necessity and proportionality. That means only in extreme situations where the failure of every possible measure to prevent the use of the coercive measure and alternatives is documented.

Rationale: This commendable apprise is an ambiguous clause. What does it mean “proportionally”? Is it proportionally and acceptable to deprive a person’s fundamental human rights and dignity because he/she is diagnosed as “mentally disordered”? Invasive treatment like psychosurgery should in general not be accepted without patient’s written consent. Administration of medication after the patient’s explicit refusal is also not proportionally. This article should to be more explicit.

Article 5 Alternative measures

91 Parties to this Protocol **shall** must promote the development and use of alternatives to involuntary placement and involuntary treatment. The medical doctors and supervising health care professionals are obligated to inform the patient and his/her person of trust and legal guardian about all possible alternatives. The pre-treatment and alternative-treatment discussion has to be complete (with all possible benefits and side effect of all feasible treatments) and documented. The involuntarily placed patient has the right to written, informed consent to treatment and the right to refuse treatment. Patients also have the right to be in a condition not influenced by prescribed psychotropic medication during the consent procedure or any consultation with a legal expert.

⁹¹ http://mdac.info/sites/mdac.info/files/march_4_torture.pdf

⁹² http://www.echr.coe.int/Documents/Convention_ENG.pdf

Rationale: For a patient and non-professional it is not possible to get informed about the current treatment options. In the German Civil code the consultant doctor has the explicit obligation to mention and clarify alternative treatment options⁹³.

Article 6 - Person of trust

94 Persons who are or may be subjected to involuntary placement or involuntary treatment must have at least one meeting with a person of his/her trust. An exhaustive search to attempt to determine whether such a persons exists is required.

Rationale: Psychiatric patients are in a special vulnerable situation; they need special regulation for their shelter. If such patients may be able to speak for themselves, they need support to maintain their rights. Article 3, 5 and 6 of the European Convention on Human Rights have to be interpreted as strict as possible in these cases.

Article 10 - Criteria for involuntary placement

109 Involuntary placement of a person may only be used if the following criteria are met:

111 i. a) the person's mental health condition represents a by two health care professionals documented significant risk of serious harm to his or her health and his or her ability to decide on placement is severely impaired. The impaired mental state of the patient to obtain his or her written consent has to be documented by two witnesses

114 ii. the placement has a clear therapeutic purpose, its written evidenced is signed by an authorized doctor and a witness, and

115 iii. no less restrictive means of addressing the risk are available. The rationale for the elimination of these possibilities must be documented in the medical reports and provided to the patient's legal aid and person of trust.

Rationale: Involuntary placement can only take place when the requirements for a lawful deprivation are verified with the utmost meticulousness.

Article 12 - Standard procedures for taking decisions on involuntary placement and on involuntary treatment

127 Involuntary placement and involuntary treatment shall only take place on the basis of examination by at least one doctor and one judge having the requisite competence and experience, in accordance with applicable professional obligation and standards.

130. 2. The decision to subject a person to involuntarily placement or to involuntary treatment, shall ~~subjected to paragraph 3~~ be taken by a court or another competent body as defined in this protocol (see line 73). The court or other competent body shall:

135: ii. Ensure that the criteria set out in Articles 10 and/or 11, as appropriate to the measure(s) concerned, are met and that any possible measure to prevent the use of the coercive measure as well as alternatives has been taken.

137: iii. Take into account the opinion of the person concerned and, where appropriate, any relevant previously expressed wishes made by that person, and in the case of a Living Will ensure noted directions and prohibitions are followed^{94,95}.

⁹³ BGB § 630e Absatz 1 Satz 3

⁹⁴ BGB § 1896; http://www.gesetze-im-internet.de/bgb/_1896.html

⁹⁵ http://www.bmjv.de/SharedDocs/Publikationen/DE/FokusKarussell/Patientenverfuegung.pdf?__blob=publicationFile&v=2

146 4. Decisions to subject a person to involuntary placement and/or to involuntary treatment ~~shall~~ must be documented and state the maximum period of 72hrs beyond which, according to law, this decision(s) shall be reviewed. Administration of unknown or experimental medications, mind altering psychiatric drugs, non-consensual administration of psychosurgery, electroshock and mind altering drugs, for both long and short-term application are regarded as malicious injury.

5. Ensure that the right to call witnesses and a second opinion before witnesses is granted and that the patient has access to his medical records in consultation with his person of trust or legal representative.

Rationale: Psychotropic drugs have severe side effects that can lead to self- and foreign endangering behaviour⁹⁶. Without medical clarification and written patients consent no one can be subjected to such a tremendous risk. Each surgical procedure is without the patient written consent regarded as malicious injury⁹⁷. Psychosurgery and electroshock are invasive procedures that can lead to irreparable physical damage, therefore its application needs a written consent, if this is not possible, treatment is regarded as illegal.

Article 13 - Procedures for taking decisions in emergency situations

154 i. involuntary placement and/or involuntary medical (not psychiatric) treatment shall only take place for ~~a short period~~ a maximum of 24hrs on the basis of a medical examination appropriate to the measures(s) concerned,

158 iii. Paragraph 2 iii, iv and v of Article 12 shall be complied with as far as possible and in case of a Living Will ensure that noted directions and prohibitions are followed;

Article 18 - Right to communicate of persons subject to involuntary placement

214 2. Their right to communicate with their person of trust and other persons and bodies, and to receive visits ~~shall not be unreasonably restricted~~ can only be restricted when:

- a) an authorized doctor, who is not involved in the patients treatment, documents significant risk of serious harm to the patients health and
- b) a legal court has confirmed this valuation and
- c) it is restricted to a maximum of 72 hrs.

Rationale: The right to a fair trial (Article 6 European Convention on Human Rights) and right to an effective remedy (Article 12,) can only be guaranteed when the patient has a close contact to his person of trust and other persons he or she wants to contact. A patient with a mental disorder must not be treated like placed under disability.

Article 20 - Monitoring

224 1. Member states shall ensure that compliance with the provisions of this protocol is subjected to appropriate independent monitoring. Independent monitoring includes but is not limited to investigating all faulty or false involuntary placement and coercive measure and is authorized to issue public warnings and in cases of actual abuse to turn the matter over for civil or criminal prosecution.

General comment

The Remarks to the „Working document concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment” intent to protect the human rights and dignity of persons with mental disorders

⁹⁶ <http://www.kvpm.de/fakten/schadensersatzklagen-wegen-psychopharmaka/>

⁹⁷ <http://dejure.org/gesetze/StGB/226.html>

carefully. I hope the comments will be taken into account during finalizing the Additional Protocol. As an assistant professor in medicine I would like to encourage the Committee to be particularly mindful in these points:

The Human Rights protect the human dignity for all humans. People who need assistance and support have the right to get it. But the right to be supported does not deduces a pressure to treatment or medication. For medical reason the self-reliance of a person may not be waived. The autonomous decision with informed consent is an important principle in health care. The patient's refusal to therapeutic options should not legitimate an involuntary treatment, even if the patient has a mental disorder.

HEALTH PROFESSIONAL

College of Psychiatrists of Ireland

'The College of Psychiatrists of Ireland is grateful for the opportunity to give feedback on the "Additional protocol to the Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment".

However the College has grave concerns about the document in its current format. The College is concerned that the document may be in breach of European Law and also has concerns about the definitions of involuntary treatment and placement and mental disorder. The College recommends that legal experts should be consulted on the protocol.'

Helsinki University Central Hospital HUS Group

In reference to the public consultation of the additional protocol concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment, we would like make the following comments:

- 1) We think that the additional protocol is valuable and well formulated. Involuntary placement and involuntary treatment of persons with mental disorders may place these persons under conditions that do not respect their human dignity.
- 2) In Finland, the official health policy is aiming to reduce involuntary placement and treatment since the results of involuntary treatments are often poor. The additional protocol should emphasize more that involuntary treatments should be evidence-based and no such treatments should be given that do not yield appropriate medical results in accordance to the "*no nocere*" principle. We point out that all current medical standards are not evidence-based.
- 3) However, it is clear on the basis of the 5th article of the Convention of Human Rights that poor mental health is a legitimate reason for involuntary placement in cases where the person's mental health condition may possess a significant risk of serious harm. We point out, however, that poor mental health with poor judgment can cause not only harm to the patient's own health but to his/her well-being in general. The current version of the additional protocol does not accept involuntary placement in cases, where serious harm is caused to one's property and living (e.g. the person is going to lose his/her apartment or profession due to mental disorder). We understand the difficulties in drawing the line in appropriate means of protecting one's property. However, it should be possible in individual cases also to use involuntary treatment when the person in question is causing serious harm for his/her own well-being (not just for his/her health).

- 4) We want to point out that the current procedures under the Finnish Mental Health Act (1116/1990) with its later amendments are in line with the proposed additional protocol.

International Society for Telemedicine and eHealth/ISfTeH

Allow me firstly to congratulate you on your work concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment.

I have been through the document and I shall give my full approval of the document. Based in my experience, the document does cover the whole field concerning to the rights and the frames of acting in this particular case- referring to humans with mental disorders. Based on the specter and the fragility of the cases aforementioned, I do suggest that a particular care to be directed towards the minors with these specific disorders in the near future- starting with a united definition of what "a minor" should be considered. Allow me to relate to conditions that most people are dealt within nowadays, particularly the wars where most of "the minors" are exposed to, thus, taking in consideration now, the main outerfactor, war, that might touch the mental sphere of them and force us to deal with the same "involuntary" placement and treatment of them as well (just to take in consideration for the near future.).

And the written consents on the patients general case delivered to "the person of trust" with a right of being updated on the issue as well as the patient, if possible, to a level, to be informed, during psychiatric sessions- on how much of improvement the one has made. Again, I congratulate you on this great protocol!

Norwegian Medical Association

Referring to letter of 22 June the Norwegian Medical Association has the following comments to the additional protocol.

Article 10 – Criteria for involuntary placement

Article 10 describes the basic conditions for involuntary placement. It states that involuntary placement may only be used if the person's mental health condition represents a significant risk to his or her health and his or her ability to decide on placement is severely impaired or the person's mental health condition represents a risk of significant harm to others. The placement must also have a therapeutic purpose and no less restrictive means are available. The Norwegian legislation also includes the treatment and the deterioration criteria. Mentally ill patients might not be able to realise what is best for them and that their health will deteriorate substantially if they are not treated. We therefore suggest including a new item c in the criteria for involuntary placement:

c) the person having significantly reduced the prospects of his/her health being cured or substantially improved or having a highly probable and substantial deterioration of his/her condition in the very near future.

Article 12 – Standard procedures for taking decisions on involuntary placement and involuntary treatment

Paragraph 2 in Article 12 puts the responsibility for deciding on involuntary placement on the court or "another competent body".

Article 69 in the Explanatory report does not explain the meaning of “another competent body,” only that the decision on involuntary treatment must be made by another body than the person proposing the measures.

In Norway the court is not involved in making decisions on involuntary placement. The decision is made by a competent doctor based on a medical examination and re-examined by another doctor representing an independent institution. The court will only be involved in a potential appeal. In our opinion a decision on involuntary placement must be based on a medical examination and can only be done by a medical doctor. Involvement of a court or another competent body could delay the whole process and put the health of a mentally ill patient that needs acute medical treatment at risk.

It is difficult for us to understand what consequences this convention will have for Norway as long as the notion “competent body” is not defined or explained. We have positive experiences with our procedures where the decision must be made by two doctors of which one is from an independent institution, and we cannot see any advantages of amending our procedures for involuntary placement. As we already have mentioned having a court making the decision could delay the process.

We would therefore suggest amending Article 12 paragraph 2 to:

The decision to subject a person to involuntary placement or to involuntary treatment shall be made by a medical doctor on the basis of a medical examination. The decision must be re-examined by a medical doctor representing an independent institution.

Article 16 – Appeals and reviews concerning the lawfulness of involuntary placement and/or involuntary treatment

Paragraph 1.i. gives the person subject to involuntary placement and/or involuntary treatment the right to appeal direct to a court. In Norway the person must first direct a complaint to two independent bodies, one for involuntary placement and one for involuntary treatment. Both institutions include a doctor and a legal advisor. The patient or his/her person of trust can appeal the decision to the court. This presupposes that the decision appealed is still current. Our experience is that this is less bureaucratic and gives the person better protection than bringing the complaint direct to the court which usually will delay the process to the disadvantage of the patient. Most complaints end with the independent bodies and are rarely brought to court. We therefore suggest to add “or another competent body” after “a court” in 1. i.

to appeal to a court *or another competent body* against the decision to subject them to measures, and

Norwegian Nurses Organisation

The Norwegian Nurses Organisation (NNO) received your request of 22. June 2015, inviting us to comment on the working document concerning Protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment.

Healthcare personnel must pay greater attention to the rights legislated in the European Convention on Human Rights and the Convention on the Rights of the Child. Autonomy, freedom and human worth are the underlying pillars for understanding human rights. A common understanding of the use of coercive measures, and dedicated legislation will avoid stigmatisation of persons with mental disorder.

Nursing is founded on respect for the individual and their inherent dignity. The NNO believes it is necessary to reduce the use of restraint through enhanced voluntary decisions. Projects and research have been conducted that demonstrate the possibility of reducing the use of restraint at the individual and system level. Restraint can be necessary to safeguard life and health. Routines must therefore be developed for the involuntary treatment and reporting of usage.

The Additional Protocol to the Convention on Human Rights and Biomedicine addresses a very important issue. NSF fully supports the aim of the Additional Protocol to protect the human rights and fundamental freedom for all persons with mental disorder with regard to the use of involuntary placement or involuntary treatment.

Promoting the use of alternatives to involuntary measures is extremely important. We must ensure that involuntary measures are implemented only when absolutely necessary after all other actions have been utilized. Further it is important to ensure that the implemented involuntary treatment is the best alternative for the individual. This includes appropriate protection and procedural safety that enables the individual to effectively exercise their rights.

The NNO supports the Additional Protocol that protects human rights and fundamental freedom for all person with mental disorder. This is an important advancement for human rights.

PATIENT ASSOCIATIONS

Alzheimer Europe

Introduction

Alzheimer Europe considers the Additional Protocol to the Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment as an important document and a positive contribution towards the promotion and protection of the rights of people with dementia by means of establishing benchmarks for the minimum provisions required.

In recent years, Alzheimer Europe has compiled an overview and considered the ethical issues related to restrictions of freedom⁹⁸. Alzheimer Europe therefore appreciates the opportunity to participate in the public consultation regarding the working document relating to protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment, reference: DH-BIO/INF (2015)7 (hereafter referred to as the working document).

At the same time, we recognise that some of the provisions do not exactly match the potential needs and situation of people with dementia. We therefore recommend certain amendments or clarifications, mainly in the working document itself, in order to ensure that

⁹⁸ Alzheimer Europe (2011), *Dementia in Europe Yearbook 2011 with a focus on restrictions of freedom*.
Alzheimer Europe

Alzheimer Europe (2012). *The ethical issues linked to restrictions of freedom of people with dementia*.
Alzheimer Europe

people with dementia benefit from the same level of protection and enjoy the same rights as other people with mental disorders in Europe.

In preparation of our response, we contacted our member associations throughout Europe and asked for their reactions to the consultation document. We would particularly like to thank the following organisations and individuals for sharing their views on this issue:

- Ligue Nationale Alzheimer Liga, Belgium
- Prof. Michel Dupuis (on behalf of The Ligue Nationale Alzheimer Liga, Belgium)
- Prof. Dr Herman Nys (on behalf of the Flemish Alzheimer's Association/The Ligue Nationale Alzheimer Liga, Belgium)
- Muistiliitto (the Finnish Alzheimer association)
- Alzheimer Society of Ireland

This response is from Alzheimer Europe but also incorporates the ideas from the above-mentioned individuals and organisations. The individuals and organisations in question should not, however, be considered as necessarily being in agreement with all the points made in this document.

Our response covers the following:

1. Preamble
2. Scope and definitions
3. Procedures concerning involuntary placement and involuntary treatment
4. Criteria for involuntary placement and for involuntary treatment
5. Procedures for taking decisions in emergency situations
6. Appeals and reviews concerning the lawfulness of involuntary placement and/or involuntary treatment
7. Information and communication
8. Conclusions

Preamble

Values, rights and principles

We acknowledge the importance of the Convention on Human Rights and Biomedicine and consider it an important European level development focusing attention on the protection of the dignity, identity, human rights and fundamental freedoms of all persons with a mental disorder with regard to the use of involuntary placement or involuntary treatment, and avoiding discrimination.

Importance of the individual as opposed to the group label

We appreciate the reference in line 18 of the Preamble to the “potential” vulnerability of persons with mental disorder and to the statement starting on line 28 that the existence of a mental disorder should not in itself justify an involuntary measure. We feel that these two statements rightly avoid generalisations/stereotypes about people with mental disorders which are central to the process of stigmatisation (Link and Phelan, 2001; 2006⁹⁹), which involves discrimination. If influenced primarily by stereotyping, involuntary placement or involuntary treatment should, in our opinion, be considered as inappropriate and unjustified.

⁹⁹ Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, pp. 363-385 and Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *The Lancet*, 367, pp. 528-529.

It might also be useful to highlight other possible attributes (e.g. age and gender), which might, especially when combined with that of having a mental disorder, lead to additional stigmatisation¹⁰⁰.

Scope and definitions

People with mental disorders

We note that the provisions of the working document apply to the involuntary placement and involuntary treatment of persons with mental disorders and that it is further stipulated in the explanatory report that “mental disorder” is defined broadly in accordance with internationally accepted medical standards. Examples given in the explanatory report include the definition of mental and behavioural disorders in the WHO International Classification of Diseases and Related Health Problems. However, we are concerned that the recommendations in the working document may not provide the same level of protection of the rights of people with neuro-degenerative pathologies involving progressive cognitive deterioration (such as people with dementia) as for people with other forms of mental disorder.

Despite international medical standards, there is no universal agreement as to whether “dementia” is a mental disorder that justifies involuntary placement. In Belgium, for example, in the Law of 26 June 1990 covering the Personal Protection of People with Mental Disorders, there is no definition of mental disorder and both the legal and medical literature, as well as jurisprudence, are divided regarding the question of whether dementia is a mental disorder that may justify involuntary placement.

People with dementia, given the complexity of the condition, are not necessarily considered as people with mental disorders although they can develop behavioural and psychological symptoms (BPSD). For this reason, it is important that the references in the explanatory report are reflected in the working document. Ideally, there could be a direct reference to neurodegenerative diseases or dementia in the working document, perhaps in the form of a couple of examples of mental disorders, one of which being dementia, in the definition on line 61.

Objection to treatment and placement

Lines 62 and 63 refer specifically to people who ‘object to the measure’ but this is not reflective of those who may object but not express that objection. We welcome the point made in Article 1, paragraph 2, lines 49-50 that States may provide more extensive protection to persons with mental disorder than required by the Additional Protocol. However, the Protocol is clearly about measures that are against the will of the person concerned and terms such as ‘involuntary’ and ‘objects to’ are the central focus of its scope. We feel that this may limit the realisation of extensive protection.

We suggest including some reference at line 62 to the incapacitated but compliant person to cover the situation of people who are not free to leave the institution in which they are cared for but who are incapable of consenting to such care. In the explanatory report, the example is given of a person who complies with a measure s/he considers unacceptable based on fear of the consequences of objecting. Another example might be a person with dementia who lacks the capacity to consent to the measure but does not object as s/he does not fully understand the issues at stake or has difficulty formulating or communicating his/her objection.

Moreover, whereas the explanatory report refers to the situation of people who cannot object but are contained, the working document does not make reference to such persons in the

¹⁰⁰ Graham et al., (2003). Reducing stigma and discrimination against older people with mental disorders: a technical consensus statement. *International Journal of Geriatric Psychiatry*, 18, 8, 670-678

scope or preamble or in the wider body of the draft. There is therefore a need to make the 'incapacitated but compliant' person more visible in the working document. In effect, there needs to be protection for persons who may not have the ability to make a decision on placement, but do not object to a placement others think necessary for them. This is precisely what can happen to people with advanced dementia and this is why including this in the working document is critical to ensure that the issues around involuntary placement and involuntary treatment for people with dementia are addressed. Addressing involuntary treatment and placement is necessary for the Protocol to be compliant with the Convention on the Rights of People with Disabilities.

Mental health establishments and the place of involuntary placement and treatment

Line 22 of the Draft Protocol refers specifically to mental health services. Very often people living with dementia experience mental health problems as part of their dementia. These are often referred to by healthcare professionals as behavioural and psychological symptoms of dementia (BPSD). In Ireland, according to the Alzheimer Society of Ireland, if a person with dementia is experiencing BPSD and having mental health issues they are usually referred to a psychiatrist of later life (old age psychiatrist) for assessment and treatment and may be provided with on-going support from the mental health services. Therefore, any changes in mental health legislation or policy at a national or EU level may, in some countries, positively or negatively impact on the lives of people with dementia.

On the other hand, not all people with dementia receive care through mental health services and not all people with dementia are referred to mental health specialists. In relation to line 128, for example, regarding doctors with the requisite competence and experience for the examination linked to possible involuntary placement and involuntary treatment, this would be a geriatrician or neurologist in Finland provided that they have experience with people with dementia (according the Finnish Alzheimer association).

It is later stated (in article 9, line 105) that involuntary placement and treatment should take place in an appropriate environment which we welcome. For people with dementia, it is often the case that involuntary treatment or involuntary placement takes place outside of mental health services, such as in a long-term residential care home. We suggest that reference is also made in the working document to social and community services.

We welcome the reference in point 5 of the explanatory notes that the working document applies to the use of involuntary treatment for mental disorder wherever that treatment is delivered, including in the person's own home and presumably in any nursing home. This should be reflected in the preamble to the working document as this point is not clear, particularly as specific mention is made to mental health services (e.g. in lines 19 to 22).

Therapeutic purpose

To reflect the situation of people with dementia, and the fact that dementia is not curable (as stated in point 16 of the explanatory report), but that it may be possible to slow down the rate of decline (stated in point 16), we would welcome a few examples in the working document of therapeutic purposes other than those which do not apply to many people with dementia. Examples might include "maintaining and facilitating autonomy as far as possible", "slowing down the rate of deterioration" and/or "working on maintaining and improving the person's quality of life".

Person of trust

In the context of neurodegenerative pathologies, it is important to specify that people who are or may be subjected to involuntary placement or involuntary treatment shall have the right to choose a person of trust and that it should be possible to express such choice in advance by means of an official, advance statement. It should also be recommended that national policies are in place to make this possible.

Procedures concerning involuntary placement and involuntary treatment

The examination by one doctor

Article 12.1 of the working document states that “Involuntary placement and involuntary treatment shall only take place on the basis of examination by at least one doctor having the requisite competence and experience, in accordance with applicable professional obligations and standards”. We suggest adding “recent” before “examination” and “independent” before “doctor” in order to reinforce the objectivity of the medical expertise (cfr. Judgment of the European Court of Human Rights in “Winterwerp”).

Previously expressed wishes

We appreciate the recognition of the value of advance directives in lines 136 to 37.

Criteria for involuntary placement and for involuntary treatment

The term “mental disorder”

Our previous comments about the interpretation of the term mental disorder in relation to dementia are also applicable here.

The voice of the person subject to possible involuntary placement or treatment.

The criteria should include some reference to the ‘voice’ of the person who is objecting to the placement. For example, a measure could be added which alludes to communication (using relevant mediums) with the person being placed or treated. The impaired communication of many people with dementia means that a range of communication mediums must be used as well as a functional approach to engaging a person in specific decisions.

Insistence on the need for a review process to be in place

It should also be stated in the criteria that it should be necessary to put in place a review system to ensure that the person’s fundamental rights are protected.

The therapeutic purpose of treatment

Although having a therapeutic purpose is part of the definition of “treatment”, it seems strange not to mention that involuntary treatment should have such a purpose in Article 11.

Procedures for taking decisions in emergency situations

It should be stated in the working document that the procedure for taking decisions in emergency situations should incorporate a review system as a safeguard.

Appeals and reviews concerning the lawfulness of involuntary placement and/or involuntary treatment

Involving people with dementia in appeals and reviews

The court may not be the most appropriate setting for people with dementia for appeals and reviews. It is difficult to envisage how practical steps to ensure full participation of the person with dementia could be effectively taken in a court environment. Examples of some of the most common practicable steps towards involving a person with dementia in a decision include:

- establishing a time of day at which a person functions best and approaching them at that time

- establishing the environment in which the person functions best and approaching them in that environment
- establishing the people with whom the person communicates best and involving them in the communication process.

Protection against over-use of medication and other forms of restraint

There is an urgent need for a regular review system and one which does not disadvantage people with dementia who have been involuntarily placed and treated (especially those who do not have family and friends to protect their interests) due to the over-use of medication and other forms of restraint in long-term care settings. Please see the following publications/reports:

1. “Policy Paper concerning the definition of “voluntary patient” under s. 2 of the Mental Health Act, 2001” of Ireland.
2. Irish Human Rights Commission Report to the Government of Ireland on the visit to Ireland carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 25 January to 5 February
3. UK study by Sube Banerjee (2009) indicating that up to a quarter of people with dementia in residential care are on anti-psychotic medication despite its “minimal effectiveness” in managing symptoms of dementia¹⁰¹.
4. Research published by Kings College London and a Norwegian research partner in the British Medical Journal online (Husebo et al., 2011¹⁰²) reporting that giving paracetamol to people with dementia was 17% more effective than anti-psychotics in relieving behavioural symptoms such as agitation or aggression. It is disturbing to note that people with dementia may frequently be in pain due to other physical conditions and be attempting to communicate this through their behaviour, which is misinterpreted as a symptom of dementia and treated with inappropriate drugs, while the underlying condition causing the pain is ignored.

Protection from such abuse is an essential part of the object of the working document which is described in article 1 as being to “protect the dignity and identity of all persons with mental disorder and guarantee, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to involuntary placement and involuntary treatment”.

Information and communication

Information and communication is critical for people with dementia. Extra time is one of the key ingredients for effective communication. There is a need for flexibility in assisting people with dementia to arrive at and communicate a decision. A system, which has the flexibility to allow people with dementia the time and support they need to understand, consider, translate information into an accessible format and communicate a decision, is essential if the working document is to be effective. This will mean considering alternative information formats, visual prompts/reminders of what has been said or discussed so far and other communication aids developed for people with dementia.

¹⁰¹ Banerjee S (2009). *The use of antipsychotic medication for people with dementia: Time for action*. The Institute of Psychiatry, King’s College London

¹⁰² Husebo BC, Ballard C, Sandvik R, Bjarte Nilsen O, Aarsland D (2011). Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial. *BMJ* 343:d4065

More precisely, the reference to the right to be informed appropriately of the reasons for the decision and the criteria for its potential extension or termination should cover not only linguistic barriers and literacy but also the level of capacity to understand. The right to be informed regularly should also include the right to receive written information. As many people with dementia have difficulties with memory, there should be an option to receive information in written form which is adapted to and maximises their ability to understand.

Regarding the right to communicate, without restrictions, with lawyers, representatives or any official body charged with the protection of the rights of persons subject to involuntary measures, it is not clear what measures are in place to ensure that this right is respected. Whilst the measure is partly intended, according to point 102 in the explanatory report, to serve a therapeutic purpose and as a safeguard from abuse, it is not clear how this right would be realistically enforced as the abuse might actually consist of denying a person this right. People who have memory and language difficulties, perhaps combined with confusion, may not be in a position to realise that their right is not being respected.

Conclusion

To conclude, Alzheimer Europe is pleased to have been able to contribute towards the excellent work of the Committee on Bioethics of the Council of Europe. We appreciate the way that representatives of civil society and patient organisations have been given the opportunity to influence the development of this document. We reiterate our thanks to the Ligue Nationale Alzheimer Liga (also to Prof. Dupuis and Prof. Dr Nys), Alzheimer Society of Ireland and Muistiliitto (Finland) for their valuable feedback and ideas.

Our overall impression of the working document is that it has the potential to make a significant contribution to protecting the rights and wellbeing of people with dementia in relation to decisions relating to and the possible experience of involuntary placement and involuntary treatment. We wish the Committee on Bioethics continued success with the development of this document.

Alzheimer Society of Finland (Muistiliitto)

In Finland we have been discussing for several years about restrictions of freedom of people with memory diseases (PwMD)/dementia. If this Additional Protocol will cover/concern also PwMD in Finland it means change in practice and ensure that PwMD benefit from the same level of protection and enjoy the same rights as other people with mental disorders in Europe.

Mental Health Act in Finland involuntary treatment criteria have been defined more narrowly than in the Additional Protocol. According to this, involuntary treatment may be given to an adult person only if he or she has been diagnosed with a mental illness (to minors, cause a severe mental disorder). In Finland, "involuntary" treatment is broader than the definition of "involuntary" used in the Additional Protocol. Finnish legislation also requires that the involuntary treatment may be used/invoked only when the person is at serious risk of causing harm to themselves or others, or less stringent measures are not sufficient or they are not available. (See comments of the National Advisory Board on Social Welfare and Health Care Ethics)

In Finland we do not have legislative provisions for involuntary placement or treatment for people with memory diseases/dementia. The draft law has been in preparation for several years. We acknowledge the significance of convention on Human Rights and it is important in Finland

- to focus attention on the protection of the dignity, human rights and fundamental freedoms of people with memory diseases

- to avoid discrimination of people with memory diseases.

In many cases involuntary treatment (like binding to the chair or locking the doors.) slow down and hinder the treatment processes and it may also, as we know, impair the situation of person.

We have been given our comments on Alzheimer Europe's (AE) response, our organization is member of AE. Here are some additional notice:

- lines 107-123: Criteria for involuntary placement and treatment: In Finland we emphasize both health and safety issues.
- line 128: Doctor with requisite competence and treatment in case of people with dementia/memory diseases: geriatrician and neurologist if they have experience with PwMD.
- line 137: Very important aspect and the value of advanced directive is emphasized.

We wish you success with the work of this document, it has potential to protect the rights of people with memory diseases also in Finland.

Association for Help to People with Intellectual Disabilities in the Slovak Republic

We have been approached with a request to submit our comments on proposed Additional Protocol to the Council of Europe Convention on Human Rights and Biomedicine. The proposed protocol deals with specific issue of deprivation of liberty of persons with mental disabilities, especially in the context of psychiatric involuntary hospitalisations.

With respect to Slovak legal order, the deprivation of liberty on the basis of disability is enabled by Act No. 576/2004 Coll. on Healthcare enables, Act No. 99/1963 Coll. the Civil Procedure Code, the adopted new legislation on non-contentious civil proceedings that will enter into force in July 2016, as well as the Act No. 300/2005 Coll. the Criminal Code. We emphasise two notable examples of deprivation of liberty in civil proceedings. *First*, the involuntary hospitalisation under Section 6 paragraph 9 letter d) of the Healthcare Act allows for the involuntary hospitalisation of a person on the ground of his or her mental illness or mere symptoms of mental illness, if he or she poses a danger to himself or herself or to the others, or if there is a risk of serious deterioration of his or her medical condition. *Second*, Section 187 paragraph 3 of the Civil Procedure Code allows for the involuntarily hospitalisation of a person in legal capacity proceedings on the basis of a recommendation of an expert. Within the criminal context, most problematic is the regime of protective treatment outlined in Section 73 of the Criminal Code. The court can impose protective treatment on an offender who commits an offence otherwise raising criminal liability in the state of insanity, if his or her presence at liberty is deemed to be dangerous. The court can also impose protective treatment on a person who commits a criminal offence in a state of diminished responsibility, where his or her presence at liberty is deemed to be dangerous.

We believe that both, the proposal of the Protocol as well as the domestic legislation, are incompatible with Article 14 of the UN Convention on the Rights of Persons with Disabilities. According to this provision the existence of a disability shall in no case justify a deprivation of liberty. At the same time this provision protects persons with disabilities from discrimination. The UN Committee on the Rights of Person with Disabilities adopted a very clear position on this topic at its session in September 2015. In the Guidelines on Article 14 CRPD, adopted during this session, the UN CRPD Committee stated that legal regulation enabling to deprive a person of liberty on the basis of his or her disability is incompatible with the CRPD. Typical examples are so called involuntary hospitalisations in psychiatric hospitals, which are also largely covered by the proposed Additional Protocol. **From this reason we believe that the proposed Additional Protocol is in direct contradiction to Article 14 CRPD, we**

disagree with its content and it should in no way be supported. Moreover, we argue that should be understood that the CPRD introduced the highest standard of human rights and each policy and legislative measure of the Council of Europe should be fully in line with the CRPD.

ASTRARESI, Transnational Association of Campaigners for better social, psychiatric and health services

Catterina Verona, President of ASTRARESI

My comments prior to the finalisation of the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning the protection of the human rights and dignity of persons with mental disorder with regard to involuntary placement and treatment

Line 39 → In the cases submitted to me, there was no monitoring of compulsory health treatment (TSO).

Chapter I – Object and scope

Article 1 - Object

Line 47 → What about persons without mental disorders who are forced nonetheless to undergo treatment normally reserved for persons with mental disorders because they are the victims of (more or less intentional) errors of diagnosis or psychiatric abuse?

Article 2 – Scope and definitions

Scope

Lines 54 and 55 → It is essential to point out that in Italy, no body or organisation checks that persons undergoing involuntary or compulsory “supervision” through the psychiatric care system are actually suffering from mental disorders. My son and I are the living proof that in a member state like Italy, it is possible to end up in psychiatric care without being ill and without even being a danger to oneself or society but simply because it was decided that this would be the case; such people can also be assessed by a court psychiatrist and treated with neuroleptics and benzodiazepines without this process eliciting any indignation within the system or associations. This is why I founded an association for the protection of persons subject to involuntary placement and treatment **with or without mental disorders**. When a person is given neuroleptics and benzodiazepines, the effects of these psychotropic substances make it impossible to assess this person’s state of mental balance objectively.

Lines 57 and 58 → I need to understand more about what is meant by “criminal law procedure”. I note that many young men and women are accused (and hence convicted) of striking hospital staff or police during a compulsory treatment or TSO “procedure”.

Definitions

Line 69 → Very often in Italy, a representative is “imposed” on persons who do not wish to be subject to compulsory treatment in circumstances other than those described under the heading “Scope” in Article 2.

Lines 71 and 72 → In view of the psychiatric abuse which I believe to be commonplace in Italy and I have often witnessed, I decided to invent a role for myself, which is precisely that of the person of trust. I accompany people who ask me to go with them to their psychiatrists. More often than not these “gentlemen” turn me away and criticise their patients for bringing somebody with them. It is therefore absolutely essential for it to become a right recognised by all the member states for psychiatric patients to be accompanied by a person of trust. In this connection, I have written a letter to the mayors and guardianship judges of Italy calling

on them to recognise that persons of trust have a legitimate role and set up a review body that is independent from psychiatric institutions.

Line 73 → In Italy courts come into play in the person of guardianship judges, who sign compulsory treatment (TSO) requests submitted by psychiatrists. From the cases I have observed, my own experience and a discussion with a guardianship judge at the Tribunal di Trento, it is clear that judges sign these requests without even finding out about any of the facts or people involved, arguing that they do not have the necessary skills to draw conclusions. I heard the same argument when I went to put my questions to mayors, who may also sign psychiatrists' requests in Italy. At this rate, 20 people might be regarded as guardians when they are actually no such thing as everyone signs simply because the person before them has signed. When I asked to talk to a judge during the time when my son was constantly being subject to compulsory treatment, the judge refused to see me. It is only now that I have been received by the judge in Trento, presumably because I am the president of this association I have set up.

Lines 74 and 75 → There is an urgent need in Italy not only to establish the institution of the "person of trust", chosen by citizens who are subject to involuntary placement or treatment, but also to set up a "competent body", independent from the psychiatric establishment, in accordance with UN Resolution 46/119 (which I translated into Italian <http://www.unric.org/it/documenti-onu-in-italiano/57>) and talks, in Principle 17, of a "review body". This was a request which I also relayed in my letter to the mayors of Italy.

Line 76 → The responsible authority in the hospital in which my son was placed told me that everything was fine as it was. At the time I had had little preparation for the crime that was unfolding before me and I did not have the mental tools and the right words which I have developed since but I did deserve to be listened to!

Chapter II – General provisions

Article 4 – Necessity and proportionality

Lines 87-89 → Only a competent body can assess whether treatment is the least restrictive and intrusive possible, and such competent bodies should be informed by the person of trust, as the psychiatrists applying an involuntary treatment measure can never be objective about their own actions. In my humble opinion, psychiatrists are too often left to their own devices and are never subject to critical scrutiny or capable of proper intellectual honesty. I founded this association which I represent precisely with the intention of applying this scrutiny, which I believe to be essential to prevent psychiatry from falling into the excesses which have characterised it since its foundation as an institution. Human beings cannot be vested with a power such as that of being entitled to arrest a fellow human on the sole basis of a psychiatric diagnosis (this is not the place to look into the scientific value of psychiatry) without being subject ultimately to the critical eye of an independent competent body or an ethics committee. Such competent bodies should be made up of ethics specialists and other persons such as independent psychiatrists, representatives of associations and lawyers. The side effects of psychotropic substances are often played down by psychiatrists and they prescribe them despite the repeated denunciations of patients, who often describe them more lucidly. All of these side effects which are overlooked by psychiatrists should be communicated to the *Farmacovigilanza*, the Italian agency for the control of medicines.

Article 5 – Alternative measures

Lines 91 and 92 → Only persons of trust can confirm whether alternative measures were considered. Thanks to my presence, one of the members of our association was able to negotiate for his hospitalisation to be organised on a voluntary basis although all the papers had been signed for involuntary placement and treatment. It is quite clear that there was no reason to opt for involuntary placement and treatment given that I succeeded in arranging a

negotiation. If I had not been called by this person, he would have been subject to compulsory treatment (TSO).

Article 6 – Person of trust

Lines 94 and 95 → The presence of a person of trust is not just essential but should figure among the fundamental rights of citizens. How can anyone be subject to involuntary placement or treatment without someone they trust (and/or an association) knowing about it? This was one of the first things to trouble me when I learned that involuntary placement and treatment existed in our societies. I asked the guardianship judge at the Tribunal di Trento whether citizens liable to involuntary placement or treatment could submit a document to a court (or even to a town hall, given that in Italy compulsory treatment requests must also be signed by mayors) designating a person and/or an association to be notified in the event of such placement or treatment. This possibility should not be left to the whim of a judge; it should be the rule for everyone.

Article 7 – Legal assistance

Lines 97 and 98 → I had a horrific experience on one occasion when I visited a young girl in a psychiatric ward with a lawyer so that she could have legal assistance. We were thrown out of the ward and the lawyer was reported. Even now that I have founded and I represent this association, last month I was asked to leave the same ward and not to meet a young man who had asked for me to come and see him. The rule I have applied since I established this association is to abide by these “totally arbitrary orders” so as not create “complications” on wards, but it goes without saying that I will continue to denounce psychiatric abuses as long as I still have the strength to do so.

It is therefore essential (and I am attempting to achieve this) for a list of lawyers to be drawn up who specialise in psychiatric institutionalisation and counter it by applying both national and European laws, resolutions and protocols.

Chapter III – Criteria for involuntary placement and for involuntary treatment

Article 10 – Criteria for involuntary placement

Lines 107 to 115 → In my opinion, my thoughts on this subject are very important. I always refer, of course, to the Italian context and what I have seen there, while knowing full well that applying this generally does not always yield good results. Very rarely have I seen cases where involuntary placement was not accompanied by involuntary treatment. The system we have in Italy is centred on involuntary treatment as is indicated by its name “Trattamento Sanitario Obbligatorio” (Compulsory Health Treatment). If psychiatrists more often considered the possibility of hospitalising people only to keep them under observation and without automatically treating them with psychotropic substances and benzodiazepines, we could avoid a large number of compulsory treatment orders, as it is very often treatments with psychotropic substances which patients refuse and only the review body can gauge subsequently, i.e. after compulsory placement, whether or not the person should be subject to treatment and, if so, what treatment.

Article 11 – Criteria for involuntary treatment

Lines 116 to 123 → There is therefore an urgent need to set up this review body, as I have repeatedly witnessed treatment being imposed for no apparent reason, including on my son, who was subject to a compulsory treatment order simply because he was thought to be schizophrenic, whereas his behaviour could not be said to pose any kind of threat to his own health or that of others. I should also point out that the diagnosis of schizophrenia was contested by several psychiatrists (in Paris and Florence) but their views were never taken into account.

Chapter IV – Procedures concerning involuntary placement and involuntary treatment

Article 12 – Standard procedures for taking decisions on involuntary placement and on involuntary treatment

Lines 130 and 131 → The other competent body referred to can only be the review body provided for by UN Resolution 46/119, which will be completely independent from the psychiatric care system. It will be made up of European university professors, ethics specialists, representatives of associations and others so as to avoid any corruption.

Article 15 – Termination of involuntary placement and/or involuntary treatment

Lines 169 and 170 → The fact is that here in Italy, some psychiatrists force people to go to psychiatric centres for treatment or otherwise be subject to involuntary treatment, and do so even if the criteria set out in Articles 10 and 11 are not met.

Line 177 → To prevent psychiatric abuse, it is absolutely essential to set up this competent body, which would be independent from the psychiatric care system.

Article 16 – Appeals and reviews concerning the lawfulness of involuntary placement and/or involuntary treatment

Lines 179 to 202 → As I have already reported above, I went with a lawyer to visit a young girl who had asked us to come and see her after she had been placed in hospital under an involuntary procedure. The lawyer was reported to the bar association and the psychiatrist tried to snatch away from me the pen which the young girl used to sign the document giving the lawyer power of attorney.

Chapter V – Information and communication

Article 17 – Right to information

Lines 204 to 209 → When the Italian institutional psychiatric care system entered my and my son's lives, nobody, least of all the psychiatrists, told me what was happening in our lives. I had to fight hard for three long years not to yield to their provocation and not to allow my son to be subjected to arbitrary mechanisms. When I discovered UN Resolution 46/119, it gave me the courage to make a legal complaint against the psychiatrists. However, this only made things worse for me and my son because none of the people involved in our case intended to comply with the resolution, not even the guardianship judge in Rovereto!

Now that I am the official translator of Resolution 46/119 and I represent this association, I will try by every means available to me to inform people of their rights and ensure that they are respected.

Article 18 – Right to communication of persons subject to involuntary placement

Lines 210 to 215 → My son was only allowed to telephone me once he had signed a document saying that he accepted the treatment using psychotropic substances and benzodiazepines. And very often the head of the department prevented me from even seeing him.

My conclusions

Urgent action is needed to provide for persons of trust and to notify citizens who are subject to involuntary placement and treatment that they have the right to appoint them. These persons should be told immediately what has happened to their “friend”.

It is also imperative to set up an independent review body, which will be informed straight away about the involuntary placement of the citizen in question and provided with the fullest possible details by the patients or the persons of trust. The body will be used to examine both measures – placement and treatment – separately and ensure that UN Resolution 46/119 is respected, together with any protocol, including the one in question here.

There is also an urgent need to draw up a list of specialised lawyers to prevent psychiatric institutionalisation in all its forms and to intervene when involuntary placement or treatment is implemented.

It is crucial to grant citizens who are subject to involuntary placement or treatment the possibility of describing their version of the facts to the review body as soon as possible.

Austrian National Council of Disabled Persons (OeAR)

The **Oesterreichische Arbeitsgemeinschaft fuer Rehabilitation (OeAR)** is the umbrella organisation of Austrian disability associations. It comprises more than 70 member organisations and represents the interests of 400,000 persons with disabilities in Austria. The OeAR is a member of and operates as the Austrian National Council to the European Disability Forum.

The OeAR welcomes the opportunity to contribute to the consultation process by providing its views and comments on the draft Additional Protocol to the Council of Europe Convention on Human Rights and Biomedicine concerning the protection of human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment.

Austria ratified the **UN Convention on the Rights of Persons with Disabilities (CRPD)** and its Optional Protocol on 26 September 2008. It is clear that the human rights instruments of the Council of Europe and the UN CRPD intersect when it comes to the human rights of persons with disabilities. International human rights standards constitute the prior reference points with regard to interpretation and implementation as international law prevails regional agreements. Since the members¹⁰³ of the Council of Europe have also signed and/or ratified the CRPD, this becomes even more evident. Regional human rights instruments may not fall behind international human rights standards. **Core principles** of the CRPD are “respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”.¹⁰⁴ These principles are reflected in all Articles of the CRPD. **Article 14** of the CRPD prohibits unlawful or **arbitrary deprivation of liberty** and the **existence of a disability** as a justification for deprivation of liberty.¹⁰⁵ It should also be mentioned, that the CRPD-Committee recommended Austria to “develop

¹⁰³ The only exception forms Liechtenstein.

¹⁰⁴ See Article 3 (a) CRPD; UN GA, Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, A/HRC/22/53, para. 27.

¹⁰⁵ As clarified for example by the Special Rapporteur on Torture in its report of July 2008, A/63/175, para 64, footnote 38.

deinstitutionalization strategies based on the human rights model of disability¹⁰⁶ and “**allocate more financial resources** to persons with intellectual and psychosocial disabilities who require a high level of support, in order to ensure that there are sufficient community based **outpatient services** to support persons with disabilities.”¹⁰⁷

Involuntary placement and/or involuntary treatment could be prevented if sufficient **alternative and preventive measures** as well as **psychosocial support**¹⁰⁸ would be available or if **reasonable accommodation** would be provided as stipulated by the CRPD.¹⁰⁹ This includes, inter alia, out-patient counselling centres, peer-counselling, psychosocial emergency services, outreach services and accompanying services, crisis-contact points, soteria, the use of dialogue-based communication, the provision of personal assistance also for persons with psychosocial disabilities, etc. The participation of self-advocates at the process of developing services in this regard is of utmost importance. Peers have to play an important role throughout the entire process including their active participation in the implementation of alternative and preventive measures. Although the OeAR is aware the discussion on the practical necessity to foresee minimum standards for those states that are not ready to foresee sufficient preventive and alternative measures and to abolish these discriminatory practices, yet, the development of alternative and preventive measures should be one of the core principles of this draft Protocol. Parties to this Protocol shall be asked to allocate sufficient resources for the **participatory development of inclusive alternative and preventive measures and support services in local communities in line with the CRPD** that would enable all persons with disabilities to choose freely with whom, where and under which living arrangements they live.¹¹⁰

Involuntary placement and involuntary treatment can further often be the result of the absence of qualified staff¹¹¹ and inclusive concepts. Therefore, this Protocol shall ensure that **special, regular and continuous awareness raising activities and training** on treatment in accordance with the human rights of persons with disabilities and other relevant norms is provided **to health care personnel, medical professionals, psychologists, therapists and other personnel in care institutions.**¹¹² The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) has noted that “ staff resources should be adequate in terms of numbers, categories of staff (psychiatrists, general

¹⁰⁶ UN Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Austria, adopted by the Committee at its tenth session, 2-13 September 2013, CRPD/C/AUT/CO/1, para 30.

¹⁰⁷ CRPD/C/AUT/CO/1, para 31; see also e.g. CRPD/C/BRA/CO/1, para. 29.

¹⁰⁸ Austrian National Council of Persons with Disabilities, Alternative Report on the implementation of the UN Convention on the Rights of Persons with Disabilities in Austria on the occasion of the first State Report Review before the UN Committee on the Rights of Persons with Disabilities, 2013, Art 14, p. 36.

¹⁰⁹ Compare, inter alia, Art 2 CRPD and Art 5 para 3 CRPD.

¹¹⁰ See e.g. CRPD/C/UKR/CO/1, para. 37.

¹¹¹ See e.g. Council of Europe, European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), CPT standards, “Substantive” sections of the CPT’s General Reports, CPT/Inf/E (2002) 1 – Rev. 2015, para. 37.

¹¹² See CRPD/C/AUT/CO/1, para. 33; CRPD/C/DNK/CO/1, para. 39; CRPD/C/KEN/CO/1, para. 30; CPT standards, paras. 128, 129, 132, 133.

practitioners, nurses, psychologists, occupational therapists, social workers, etc.), and experience and training” and found that “deficiencies in staff resources [...] can lead to high-risk situations for patients, notwithstanding the good intentions and genuine efforts of the staff in service.”¹¹³ Examinations shall take place by at least one doctor and at least one other qualified specialist. The basis for developing regulations must be professional standards that go far beyond medical standards, but consider as well other fields, like, e.g. experiences from the social work sector or the expertise of peers.

Persons subject to involuntary placement or involuntary treatment and their relatives shall be provided with **free and participatory advisory services**¹¹⁴ and shall have the right to not only free but also **accessible legal aid**. It must be ensured that **the State is directly responsible** for the action of private institutions when it outsources its medical services.¹¹⁵ Victims shall further be entitled to and provided with **redress and adequate compensation**.¹¹⁶ Monitoring shall be conducted by a **Committee** which must be **independent, adequate, participatory**¹¹⁷ and **effective** and provided with **adequate financial resources**. The Committee shall be authorized to **talk in private** to patients and to receive any complaints that they may have.¹¹⁸

Finally, the OeAR stresses that the term “mental disorders” must be considered as overcome language. The usage of this wording is especially surprising as the same sentence refers to the UN CRPD. Hence, the usage of a CRPD-conform language would be appropriate. The CRPD-Committee uses, e.g. the term “**persons with psychosocial disabilities**” in its Concluding Observations on Austria.¹¹⁹

Citizens Commission on Human Rights (CCHR)

Introductory and general comments

The Citizens Commission on Human Rights is a global mental health rights organization that has represented the interests and concerns of patients in the mental health system and their families since 1969. Worldwide it has been responsible for helping achieve more than 175 laws that protect the rights of patients against coercive mental health treatment and abuse. The comments made by Citizens Commission on Human Rights (CCHR) in this paper reflects those interests and rights.

¹¹³ CPT standards, paras. 42-46.

¹¹⁴ Alternative Report, Art. 25, p. 134.

¹¹⁵ Committee on the Elimination of Discrimination against Women, Communication No. 17/2008, para. 7.5.

¹¹⁶ CRPD/C/CZE/CO/1, para. 33.

¹¹⁷ Compare also Art. 33 (2) CRPD.

¹¹⁸ See e.g. CRPD/C/KEN/CO/1, para. 32.

¹¹⁹ See CRPD/C/AUT/CO/1, para. 29.

The comments are particularly mindful of the following points in the "Working document concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment."

- Considering that the aim of the Convention on Human Rights and Biomedicine, as defined in Article 1, is to protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine,
- Stressing the importance of the principle of free and informed consent to interventions in the health field,
- Recalling that the existence of a mental disorder in itself shall in no case justify an involuntary measure, and
- Recognising that the use of involuntary placement and involuntary treatment has the potential to endanger human dignity and fundamental rights and freedoms.

Given the more than four decades of CCHR's experience, involuntary detainment (without consent) for "mental" reasons ideally should not be enforced. Whatever treatments that are provided in such circumstances have such potential serious risks and can permanently damage the person receiving them, as to outweigh the reasons for commitment.

Furthermore, coercive treatment does not have a verified and proven scientific beneficial therapeutic effect. That the mental health system has not evolved from such a punitive approach to treating such vulnerable individuals is indicative of social narrowmindedness and ignores the fact that involuntary commitment laws have been abused over and over again.

According to the late Professor of Psychiatry, Thomas Szasz, CCHR's co-founder, "Whether we admit it or not, we have a choice between caring for others by coercing them and caring for them only with their consent." Care without coercion, he said is not considered in deliberations on mental health policy because "The conventional explanation for shutting out this option is that the mental patient suffers from a brain disease that annuls his capacity for rational cooperation." Professor Szasz said this is false and that "All history teaches us to beware of benefactors who deprive their beneficiaries of liberty."^{vii}

CCHR does recognize that public authorities, families and society are faced with the problem that a very small number of insane persons exhibit unpredictable psychotic behaviour and that, especially when prescribed mind-altering drugs, can exhibit violent or destructive traits. The societal problem persists mainly due to the failure of psychiatry to identify and appropriately deal with these relatively few cases.

Where in such cases interventions without consent may be considered, there needs to be stronger safeguards than even those recommended in the Protocol, including ensuring that such detainment can only be determined by a court of law or tribunal. And the individual must have the right to state-funded legal representation and the right for an appointed guardian to consent to treatment on their behalf if a court finds the individual is incompetent to consent.

George Hoyer, Professor of Community Medicine at the University of Tromsø in Norway, discounts the idea that such individuals should be denied the right to consent, stating: "Seriously mentally disordered patients neither lack insight, nor is their competency impaired...."^{viii}

All this aligns with Article 5 of the European Convention on Human Rights which guarantees, "Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful."

Governments, courts and mental health tribunals must be apprised of current psychiatric thinking and realize that decisions mandating involuntary detention and "treatment" do not, in themselves, mean that the individual (or, indeed, society) will be protected or even helped.

The diagnostic criteria upon which involuntary commitment rests, remains faulty. There are trivial differences between the disorders in *The Diagnostic and Statistical Manual of Mental Disorders* (DSM) and the *International Classification of Diseases* (ICD) mental disorder section. Allen Frances, chairman of the DSM-IV Task Force, and Duke University professor of psychiatry emeritus worked with the ICD-10 task force in an attempt to align the two manuals.^{ix}

He blames the DSM-IV [and by association, therefore, ICD] for creating a false epidemic in childhood mental disorders, especially Attention Deficit Hyperactivity Disorder (ADHD), Bipolar Disorder and autism. He stated: "We now have a rate of autism that is 20 times what it was 15 years ago. By adding bipolar II, that has resulted in lots more use of antipsychotic and mood-stabilizer drugs. We also have rates of ADHD that have tripled, partly because new drug treatments were released that were aggressively marketed." ^x

He is even more outspoken against DSM-5 published in 2013, warning: "My advice to clinicians, insurance companies, educators and policy makers is simply to ignore DSM-5. Its suggestions are reckless, unsupported by science, and likely to result in a great deal of loose, inaccurate diagnosis and unnecessary, harmful and costly treatment."^{xi}

Thomas Insel, Director of the U.S. National Institute of Mental Health (NIMH) that collaborates with European and other world agencies on research, said that DSM's "weakness is its lack of validity. Unlike our definitions of ischemic heart disease, lymphoma, or AIDS, the DSM diagnoses are based on a consensus about clusters of clinical symptoms, not any objective laboratory measure. In the rest of medicine, this would be equivalent to creating diagnostic systems based on the nature of chest pain or the quality of fever."^{xii}

Psychiatrists admit they do not know the aetiology (cause) of any mental disorder and have no cures and, therefore, treatment is aimed not at curing but only the control of symptoms. Yet involuntary commitment laws give them the power to deprive hundreds of thousands of people, including children, of their liberty every year when they have committed no crime. These laws enforce treatment on individuals that the UN Special Rapporteur on Torture, Juan Méndez, in February 2013 said administered coercively, are inhuman and degrading and could amount to torture. Mr. Méndez recommended an "absolute ban" on all forced and "non-consensual administration of psychosurgery, electroshock and mind-altering drugs such as neuroleptics, the use of restraint and solitary confinement" of those people determined mentally disabled.^{xiii}

The Additional Protocol to the Convention on Human Rights and Biomedicine, while increasing some protections of human rights and dignity of persons involuntarily detained in psychiatric facilities, falls short of ensuring the level of protections that the UN Special Rapporteur report envisions.

Instead, a large number of people said to be socially maladjusted or having acute or chronic behavioural or mental problems but who could take care of their own lives have been

incarcerated against their will and subjected to coercive "treatment" that do nothing to cure them.

In essence, psychiatry has:

1. not yet been able to identify those among the insane who are actually dangerous or who will cause harm to others or society, and
1. not developed treatments that actually have a documented and unquestionable therapeutic effect on the state of mind or prevent future harmful acts being carried out by these few individuals.

Instead, psychiatry has developed practices that arguably can create violent and suicidal behaviour—for which people can be involuntarily committed. For example:

- This year British researchers studied Sweden's prescribed drug register and its national crime register over a three-year period and reported their findings in *PLoS Medicine*: that 15 to 24 year olds taking antidepressants were about 43% more likely to be convicted of a serious crime such as homicide, assault, arson, robbery, kidnapping, and sexual offense when taking the antidepressant than when they weren't.^{xiv}
- Researchers have identified **25 psychiatric medications disproportionately associated with violence, including physical assault and homicide.**^{xv}
- There are 22 international drug-regulatory agency warnings about these drugs causing violent behaviour, mania, psychosis and homicidal ideation. Almost 50 international drug-regulatory agency warnings report suicidal ideation linked to psychotropic drugs.
- According to a study in *Social Psychiatry and Psychiatric Epidemiology* published in June 2014, taking psychotropic drugs could make people nearly six times more likely to kill themselves, while having spent time in the previous year in a psychiatric hospital makes them over 44 times more likely to kill themselves. Researchers looked at Danish residents who died by suicide between 1996 and 2009 and compared those who had no psychiatric treatment in the previous year and after adjustment for other risk factors. They found that those who only received psychiatric medication had 5.8 times the risk of suicide; those who had most outpatient psychiatrist treatment had 8.2 times the risk of suicide; non-admitted patients who had contact with emergency departments had 27.9 times the risk of suicide; and admitted patients had 44.3 times of the risk of suicide.^{xvi}
- Another study, published in the *British Medical Journal*, reported that antidepressants were estimated to cause 10 to 44 deaths out of 1000 people over a year, depending on the type of antidepressant.^{xvii}
- David Healy, an internationally renowned professor of psychiatry, psychopharmacologist, scientist, and author from the UK also determined from a review of published SSRI antidepressant clinical trials that the drugs increase the risk of suicide.^{xviii}

These are but a small example of considerable contemporary research that shows the risks of psychiatric treatment and the diverse views within psychiatry itself. It is imperative that no Protocol be determined without factoring in these issues. It cannot be discounted that when depriving someone of liberty in the mental health system, there are consequences—the potential destruction of an individual's right to his own mind and body (when he or she has committed no offense).

Summary

Psychiatric commitment laws have been adopted on the basis that they may prevent someone being a danger to themselves or others but, in doing so, enforce "treatments" that are documented to cause the very effects that incarceration is supposed to protect society from. These laws violate the most basic human rights and fundamental freedoms and to the detriment of the many.

CCHR is therefore very reluctant to accept any broad codification for seizing and detaining someone, when the act itself destroys the human rights and freedoms of any person claimed to have socially unacceptable behaviour or mental so-called disorders. CCHR stresses that the existence of a mental disorder in itself shall in no case justify an involuntary measure.

CCHR recognizes that deprivation of liberty for psychiatric reasons is practised in every European country and that coercive measures do take place in psychiatry and therefore welcomes the initiative to protect the rights of those that may be subjected to such measures. However, this in no way is meant to be a support for or acceptance of such measures being used.

CCHR also wishes to emphasise that misuse and abuses are widespread in the mental health systems, even in developed countries. There is a long tradition of coercive measures in psychiatry that have harmed in the name of mental health "care" and "protection." Therefore, there must be caution when considering or implementing too wide and unclear guidelines for "safeguards" for a society that may feel threatened by certain behaviours versus the much needed protection of the rights and freedoms of these individual being incarcerated against their will.

CCHR notes that human rights can be defined as freedom from false accusations, brutality and punishment without offense.

CCHR is in agreement with the documents and conventions listed in the preamble and Article 1 but note that there is a need to clarify some points in the Additional Protocol to the Convention for the Protection of the Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine itself.

Depriving the liberty of a "mentally disordered" person by involuntary incarceration in a psychiatric facility and then forcing treatment upon him/her, especially after an explicit refusal to undergo potentially dangerous treatment, violates the above definition and the most fundamental freedoms which all other citizens undergoing medical treatment enjoy.

The Additional Protocol lists out a series of very needed and important safeguards that could be very helpful for people who are subjected to involuntary and coercive measures in psychiatry and for legal bodies adjudicating such measures—to guide them when considering whether the state has the right to mandate coercive measures if a threatening situation has arisen.

However, to ensure the intention of the Protocol exemplifies the spirit of the human rights and fundamental freedoms of the individual in every case, the following amendments are needed:

Specific comments on required amendments to the Additional Protocol

Legend:

Line number of comment to Additional Protocol text is indicated.

Black indicate existing unchanged text.

Blue indicate new text.

Red indicate deletion of existing text.

61: "mental disorder" is defined in accordance with internationally accepted medical standards **that can be demonstrated or confirmed by physical or other tests**;

63: - "involuntary" refers to a placement or treatment measure applied to a person with mental disorder who **has not consented** ~~objects~~ to the measure;

65: ... "treatment" means an intervention (physical or psychological) on a person with mental disorder that has a therapeutic purpose in relation to that mental disorder **and which does not have secondary effects that may harm in excess of a reasonable risk/benefit ratio**;

68: "therapeutic purpose" includes management ~~or~~ **and** cure of the disorder and rehabilitation, **and which does not merely subdue or control symptoms, perceptions or feelings**;

73: "court" refers to a judicial body, **assisted by an independent body comprising four members of which one is a medical doctor, one a representative of a patient advocacy organization and supplemented by two lay members who could be selected based on the same principles as for lay judges or jury members**;

85-89: Measures for involuntary placement and involuntary treatment shall only be used in accordance with the principles of necessity and proportionality— **i.e., only in extreme situations where every possible measure to prevent the use of the coercive measure and alternatives has documented themselves to have failed**. Persons subject to involuntary placement and/or involuntary treatment shall be cared for in the least restrictive environment available and with the least restrictive or intrusive treatment available, ~~taking into account their health needs~~ and the **documented** need to protect **themselves and** other persons from harm, **which must be determined by a court with due process of law**.

90: Article 5 – Consent and alternative measures

91-92: **The involuntarily placed patient has the right to written, informed consent to treatment and the right to refuse treatment. Patients also have the right to be in a state not influenced by prescribed psychotropic medication during the consent procedure or any consultation with a legal counsellor. Parties to this Protocol shall continuously promote the development and use of alternatives to involuntary placement and involuntary treatment. The government shall ensure that strategies that reduce and eventually make involuntary measures unnecessary are developed and executed.**

98: A person who is or may be subject to an involuntary measure shall have the right to a lawyer and, ~~according to the conditions provided for by law,~~ to free legal aid **sufficient to cover the legal consultation, advice, witnesses, interpreters as needed and any other legal costs**.

109-110: Involuntary placement of a person with a mental disorder may only be used if the following criteria are met:

111-112: i. a) the person's mental health condition represents a **documented** significant risk of serious harm to his or her health (**adjudicated by a court**) and his or her ability to decide on placement is severely impaired **to the degree that he or she and is not able to make an informed decision on the placement and there is no guardian available to consent on the individual's behalf**.

114. ii. the placement has a therapeutic purpose, which must be recorded in writing and signed by an authorised doctor (as the responsible agent) and

115. iii. no less restrictive means of addressing the risk are available, all of which must be recorded in the medical records and provided to the appropriate court and the patient's legal counsel and guardian.

117-118: Involuntary treatment of a person with a mental disorder may only be used if the following criteria are met:

119-120: i. a) the person's mental health condition represents a significant risk of serious harm to his or her health and his or her ability to decide on treatment is severely impaired to the degree that he or she is not able to make an informed decision on the measure; or

123 ii. no less intrusive means of addressing this risk are available, all of which must be recorded in the medical records and provided to the appropriate court and the patient's legal counsel and guardian.

Article 12 – Standard procedures for taking decisions on involuntary placement and on involuntary treatment

130: 2. The decision to subject a person to involuntary placement ~~or to involuntary treatment~~ shall, ~~subject to paragraph 3~~, be taken by a court or another competent body assisted by an independent body comprising four members of which one is a medical doctor, one a representative of a patient advocacy organization and supplemented by two lay members who could be selected based on the same principles as for lay judges or jury members. The decision to subject a person to involuntary treatment shall be taken by a court or another competent body. The court or other competent body shall:

135: ii. ensure that the criteria set out in Articles 10 and/or 11, as appropriate to the measure(s) concerned, are met and that any possible measure to prevent the use of the coercive measure as well as alternatives have been taken. Secondly, the court or other competent body must first verify that the placement or coercive measure would be likely to result in a beneficial treatment effect of the concerned person;

137: iii. take into account the opinion of the person concerned and, where appropriate, any relevant previously expressed wishes made by that person, and in the case of the existence of a Living Will ensure noted directions and prohibitions are followed;

146: 4. Ensure that no treatment, including medication may be administered without the patient's consent.

5. Ensure the normal rules of evidence apply concerning the taking and giving of evidence, admission of documents, etc., the right to call witnesses and to cross examine witnesses is granted and that the patient has access to his medical records in consultation with his legal representative.

6. Decision to subject a person to involuntary placement and/or to involuntary treatment shall be documented and state the maximum period beyond which, according to law, this decision(s) shall be reviewed.

150-153: 1. When there is insufficient time to follow the procedures set out in Article 12 because of the imminent risk of serious harm, either to the health of the individual concerned, or to others, the decision to subject a person to involuntary placement and/or to involuntary treatment may be taken by a competent body, under the following conditions:

158: iii. paragraph 2 iii, iv and v of Article 12 shall be complied with as far as possible and in the case of the existence of a Living Will ensure that noted directions and prohibitions are

followed;

201: If it is found that the detainment has been wrongful or in violation of the law, the concerned is entitled to compensation in accordance with standard rates and equal to that of persons being illegally arrested. If the court identifies any violations of the relevant national legislation it shall report these in the framework of the monitoring referred to in Article 20.

224: Independent monitoring includes but is not limited to investigating all faulty or false involuntary placement and coercive measure and is authorized to issue public warnings and in cases of actual abuse to turn the matter over for civil or criminal prosecution. Facilities designed for the involuntary placement of persons with mental disorder shall be registered with an appropriate authority.

Clarifying text to required admendments

In Article 2, section on Definitions (line 61) the term "mental disorder" should be better defined and clarified.

The criterion for what constitutes mental disorders/illness/insanity in both of the leading psychiatric diagnostic manuals changes frequently and their subjectivity has made the criteria unreliable. If on the one hand psychiatrists claim that mental disorder is the result of a "chemical imbalance" in the brain or some neurobiological dysfunction, then physical tests would need to confirm this and, thus, be a demonstrable condition. The "disorder" can also differ based, among others things, on cultural and ethnic environments. What is considered a paranoid or schizophrenic in one society is a wise man or Shaman in another. Furthermore, in some cases the condition may be a manifestation of an underlying, untreated physical condition—in fact, the person is not "mentally" but "physically" ill and this should be ruled out before any consideration that involuntary detainment can occur.

In Article 2, section on Definitions (line 63) the term "involuntary" is clarified to "has not consented to." Some persons may be too timid, scared, frightened, overwhelmed, strongly medicated, apathetic or otherwise be in a mental state where they would not actively object to a placement or measure, when in an unaffected emotional state or condition, they may oppose such an intervention. Informed consent is vital in this process. Patients admitted involuntarily should be able to decide about their own treatment. Experience shows this is possible and it is the most beneficial approach and according even to psychiatrists, is also better in terms of a working with a professional and treatment outcomes.

In Article 2, section on Definitions (line 65 and 68) the term "treatment" is clarified to not just having a "therapeutic purpose" in relation to treating the mental disorder but also ensuring an expected outcome and reasonable beneficial risk/benefit ratio. The need to specify this in the Additional Protocol is due to historical observation that psychiatrists have claimed that such treatment interventions as chains, flogging, straight jackets, leather straps, lobotomy, locotomy, crude electroshock, insulin shock, sterilisations, and many psychotropic drugs had a "therapeutic purpose." Today, these could be supplanted by brain-damaging interventions and electrical impulses to the brain. The individual is not viewed holistically but in a biological sense: treating the brain and not the individual him or herself. Many psychiatric measures, such as powerful antipsychotic drugs that are still in use have documented harmful effects that must be considered in risk/benefit ratio. Using such interventions should only be done with the full informed consent of the individual but should not forced on a person where it could cause possible irreversible harm and decrease quality of life of the individual—CCHR reiterates that by majority, these individuals have not committed a crime and, as such should not be punitively treated simply because of a troubled mind.

The Protocol currently doesn't provide any protection against the known and documented adverse effects of mental health treatment but provides for them to be given without sufficient legal safeguards—it is also why CCHR insists upon showing that all alternative approaches have been exhausted and are recorded in the medical files and judicial proceedings before determining involuntary commitment.

In Article 2, section on Definitions (line 73) it is specified that the "court" is aided by an independent body that represent both the medical speciality, the patient organizations and lay members who could be selected based on the same principles as for lay judges or jury members. This will add an impartial and professional aspect to the decision making thus aiding and differentiating the deprivations of liberty in psychiatry from a purely judicial judgement of a criminal as a law breaker.

In the Article 4 – Necessity and proportionality (line 86) the caution on using an involuntary measure is further specified. Depriving the liberty of a "mentally disordered" person by involuntary incarceration and then forcing treatment upon him/her, especially after a person's explicit refusal to undergo potentially dangerous treatment, violates the most fundamental freedoms which all other citizens undergoing medical treatment enjoy. Yet, it is a common occurrence.

Additionally, no effective treatment exists that *cures* the conditions people are incarcerated for. Current psychiatric theory is deficient in knowledge of what even constitutes insanity. Given the lack of positive and predictable outcomes of enforced treatment, the high recidivism rate from psychiatric hospitalization generally, and the potential for abuse and death in a psychiatric hospital, the most stringent safeguards are needed to protect people from unneeded and damaging coercive detainment and treatment.

Article 5 (line 90-92) is expanded to "Consent and alternative measures." Patients—even those involuntarily committed—must have the right to give full, *written* informed consent for all psychiatric treatments. Without such notification, a person does not know of and cannot enforce his or her rights when violated. Consent includes being given *written* information on what his/her legal and other rights as a patient are and what the treatment they are to be given entails (i.e. procedure, risks, side effects, expected results, whether there is a division of medical opinion about any procedure such as Electroshock therapy, etc.) In this way, the law can represent the patient's and not the doctor's interests and overcome the imbalance of power between patient and psychiatrist.

However, even written information does not overcome coercion and wrongful consent which are both very real threats to any patient entering a psychiatric facility. Wrongful consent includes consent obtained while the person is drugged or under threat.

Ideally, no detention and treatment in a psychiatric hospital would be without the full and voluntary informed consent of the patient. Instead of working towards the "control" and "maintenance" of "mental illness," the system would work towards true mental "health," with tangible results—ultimately, no involuntary commitment. There should be no law or legal instruments denying people rights as guaranteed in The International Bill of Human Rights, whether this is for social (non-criminal) or health reasons.

The Article 7 – Legal assistance is expanded upon to ensure that proper legal assistance is provided. It has been well documented by CCHR and others that despite Denmark providing free legal aid, in many cases this is simply not sufficient to cover the expenses for legal research, proper documentation of the case and pleading in the court. A fixed amount of 5 or so hours is provided which may be acceptable for many cases, but for others not. Thus a need to have way to cover the full preparation for, proceeding and appeal is vital. In some cases interpreters are also needed as per the International Covenant on Civil and

Political Rights, Article 14, paragraph 3, point f: "To have the free assistance of an interpreter if he cannot understand or speak the language used in court;"

In Article 10 – Criteria for involuntary placement (line 112) and treatment (line 120) the point of "ability to decide" has been clarified. There has been a long tendency in psychiatry to categorize (stigmatise) patients which becomes "a diagnosis." For example, a patient may be labelled "paranoid schizophrenic" which tend to make the person become considered an incurable patient etc. Such labeling should not constitute this person being automatically considered to be incapable of understanding his or her own situation or what is appropriate treatment. Ten years later the mental state of this person may be quite different, yet, the earlier diagnosis sticks and in a court one simply can refer to a "history of mental instability" and by itself guarantees an involuntary placement.

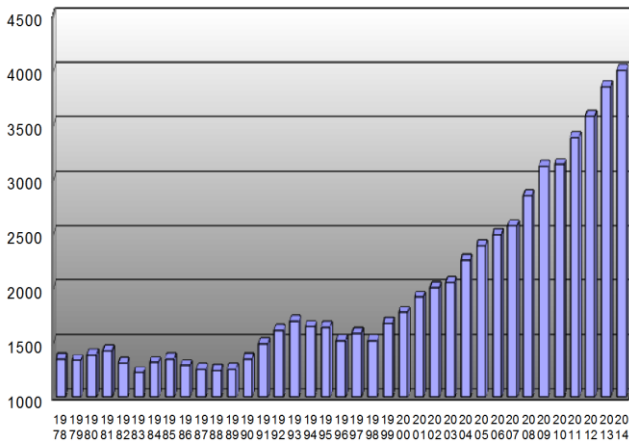
CCHR has many case files of persons forced to undergo psychiatric drug treatment without their consent even though they had the capacity to consent and were fully capable of expressing sound views. At times, treatment has been enforced simply (and solely) because of the person having a prior psychiatric diagnosis or hospital admission.

Experience during the national trial of the so-called breakthrough methode (gennembrudsmetoden) in Denmark shows that even heavily-psychotic patients could be spoken to and that they improved when they were given the responsibility to decide on the measures to be taken and what consequences are for violations of rules.

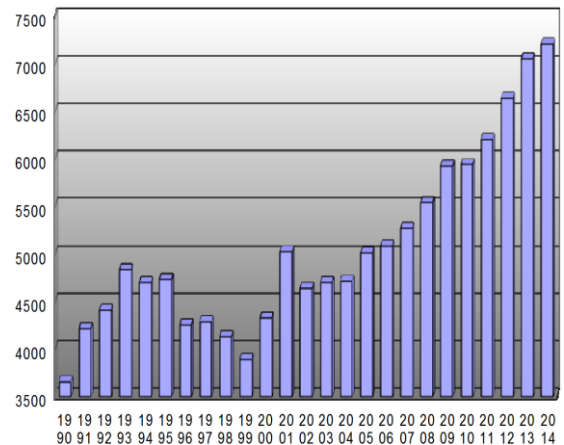
In Chapter IV, Article 12 – "Standard procedures for taking decisions on involuntary placement and on involuntary treatment" (line 130) strengthens the involuntary commitment procedure. Denmark serves as an example of how a less legally stringent committal procedure opens the door to civil and human rights "abuse". Under the Danish Mental Health Act of 1989, the involuntary commitment and total deprivations of liberty (including involuntary detainments, that is, the transferring of a voluntary patient to a closed ward involuntarily and keeping him under the same conditions as an involuntary commitment) have increased annually to hitherto unpredicted levels despite the stated purpose of the law was to decrease coercive measures. None have been taken before a judge or an independent legal body prior to being committed.

Per research half a decade after the implementation of the law it was found that less than half the cases was the decision to commit confirmed by an independent authority or body; i.e., another medical doctor.

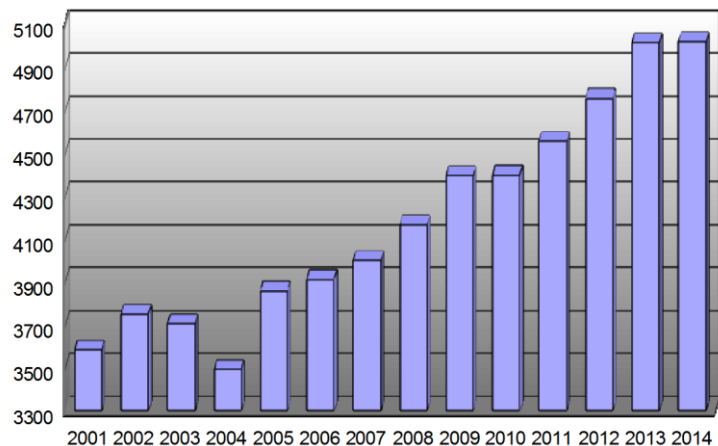
Involuntary Commitments in Denmark



Total Deprivations of Liberty in psychiatry



Number of persons deprived of their liberty (involuntary) in psychiatry in Denmark



This opens the door to wrongful detention (false imprisonment), which CCHR has documented. Add to this the fact that anyone being presented for admission to a psychiatric facility against his/her wishes is placed into a traumatic experience about which they will be justifiably upset. The unexpected seizure from the person's home or environment, followed by placement in an institution, is known to cause emotions ranging from apathy to strong and violent protest. This is misconstrued as symptomatic of the person's mental illness.

Following the implementation of the Danish Mental Health Act of 1989 that legalised the involuntary institutionalisation of people who are in a condition of "resembling insanity" more and more people were deprived of their liberty—forcefully incarcerated in psychiatric institutions. This was a clear change of the previous involuntary placement pattern. Rather than decrease abusive, coercive treatments, all forms of involuntary commitments and treatments increased. The compulsory psychiatric drugging of patients increased nearly seven times from 1990 till 1998 and enforced electroshock increased three times. The numbers of commitment declined only in 1994-1996 at the time the law was being reviewed to see the effects it had had and after considerable adverse publicity and complaints filed

with various authorities by concerned groups such as CCHR. The number of involuntary commitments has since the completion of the law review in 1995 increased year by year and never been higher and still increases.

In Denmark, the National Forensic Psychiatric Clinic of the Danish Ministry of Justice as part of the law review in 1995 conducted a study on involuntary placement and treatment in psychiatry. The study, entitled, "Investigation of the Psychiatry Act," had been ordered by the Ministry of Justice to obtain scientific data on how the Danish Mental Health Act of 1989 had been working in practice. Only preliminary findings were released during the law revision process, the final findings of this study--considered the most authoritative ever conducted in Denmark--were released in the report appropriately entitled, "Coercion in Psychiatry." It concluded that 93% of the persons who had been studied were released within a 2 ½ year period and that except for this, "it was not possible to more closely document the treatment effect" of involuntary measures in psychiatry. The lack of actual treatment results wasn't caused by the patients being released too early, nor that they received "insufficient" treatment. Rather, the study concluded that patients were treated intensively and mainly with psychotropic drugs, especially neuroleptics (antipsychotics). Despite all efforts to establish treatment efficacy, this had not been possible, which the study's author, Dr. Per Maegaard Poulsen found alarming.^{xix}

The Article 12, paragraph 2, point ii (line 135) is clarified. In addition to the comments and data above it can be mentioned that experience from Denmark show that psychiatric practice often is to administer powerful mind-altering psychotropic drugs on admission, which often incapacitates the person's ability to think and speak clearly. He/she is less capable of defending him/herself or to file a complaint. The drugs' side-effects can frequently cause the person to appear abnormal which further confirms the apparent need of treatment. And the mere fact that the person has been presented to the facility and has already been labelled with a psychiatric diagnosis, presumes the person is mentally disordered anyway.

The International Covenant on Civil and Political Rights establishes in article 10, section 1: "All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person."

No involuntary placement should occur without specific verification by an independent and qualified medical practitioner that no underlying physical problem exists and is manifesting as mental disorder, and without a full and searching physical examination.

Article 12 – "Standard procedures for taking decisions on involuntary placement and on involuntary treatment", paragraph 2, point iii (line 136-137) is indicating the need to taking previously expressed wishes made by the person subjected to involuntary measures in to consideration. However, missing is that individuals of sound mind have signed a Living Will that specifies what treatments they accept or reject should they be labeled mentally "ill" or incompetent. The Living Will is a valid legally binding document that can not be ignored— even when the person may be subjected to involuntary commitment. Should such a document exist and is registered it must be consulted and respected with no exceptions.

Two paragraphs are added to Article 12, which are specifying treatment options prior to determining involuntary commitment and regulations applying to the commitment procedure.

There must be a differentiation between a serious threat to himself and to others. If the person is a serious threat in that he is destructive towards others, then this must be dealt with through the penal codes.

If the person's behaviour fits the definition of psychosis (see further comments on diagnosis in comments to Article 2 clarification of the term "mental disorder" and in the Introductory

and general comments, page 2-3 above) and he/she is being destructive to him/herself, then for his/her own protection, an emergency procedure might be necessary. However, bear in mind that admission to a psychiatric establishment does not, in itself, prevent violence, suicide or risk to the patient's health.

The importance of finding, establishing and funding alternatives to the punitive system of involuntary incarceration is also essential if human rights are truly to be upheld.

Article 13 – "Procedures for taking decisions in emergency situations" (line 158) is clarified. See data in comments to Article 12 above.

A point was added to Article 16 – "Appeals and reviews concerning the lawfulness of involuntary placement and/or involuntary treatment," as paragraph 7 (line 201) which specifically states in the Additional Protocol that a wrongful detainment or placement in violation of the law should result in compensation. The International Covenant on Civil and Political Rights states in article 9, section 5 that: "Anyone who has been the victim of unlawful arrest or detention shall have an enforceable right to compensation."

A point was added to Article 20 – "Monitoring" (line 224) as a consequence of the fact that violating patients' rights and outright abuses have little to no consequences even when fatal to patients. Involuntary placement essentially means depriving the person of his liberty.

Accountability and Prosecution

Wrongful detention, punitive use of treatment or restraints, and sexual interference with a patient goes beyond medical negligence because the professional is wilfully or maliciously depriving a person of their liberty, detaining them against their will, and subjecting them to unwanted and unnecessary treatment, thereby constituting assault—all without the patient having committed any offence. When such a violation occurs, the responsibility for this rests solely with the psychiatrist, mental health worker or staff who has power to involuntarily detain and commit another or provide the false information on which the decision is based. Currently there are little or no protections or recourse for people who are accused of being "mentally ill" and being detained illegally. Any proposal regarding involuntary placement must contain criminal penalties for violation of a person's legal rights.

Institutions that Care and Cure

Institutions should be turned into safe establishments where people will voluntarily seek help without fear of indefinite incarceration. If admitted, they need a quiet environment, nutrition, good food, security, rest and exercise. Only then should individual therapy begin. Such institutions should be well fitted with medical diagnostic equipment. Undiagnosed and untreated physical conditions can manifest as "psychiatric" symptoms. No single psychiatric symptom exists that cannot at times be caused or aggravated by various physical illnesses.

The person should have the certainty that treatment will not be forced upon him/her, and that a relationship with the staff is based on a policy of kindness, patience, cheerfulness, trustworthiness, and work. The staff should be trained in avoiding the use of physical restraints. The use of coercion, threats and arbitrary penalties should be prohibited.

If mental facilities were places of rest, where people did not fear to seek help, knowing they would not be assaulted with drugs and electroshock, or even sexually abused—but where they could receive real medical help—people would be more approachable about being helped.

Citizens Commission on Human Rights

The Citizens Commission on Human Rights (CCHR) was established in 1969 by the Church of Scientology and co-founded by professor of psychiatry, Dr. Thomas Szasz. It has the mission to investigate and expose psychiatric violations of human rights, and to clean up the field of mental healing.

Dr. Thomas Szasz, considered that "*Civil commitment "entails far greater deprivation of rights than does incarceration in prison, a penalty carefully circumscribed by constitutional guarantees and judicial safeguards."*

Today, CCHR has hundreds of chapters in over 30 countries. Its board of advisers, called Commissioners, includes doctors, lawyers, educators, artists, businessmen, and civil and human rights representatives.

European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP)

The **European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP)**¹²⁰ is the grassroots, independent representative organisation of mental health service users, ex-users and survivors of psychiatry at a European level.

The European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP) takes this opportunity to provide comments on the draft Additional Protocol concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment.

We have very serious concerns regarding the compatibility of the draft Additional Protocol with the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). Our main concerns arise in relation to equal recognition before the law, liberty and security of a person, the prohibition of torture and ill-treatment, and access to justice. We are also extremely concerned about the deformation of human rights concepts by conflating terminology used in the Draft Additional Protocol.

ENUSP emphasizes that there is a fundamental difference between coercion and care, and the references to the claimed beneficence of involuntary placement and involuntary treatment are outdated and misplaced. It is widely acknowledged that coercive practices are not a therapeutically beneficent intervention. Rather, such interventions constitute discriminatory and harmful practices that can cause severe pain and suffering, as well as deep fear and trauma in its victims. Deprivation of liberty can in itself be harmful. Indefinite detention is especially harsh, and commonly practiced against persons with psychosocial disabilities in mental health settings. Mental health detention is regularly accompanied by intrusive and involuntary medical interventions such as forced drugging, forced electroshock (ECT), restraint and solitary confinement. These practices should not be characterized as treatment in any sense, but rather constitute forms of ill-treatment.

The fact that a person has psychosocial disabilities, or may have a need to overcome a mental health crisis situation does not justify the deprivation of fundamental rights. What is needed is support, not confinement or involuntary treatments. When persons experience a mental health problem or crisis, responding by subjecting them to primitive restrictions, such as confinement, forced drugging and physical restraints, is the opposite of mental health

¹²⁰ www.enusp.org

care and support, and leads to segregation, emotional and physical abandonment, and suffering. Obviously, involuntary placement and involuntary treatments are counter-effective to the wellbeing of the person subjected, and do not support personal recovery. These interferences cause more struggle, distance, and psychosocial problems, which in itself increases the risk of new or additional crises and does not contribute to safety or a healthy community at all. The claimed necessity of these interventions to avert risk of serious harm to the person concerned is further refuted by the fact that subjecting persons to involuntary institutionalization, forced treatment and other forced psychiatric interventions, represents in itself a significant risk of serious harm, as well as violating the fundamental rights of persons with disabilities.

The suggested criteria and procedures in the Draft Additional Protocol for involuntary placement and involuntary treatment in the context of mental health care conflate the distinguished concepts of care and confinement and authorize deprivation of liberty based on psychosocial disabilities combined with other criteria, such as the presumptive risk of serious harm to self or others. Besides being discriminatory, such criteria for deprivation of liberty also contain the paradox of applying detention regimes that cause serious harm for the purpose of preventing some speculative and hypothetical harm in the future. Therefore in itself, the Draft Additional Protocol should be aborted.

Furthermore, the decision to elaborate a legally binding instrument on “the Protection of the Human Rights and Dignity of Persons with Mental Disorder with regard to Involuntary Placement and Involuntary Treatment” was taken based on observations of the Steering Committee on Bioethics (CDBI) which found legal gaps in certain Member States of the CoE in the implementation of Recommendation(2004)10 on the protection of human rights and dignity of persons with mental disorders. However, this recommendation was developed before the UN CRPD, and is based on now outdated standards contrary to the CRPD. There is therefore no longer a need to bridge the gap between Rec(2004)10 standards and domestic legislation. Instead, there is a need to implement the CRPD in domestic law.

In the preamble to the draft Additional Protocol it is stated that it is taking into account “the work carried out at the international level on the protection of dignity and rights of persons with mental disorders, in particular the United Nations Convention on the Rights of Persons with Disabilities”. However, the very title of the draft Additional Protocol itself, just like Rec(2004)10, immediately and clearly show that the draft Protocol is a medical model-based instrument that runs counter to the CRPD by authorizing mental health detention and non-consensual psychiatric treatment.

The Draft Additional Protocol to the Oviedo Convention is contrary to the CRPD in its object and purpose, and in every one of its provisions that refer to involuntary treatment and involuntary placement. Contrary to paragraph 46 of the Explanatory Report accompanying the draft Protocol, the CRPD prohibits all involuntary placement and involuntary treatment of persons with disabilities, and does not allow any exceptions. The jurisprudence of the CRPD Committee makes this absolutely clear in both General Comment No. 1¹²¹ on Article 12, and its most recent Guidelines on Article 14¹²².

The CRPD guarantees the equal enjoyment of all human rights and all fundamental freedoms on an equal basis to all persons with disabilities. Among these rights are legal capacity, liberty, freedom from torture and other ill-treatment, and the right to health care based on free and informed consent. There is no room under the CRPD for a separate and

¹²¹ CRPD Committee General Comment no.1 on article 12 Equal recognition before the law (April 2014)

¹²² CRPD Committee’s Guidelines on article 14 Liberty and security of person (September 2015)

unequal regime of non-consensual interventions applicable uniquely to persons with alleged mental disorders, contrary to Article 7 of the Oviedo Convention and to the object and scope of the draft Protocol (Articles 1 and 2).

General Comment No. 1 establishes that people with psychosocial disabilities cannot be deprived of their right to make decisions, including decisions about treatment, on the basis of another person's negative assessment of their mental capacity or decision-making skills. Once again, there is no room under the CRPD for a separate and unequal regime of involuntary measures based on an alleged impairment of the person's decision-making skills, as the draft Protocol attempts to do through its provisions on involuntary placement and involuntary treatment, found in Articles 10 and 11 of the draft Protocol.

General Comment No. 1 and the Guidelines on Article 14 both make clear that free and informed consent of the person concerned continues to apply in emergency and crisis situations. There is no room under the CRPD for refusal to recognize a person's legal capacity and performing forced interventions based on the characterization of a person's situation as amounting to an emergency, contrary to the provisions suggested under Article 13 of the draft Protocol.

The Guidelines on Article 14, which summarize the CRPD Committee's jurisprudence, establish that neither the risk of harm to the person or to others, nor the person's alleged need for treatment, can justify involuntary placement in mental health facilities or involuntary treatment. In fact these practices are absolutely prohibited and constitute serious human rights violations. Involuntary placement in mental health facilities, as an instance of disability-based deprivation of liberty, is a form of arbitrary detention; forced treatment is among the practices found to be inconsistent with the prohibition of torture and cruel, inhuman or degrading treatment or punishment. There is no room for exceptions to this absolute prohibition, contrary to Articles 3, 4, 10, 11, 12 and 13 of the draft Protocol.

The remaining articles in the draft Protocol refer to auxiliary measures that have no relevance once the CRPD absolute prohibition against involuntary treatment and involuntary placement are upheld.

The Committee on Bioethics has rejected the CRPD Committee's authoritative interpretation of the CRPD in the draft Additional Protocol, and claims the draft is in line with the treaty. In the preamble, the Bioethics committee alludes to CRPD Art. 14, but changes the wording to reflect their own outdated standard, so that their version reads "the existence of a mental disorder **in itself** shall in no case justify an involuntary measure".

Regional human rights standards should not undermine or be in conflict with international human rights standards. The Committee on Bioethics should acknowledge and address the discrepancies between the draft Additional Protocol, as well as the Oviedo Convention Articles 6 and 7, and the UN CRPD.¹²³

The Bioethics Committee could look to another regional mechanism, the Organization of American States (OAS) Committee for the Elimination of All Forms of Discrimination against persons with disabilities (CEDDIS), which has already started the process of interpreting the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons

¹²³ Article 6 of the Oviedo convention authorizes substituted decision-making and withdrawal of legal capacity based on mental disability. There is a need for change of paradigm away from substitution of a person's will to the new paradigm based on supported decision-making as set forth by the CRPD Article 12. Article 7 of the Oviedo convention runs counter to the CRPD by authorizing forced psychiatric interventions.

with Disabilities in the context of the CRPD.¹²⁴ The Inter-American Convention has a provision contradicting the CRPD reading “If, under a state’s internal law, a person can be declared legally incompetent, when necessary and appropriate for his or her well-being, such declaration does not constitute discrimination” (Article I.2(b)). CEDDIS has addressed this discrepancy by adopting interpretation criterion declaring that;

*“This Committee declares that the criterion established in Article I.2(b) in fine of the OAS Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, (...) **seriously contradicts the provisions of Articles 2 and 12 of the United Nations Convention, and the Committee therefore construes that the aforementioned criterion must be reinterpreted in light of the latter document currently in force.**”*

CEDDIS has also requested the OAS Secretary General to order a revision, by appropriate legal bodies, of Article I.2(b) *in fine* of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, with a view to aligning it with Article 12 of the UN CRPD.

Just as with Article I.2(b) of the Inter-American Convention, there is an urgent need to bring outdated, discriminatory Council of Europe provisions, such as the Oviedo Convention articles 6 and 7 (together with the European Convention on Human Rights article 5.1e) in line with the global standards protecting the human rights and dignity of persons with disabilities.

41 out of 47 Member States of the Council of Europe have ratified and are legally bound by the UN CRPD. In addition, 5 Member States have signed the CRPD and are therefore obligated to refrain from acts that would defeat the object and purpose of the treaty. The UN CRPD as the newest and most specialized international instrument on the human rights of persons with disabilities should, based on *lex posterior* and *lex specialis* principles, supersede provisions of regional instruments in case of conflict. Moreover, states are obligated to follow the highest standard of human rights protection that is applicable to them. A state that has ratified both the Oviedo Convention and the CRPD must therefore prohibit mental health detention and involuntary treatment and cannot use the contrary standard of the Oviedo Convention as an excuse for its failure to do so.

ENUSP is deeply concerned about the fact that forced institutionalization and forced treatment of persons with psychosocial disabilities is currently authorized in the laws of all European countries to various degrees, and under certain binding Council of Europe instruments, such as the European Convention on Human Rights article 5.1.e, and the Oviedo Convention, which run counter to the CRPD by authorizing mental health detention and non-consensual psychiatric treatment.¹²⁵ This discriminatory international and domestic legislation does not only authorize harmful practices against persons with psychosocial disabilities, but it also poses insurmountable barriers to effective access to justice for

¹²⁴ Committee for the Elimination of All Forms of Discrimination Against Persons with Disabilities, *General Observation of the Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities on the need to interpret Article I.2(b) in fine of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities in the context of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities*, OEA/Ser.L/XXIV.3.1, CEDDIS/doc.12(I-E/11) rev.1 (28 April 2011).

¹²⁵ EU FRA report: Involuntary placement and involuntary treatment of persons with mental health problems (2012)

persons with psychosocial disabilities who have been harmed, ill-treated, tortured or even killed by forced psychiatric interventions, and the perpetrators are generally treated with impunity, since these violations can be considered as legal under these outdated standards.

Finally, ENUSP also points to the ethical principle of “doing no harm”, which applies both from the care ethics perspective, as well as from the human rights perspective, and emphasizes moreover, that the Draft Additional Protocol does not correspond to the responsibilities of the Committee on Bioethics. The administration of severe mental or physical pain and suffering, by or in acquiescence of the State, with the goal of changing someone’s opinion falls under the scope of torture and ill-treatment, which is absolutely prohibited, including in emergency or crisis situations. Perpetrators cannot hide behind “superior orders”¹²⁶, which means that the Draft Additional Protocol is not practicable, and not only puts persons with psychosocial disabilities at risk, but also care givers and States, including the authors of the Draft Additional Protocol themselves.

ENUSP emphasizes that there are a growing number of approaches to psychosocial disabilities and crisis situations in the field of mental health which practice supported decision making instead of substitute decision making, and reflect the paradigm shift as enshrined in the CRPD. Typically, these good practices are not focused on the medical model, but take a human rights-based approach and focus on personal wellbeing and recovery¹²⁷ of the person concerned.

Examples of such good practices are: The Personal Ombudsman in Sweden, Intentional Peer Support (IPS), WRAP (Wellness Recovery Action Plan), Family Group Conferencing, Open Dialogue, Soteria houses, peer-run respite-houses, community support and also some practices of progressive, community-based, professional, voluntary mental health support.

This shows that there are a range of possibilities which can be developed and explored further.

We encourage the Committee on Bioethics to withdraw the draft Protocol and initiate a process of aligning the Oviedo convention Articles 6 and 7 with the CRPD in cooperation with the Steering Committee for Human Rights (CDDH) and other relevant CoE bodies, and with consultation and involvement of disabled persons’ organizations (DPOs).

Irish Advocacy Network

Suggestions for the Preamble and general comments

Point 18 ‘Recognising the potential vulnerability of persons with mental disorder’. Add to this statement something more positive such as: ‘and also recognising, engaging and acknowledging the capacity of person’s labelled mentally disordered as having the ability to choose and recover from their temporary disability.’

During the preamble we also suggest you add that person’s regardless of disability are first and foremost sentient beings and should be treated accordingly.

Following on from the above we would like to see included in the preamble a statement highlighting evidence of a causative route from traumatic life events into major mental health

¹²⁶ Convention Against Torture (CAT) article 2

¹²⁷ The recovery approach, which has flourished since the 1990s, focuses on the personal journey to achieving a satisfying, hopeful, and meaningful life even with limitations or barriers.

problems eg; psychosis and that as part of a social justice response we need to be mindful of the potential of to re-traumatise such persons when voluntary measures are applied.

The Right to Advocacy should be included, in particular models or approaches that aim to educate and enable the person labelled mentally disordered to self-advocate becoming more aware of their rights as mental health service users and citizens.

Chapter One – Object and Scope

49-51 - '2. The provisions of this Protocol do not limit or otherwise effect the possibility for a member state to grant persons with mental disorder a wider measure of protection than is stipulated in this Protocol'. Encouraged about this statement.

There are several references to 'Therapeutic purpose' in the document. To serve who's purpose, who decides and what if the therapy is experienced as damaging or/and is observed to be causing more harm than good? We would like you to consider this scenario which is a reality for a lot of people being treated

Article 5 – alternative measures to involuntary placement or treatment.

We are happy about this statement but would like, if possible encouragement to promote alternative services to hospital and involuntary interventions (eg; Open Dialogue, Finland) which for us widens the possibility of others to follow suit.

Article 6 - Person of trust – to what end and what right has the person of trust to accompany the person labelled mentally disordered?

Mental Health Europe

Introduction

Further to the joint-letter which Mental Health Europe (MHE)¹²⁸ submitted along with other concerned organisations, we would like to individually respond to the working document of the draft Additional Protocol to the Oviedo Convention on human rights and biomedicine¹²⁹ (the draft Additional Protocol) and thank the Committee on Bioethics for affording us the opportunity to contribute. We regret, however, that we could not respond in a more detailed manner due to late notification relating to the public consultation.¹³⁰ Unfortunately, despite some positive aspects reflected in the document, MHE is concerned that the Additional Protocol remains poorly timed and as a result could serve to undermine, rather than protect, the rights of persons with psychosocial disabilities in Europe as well as contribute to a fragmentation of human rights law. While groundbreaking at its inception, the Oviedo Convention itself is now out-of-step with the paradigm shift required by the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD); introducing a new Additional Protocol based on the Oviedo Convention therefore seems, to MHE and others, to

¹²⁸ Mental Health Europe (MHE) is a European non-governmental network organisation committed to the promotion of positive mental health, the prevention of mental distress, the improvement of care, advocacy for social inclusion and the protection of human rights for (ex)users of mental health services, their families and carers. MHE's membership includes associations and individuals active in the field of mental health in Europe, including people with (a history of) mental health problems, as well as volunteers and professionals in a variety of related disciplines. For more information please see our website at: <http://www.mhe-sme.org/>

¹²⁹ The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, opened for signature in Oviedo, Spain on 4 April 1997.

¹³⁰ We have provided a textual analysis of some of the more problematic provisions in the text in the accompanying annex.

be unwise. As noted repeatedly in several responses to last year's questionnaire launched by the Council of Europe on the draft Additional Protocol, the UN CRPD requires a shift away from the medical approach to disability which unfortunately is not reflected in this draft. As drafted, the Additional Protocol appears to run contrary to the UN CRPD, in particular Articles 5 (discrimination), 12 (equal recognition before the law), 14 (liberty and security of the person), 15 (freedom from torture, inhumane and degrading treatment) and 25 (right to health).

Maintaining the status quo

Traditional mental health and guardianship laws in Europe have led to many human rights abuses against persons with psychosocial disabilities/mental health problems, a fact acknowledged by the Commissioner for Human Rights of the Council of Europe who recommended to Member States that, in light of the UN CRPD, they should 'identify and remedy possible flaws and gaps depriving persons with disabilities of their human rights in relation to legislation concerning, inter alia, guardianship, voting rights and compulsory psychiatric care and treatment'.¹³¹ MHE is worried that the draft Additional Protocol will serve as a justification to continue with the status quo despite the fact that State Parties to the UN CRPD, which includes a majority of Member States of the Council of Europe as noted in the joint-letter, are required to implement a move away from treating persons with disabilities as objects rather than subjects of the law. In addition, the draft Additional Protocol appears to reinforce commonly held misconceptions about the perceived dangerousness of persons with mental health problems.¹³²

The draft Additional Protocol also suffers from a false presumption that forced interventions are justified as they fulfill 'therapeutic purposes'. There are increasing numbers of psychiatrists who would question the 'therapeutic' nature of such involuntary measures particularly as other alternative and consensual measures can be more effective and indeed more human rights compliant. In this regard, while MHE is happy to see the importance placed on alternative and least restrictive measures, the draft Additional Protocol largely supports business-as-usual, meaning that the decisions of persons with psychosocial disabilities can be overridden by one doctor on the basis of factors linked to their disability. The draft ignores the reality of the stigma experienced by persons with psychosocial disabilities both in legal and health care systems. Of course, one hopes that our judges and health professionals deal with persons under their care in a disability neutral way but the reality is very different and has arguably led to the system we have today where persons with psychosocial problems have been deemed incapable of making their own decisions predominately on the basis of their disability.

Jurisprudence of the Committee on the Rights of Persons with Disabilities

As the Committee on Bioethics will be aware, the Committee on the Rights of Persons with Disabilities (CRPD) recently issued Guidelines on Article 14 of the UN CRPD.¹³³ The Guidelines clarify that there should be an absolute prohibition of detention on the basis of

¹³¹ Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities, Issue Paper published by the Council of Europe Commissioner for Human Rights, 2012, available at:

https://www.coe.int/t/commissioner/source/prems/IP_LegalCapacity_GBR.pdf

¹³² For more information please see MHE's Myth Buster on Compulsory Psychiatric Treatments and its Alternatives, available at http://www.mhe-sme.org/fileadmin/Position_papers/What_is_forced_treatment_-_a_myth_buster.pdf

¹³³ Committee on the Rights of Persons with Disabilities, Guidelines on Art 14 of the Convention on the Rights of Persons with Disabilities: The right to liberty and security of persons with disabilities, September 2015, available at:

<http://www.ohchr.org/Documents/HRBodies/CRPD/GC/GuidelinesArticle14.doc>

impairment including for reasons related to perceived dangerousness of persons with psychosocial or intellectual disabilities as well as for alleged need of treatment as these reasons are tied to disability and therefore discriminatory and amount to an arbitrary deprivation of liberty. The Guidelines specifically referenced the intention of some regional bodies to adopt additional binding instruments which would allow for involuntary internment and forced treatment of persons with psychosocial disabilities. As a result, these Guidelines could be seen as a direct and negative response to the draft Additional Protocol.

The Guidelines go on to state that mental health services should be based on free and informed consent of the person concerned and refer to General Comment No.1 on Article 12 of the UN CRPD, published by the CRPD last April. General Comment No. 1 articulates an understanding of legal capacity which is not reflected in the current draft of the Additional Protocol as it still allows for substituted decision-making on the basis of a person's psychosocial disability. There are positive aspects within the text which do reflect the need for supported decision-making including references to the need for support in order to allow people to exercise their autonomy as well as to 'persons of trust'. However, taken as a whole the text largely supports the status quo for substituted decision-making and allows for 'best interest' type determinations to be made even though the UN CRPD requires States to do away with this approach and move towards a standard based on the 'will and preferences of the person'. MHE is of the view that this standard is not adequately reflected in the current draft.¹³⁴ The Guidelines also include reference to access to justice and reparation and redress for persons with disabilities deprived of their liberty and quotes from the 'United Nations Basic Principles and Guidelines on remedies and procedures on the right of anyone deprived of their liberty to bring proceedings before a court', recently adopted by the Working Group on Arbitrary Detention.¹³⁵ These Basic Principles state that persons with disabilities should be provided with compensation for arbitrary or unlawful deprivations of their liberty. Regrettably, MHE notes that this key human rights issue is absent from the draft Additional Protocol.

Views of the Special Procedures of the United Nations Human Rights Council

Several UN Special Rapporteurs have also taken firm stances on forced placement and treatment on the basis of disability including the Special Rapporteurs on the right to health¹³⁶, the rights of persons with disabilities and torture. The Special Rapporteur on the right to health has requested the Human Rights Committee to re-draft its General Comment on Article 9 of the UN International Covenant on Civil and Political Rights in order to bring it into line with the UN CRPD, stating that 'mental health detention is never justified and must be abolished, and that laws permitting such detention, including laws that authorize institutional confinement or treatment based on the consent of a substitute decision-maker, must be repealed'.¹³⁷ The Special Rapporteur on torture, in his report focusing on human rights abuses in healthcare systems, recommended that States should 'impose an absolute

¹³⁴ Please see the section on Article 12.2 iii) of the draft Additional Protocol in the annex for a further critique of that Article in light of Article 12 of the UN CRPD.

¹³⁵ United Nations Basic Principles and Guidelines on remedies and procedures on the right of anyone deprived of their liberty to bring proceedings before a court, Working Group on Arbitrary Detention, A/HRC/30/36, April 2015, available at: <http://www.ohchr.org/Documents/Issues/Detention/DraftPrinciplesAndGuidelinesRightCourtReview.pdf>

¹³⁶ Report of the Special Rapporteur on the right to the highest attainable standard of physical and mental health, A/64/272, 2009, available at: <http://daccess-ods.un.org/TMP/445480.197668076.html>

¹³⁷ Letter to the Human Rights Committee from the UN Special Rapporteur on Disability regarding: urgent request to amend the Human Rights Committee's draft version of General Comment No. 35 (CCPR/C/107/R.3) on Article 9 (Right to liberty and security of person) bringing it in line with the UN Convention on the Rights of Persons with Disabilities dated 27 May 2014, available at: <http://www.ohchr.org/Documents/HRBodies/CCPR/GConArticle9/Submissions/SRDisability.doc>

ban on all forced and non-consensual medical interventions against persons with disabilities, including the non-consensual administration of psychosurgery, electroshock and mind-altering drugs such as neuroleptics, the use of restraint and solitary confinement, for both long- and short-term application. The obligation to end forced psychiatric interventions based solely on grounds of disability is of immediate application.¹³⁸

These statements, along with those authoritative comments made by the CRPD, taken together would seem to raise serious concerns about whether a Protocol pertaining to the non-consensual placement and treatment of persons with disabilities could ever be seen to be human rights compliant if enforced for reasons linked to disability or impairment.

Conclusion

The paradigm shift required by the UN CRPD is still in its infancy and the jurisprudence of the CRPD is still evolving. However, the two recent authoritative pronouncements from the CRPD on Articles 12 and 14 appear to contradict the underlying ethos of the draft Additional Protocol. MHE remains of the view that given that this initiative intends to establish a completely different set of human rights standards which justify the denial of key human rights for persons with psychosocial disabilities, it is therefore, at its core, discriminatory. MHE is deeply concerned that, in its current form, the Protocol could solidify mental health laws which have resulted in the stigmatisation, mass detention and forced treatment of persons with psychosocial disabilities across Europe as well as create uncertainty for Member States who could face the unenviable task of trying to implement opposing regional and international human rights obligations. Furthermore, this draft comes at a crucial time when many Member States are in the process of reforming their mental health laws in order to transition to the social model of disability. In light of these concerns, MHE believes that the efforts of the Council of Europe would be better spent harmonising European human rights standards with the UN CRPD. We urge the Council of Europe and its Member States to withdraw the draft Additional Protocol in light of recent and ongoing developments relating to persons with psychosocial disabilities in the field of human rights. Lastly, the UN CRPD itself is revolutionary because persons with disabilities were represented in the room during negotiations and at every stage of the process, with a level of access to the treaty making process that remains unprecedented today. MHE recommends that should the Council of Europe remain determined to continue this process, the Committee on Bioethics should take a more participative approach to the drafting of this document.

National collaboration for mental health (NSPH)

National collaboration for mental health (NSPH) is a network of organisations consisting of patients, next of kin, and others within the psychiatric field. The network has 12 members. These organisations are RFHL, RSMH, Riksförbundet Attention, Sveriges Fontänhus, Balans, Schizofreniförbundet, Frisk & Fri, SPES, SHEDO, Svenska OCD-förbundet, ÅSS och FMN.

NSPH monitor the human rights of people who suffer from mental health issues to ensure that they receive access to such rights without discrimination. NSPH also produce and emit information about mental health and endeavour to increase patient participation in society at large.

¹³⁸ Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, 2013, A/HRC/22/53, available at:

http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

Civil Rights Defenders is an independent expert organisation with the purpose of defending civil and political rights and assist vulnerable human rights defenders.

We have viewed the Committee's working document and draft explanatory report (DH-BIO/INF (2015) 8) from a human rights perspective and have the following views:

Preamble

NSPH and Civil rights defenders regard patient participation as a means to ensure that each person is represented including those who cannot speak for themselves. We also hold the view that patient participation is a prerequisite for good care and as such must be included all activities related to planning and quality controls also in involuntary placement and involuntary treatment. We recommend that the preamble specifies that professional care shall always be planned and conducted in collaboration with patients and patient's organisations.

Lines 28-29 recall that the existence of a mental disorder in itself shall in no case justify an involuntary measure which is an important clarification. However, with regards to the *Convention on the Rights of Persons with Disabilities*, we recommend that the protocol adds that a behaviour which is a symptom of a disability cannot in itself justify an involuntary placement.

We further recommend, on the basis of the *Convention on the Rights of Persons with Disabilities*, that the environment or settings in which involuntary treatment takes place shall be accessible to people with physical disabilities.

Article 2

Third paragraph: We disagree with the protocol. We hold the view that the protocol should apply to placement and treatment ordered in the context of a criminal law procedure. We consider that patients being held in this context shall benefit from the rights enshrined in this protocol. We acknowledge that there is a difference in the criteria for admission and discharge for such patients. However, this protocol contains many provisions beyond criteria for admission and discharge. By separating the legal requirements on involuntary treatment subsequent case law will distinguish on that basis. This would in effect discriminate against patients in the context of a criminal law procedure despite the diagnosis and needs of such patients may not differ from the diagnosis and needs of patients not held in the context of a criminal law procedure. We cannot accept this general distinction, in particular considering that the preamble states that the aim of the Convention on Human Rights and Biomedicine is to protect the dignity and and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms.

As such, we recommend that all articles within this protocol that do not pertain to criteria for admission and discharge shall be applicable in the context of a criminal law procedure.

Fourth paragraph: We wish to express that the terminology for the group is under debate. We accept that a mental disorder is defined broadly in accordance with internationally accepted medical standards. Nevertheless, we recommend that the preamble observes that the terminology is under constant evolution. The term "mental disorder" has some negative associations and it is not unreasonable to expect other terms to surface. The best example hereof is the evolution of handicap to disability.

We accept the term "mental disorder" but advice that it may become outmoded.

Article 5

We recommend that the protocol should be stricter and that rather than to “promote” the protocol uses the term “undertake to develop and use alternatives to involuntary placement and involuntary treatment”.

Psychiatry is a field which lacks resources in the form of knowledge, science and money. Access to psychiatric care worsens during times of economic hardship despite the fact that the needs increase. This is a very obvious experience of ours. Despite this it is hard to criticize a country for a lack of priorities. As such, we find that a requisite upon parties to “promote” and not “undertake” will fail to address and rectify this widespread problem.

Article 6 and Article 2 fourth paragraph “person of trust”

We wish to point out that not all people know someone who they could designate as a “person of trust”. We recommend, therefore, that the committee considers an order whereby a patient can sign a document outlining how he or she wishes to be treated in an involuntary setting. At the point of admission, and at any time during the involuntary placement, they may have severely impaired cognition. However, patients who are recurrently taken into involuntary placement due to a mental disorder have experience from such placement and treatment. Therefore they often know what helps their recovery. As such, it is possible for them to express beforehand in writing how they wish to be treated if involuntary placement and treatment becomes necessary. In cases where such patients lack a “person of trust” this kind of document offers an alternative and allows the wishes and preferences of these patients to be known to the providers of involuntary treatment.

Article 7

We consider that this article is flawed. We consider that people subject to an involuntary measure must always have the right to free legal aid. This article affords the parties discretion on whether to provide free legal aid or not. An involuntary measure is a serious violation of a person's integrity and must be subject to thorough checks and balances. People subjected to involuntary measures can rarely pursue their case without assistance.

Furthermore, we insist that the lawyer must be adequately compensated for their assistance. If the lawyer is not adequately compensated the person subjected to the involuntary measure will only have access to legal redress in name and not in practice.

Article 8

We wish to inform that good care does not only consist of competence and experience. One of the most important factors in recovery from a mental disorder in an involuntary placement is a positive and kind attitude and personal response on the behalf of the care staff.

We recommend that this article is extended and mentions attitude, or personal response, in some manner.

Article 12

First paragraph: We recommend that the committee considers adding a requirement that the doctor must be unbiased in all decisions. We have knowledge of doctors who subscribe certain medication to patients while simultaneously being employed by the manufacturers of said medication.

Second paragraph: We recommend that this article is extended and that the court or competent body ensure that the patient's participation is not impaired by communicative or linguistic barriers. In such cases an interpreter should be designated.

Fourth paragraph: We recommend that the committee considers and includes the maximum period in which decisions shall be reviewed.

Article 15

We recommend an addition to the article. When criteria of an involuntary placement or treatment is no longer met, the doctor in charge or other health personnel designated by law, is under an immediate obligation to inform the patient hereof.

Article 16

First paragraph: We suggest following amendment -"Member states shall ensure that persons subject to involuntary placement and/or involuntary treatment *have knowledge of and can effectively exercise the right:*"

A person must have knowledge of a right in order to exercise it. Our extensive experience tells us that patients in involuntary placement have scant knowledge of their rights.

Fourth paragraph: We consider that this paragraph is flawed. We consider that any restrictions must be possible to appeal to a court or other competent body. Any person subject to restrictions under this paragraph must also have the right to free legal assistance during the appeal. Whereas we acknowledge the needs of safety for those close to the patient, we hold the opinion that the process of withholding information must be subject to the rule of law. Otherwise, information may be kept from the patient in an arbitrary manner, and in contradiction of the intentions of this protocol.

Article 17

We wish to emphasize that when there is a suspicion that an interpreter is needed, whether it is due to a different language or due to a neuropsychiatric disability, that the interpreter must be present during all important meetings. The right to information is otherwise rendered useless, and it would also constitute a form of discriminatory practice.

OTHER NGOs

The Hallmark Disability Research Initiative at the University of Melbourne

About the Hallmark Disability Research Initiative

The Hallmark Disability Research Initiative (DRI) at the University of Melbourne co-ordinates interdisciplinary projects with the involvement of community partners and those with lived experience of disability. Its brief is to develop high-quality applied research, policy and education programs. The aims of the DRI are to:

- enable the development of disability research in collaboration with the wider community;
- bring together people with disabilities and their representative organisations with academic researchers; and,
- foster a rich understanding of how to match research to the needs and desires of the community.

Summary of the Submission

The DRI provides this written submission to the Committee on Bioethics (DH-BIO) of the Council of Europe regarding the Additional Protocol to the Convention on Human Rights and Biomedicine (Additional Protocol). We welcome efforts to advance understandings of the Convention on Human Rights and Biomedicine particularly with regards to detention and involuntary treatment in the mental health context. At the same time, we wish to raise serious concerns about the content of the Additional Protocol, with regard to recent

developments in international human rights law, particularly related to the UN Convention on the Rights of Persons with Disabilities (CRPD).

Our submission draws on international human rights law regarding persons with disabilities, particularly persons with psychosocial (mental health) disability. We consider how the human rights of persons with disabilities have been interpreted, monitored and implemented to date, including with regard to the CRPD, but also the Convention against Torture (CAT) and the International Covenant of Economic, Social and Cultural Rights (ICESCR). Interpretive guidance from UN treaty bodies and legal instruments will also be considered, including the Special Rapporteurs for Torture, the Rights of Persons with Disabilities and the Right to Health. We will also draw upon interpretations of the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) and the Council of Europe (namely the Commissioner for Human Rights) and will have regard to scholarship in related fields.

On the basis of this material, we recommend that the Additional Protocol should be withdrawn, with a view to shifting the focus from restraining rights to liberty and consent to healthcare, and instead to a focus on facilitating access to support.

This submission is not meant as a critique of individual clinical mental health professionals, who are typically humanist, hard-working and compassionate. Instead the submission is meant as a contribution to the ongoing conversation about mental health law and policy, even as we hope to shift debate and practices in this area.

International context

To be maximally effective, general discussion about the human rights and dignity of persons with mental impairments¹³⁹ has to be positioned in a broader discussion of international human rights law related to persons with disabilities. As such, we welcome the aspiration to align the Protocol with the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) (lines 11-13). We also applaud efforts to elaborate on the implications of Article 1 of the Convention on Human Rights and Biomedicine to ‘protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine’.

Nevertheless, we wish to raise the following concerns about the inconsistencies between the Additional Protocol and the CRPD. The following articles of the CRPD appear to be inconsistent with the general premise of the Additional Protocol.

Article 5, for example, prohibits disability-based discrimination (para. 2), and paragraph 1 directs States Parties to “recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law”. Laws that discriminate on the basis of disability also may contradict the fundamental principles in Article 3 of the CRPD, particularly with regards to paragraphs (a) (“[r]espect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”); (b) (“non-discrimination”); and (e) (“equality of opportunity”).

Article 14(1) refers to the right to liberty and states that, “the existence of a disability shall in no case justify a deprivation of liberty”. It is true that the words, “the existence of a disability shall in no case justify a deprivation of liberty” have been interpreted in two ways. According to the first reading, “the existence of a disability *alone*” cannot justify such laws. According to the second reading the use of disability as a criterion for the deprivation of liberty, even when

¹³⁹ Article 1, CRPD.

used in conjunction with other criteria to justify detention (such as risk of harm to self or others), would violate Article 14. The CRPD Committee has decisively endorsed the latter view, in its General Comment 1, stating that:

legislation of several states party, including mental health laws, still provide instances in which persons may be detained on the grounds of their actual or perceived disability, provided there are other reasons for their detention, including that they are dangerous to themselves or to others. *This practice is incompatible with article 14 as interpreted by the jurisprudence of the CRPD committee.*¹⁴⁰

Other articles of the CRPD appear to be violated by typical powers to detain and treat involuntarily. Article 17 states that “(e)very person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.” With regard to the right to health, Article 25 (d) directs that States Parties shall “(r)equire health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent”. Finally, Article 12 directs that States Parties shall not place restrictions on legal capacity on the basis of a disability, which mental health legislation clearly does.

The CRPD explicitly prohibits laws that discriminate on the basis of disability and recent statements by UN bodies, such as the CRPD Committee¹⁴¹ and the United Nations Office of the High Commissioner of Human Rights (OHCHR),¹⁴² advance the view that discriminatory mental health laws should be replaced.

United Nations treaty bodies have provided interpretive guidance on how mental health legislation can be understood in relation to the CRPD. The OHCHR, for example, has expressed the view that mental health legislation is unjustly discriminatory against people with psychosocial disability because it systematically uses mental illness as a criterion to limit legal capacity.¹⁴³ In 2009, the OHCHR made the following statement:

Legislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent must be abolished. This must include the repeal of provisions authorizing institutionalization of persons with disabilities for their care and treatment without their free and informed consent, as well as provisions authorizing the preventive detention of persons with disabilities on grounds such as the likelihood of them posing a danger to themselves or others, in all cases in which such grounds of care, treatment and public security are linked in legislation to an apparent or diagnosed mental illness.¹⁴⁴

¹⁴⁰ Para. 1 (emphasis added).

¹⁴¹ United Nations Committee on the Rights of Persons with Disabilities, ‘Equal Recognition Before the Law—Article 12; Liberty and Security of the Person—Article 14’ CRPD/C/CHN/CO/1 Distr.: General 27 September 2012. Available online: http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-CHN-CO-1_en.doc (accessed on 8 October 2012).

¹⁴² United Nations General Assembly, OHCHR, Tenth session Agenda item 2. “Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary-General: Thematic Study by the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities.” Distr. GENERAL A/HRC/10/48 26 January 2009. Available online: <http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.48.pdf> (Accessed 4 June 2015).

¹⁴³ Ibid.

¹⁴⁴ Ibid, para 49.

The CRPD Committee echoed the view of the OHCHR (though not in such decisive terms). In its concluding observations on the compliance of China with the CRPD, the CRPD Committee recommended “the abolishment of the practice of involuntary civil commitment based on actual or perceived impairment”.¹⁴⁵ The most recent concluding observations to Australia—in the strongest terms of a concluding observation yet—directed that Australia repeal “legal provisions that authorize commitment of individuals to detention in mental health services, or the imposition of compulsory treatment either in institutions or in the community via Community Treatment Orders (CTOs)”.¹⁴⁶

The CRPD Committee elaborated further on the matter of repealing mental health law in its General Comment 1. Paragraph 42 of the Comment refers to Article 12 in conjunction with Articles 15, 16 and 17 of the CRPD, regarding respect for personal integrity and freedom from torture, violence, exploitation and abuse:

As has been stated by the Committee in several concluding observations, forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (art. 17); freedom from torture (art. 15); and freedom from violence, exploitation and abuse (art. 16). This practice denies the legal capacity of a person to choose medical treatment and, is therefore, a violation of article 12 of the Convention. States parties must, instead, respect the legal capacity of persons with disabilities to make decisions at all times, including in crisis situations; must ensure that accurate and accessible information is provided about service options and that non-medical approaches are made available; and must provide access to independent support. States parties have an obligation to provide access to support for decisions regarding psychiatric and other medical treatment. Forced treatment is a particular problem for persons with psychosocial, intellectual and other cognitive disabilities. *States parties must abolish policies and legislative provisions that allow or perpetrate forced treatment, as it is an ongoing violation found in mental health laws across the globe, despite empirical evidence indicating its lack of effectiveness and the views of people using mental health systems who have experienced deep pain and trauma as a result of forced treatment.* The Committee recommends that States parties ensure that decisions relating to a person’s physical or mental integrity can only be taken with the free and informed consent of the person concerned.¹⁴⁷

The CRPD Committee directs States Parties to replace mental health law with a ‘supported decision-making regime’. Such a regime would involve providing new measures under the imperative to provide support to exercise legal capacity to persons with psychosocial disability, and seemingly to replace any functions of mental health law that are necessary to uphold other rights.

¹⁴⁵ United Nations Committee on the Rights of Persons with Disabilities, ‘Equal Recognition Before the Law—Article 12; Liberty and Security of the Person—Article 14’ CRPD/C/CHN/CO/1 Distr.: General 27 September 2012. Available online: http://www.ohchr.org/Documents/HRBodies/CRPD/8thSession/CRPD-C-CHN-CO-1_en.doc (accessed on 8 October 2012).

¹⁴⁶ United Nations Committee on the Rights of Persons with Disabilities. “Committee on the Rights of Persons with Disabilities. ‘Concluding Observations of the Committee on the Rights of Persons with Disabilities (Australia) (Advance Unedited Version) CRPD/C/AUS/CO/1 10th sess.” 2–3 September 2013. Available online: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fAUS%2fCO%2f1andLang=en (accessed on 2 December 2013).

¹⁴⁷ United Nations Committee on the Rights of Persons with Disabilities, General Comment No. 1—Article 12: Equal Recognition before the Law, UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session (April 2014) Para. 42 [emphasis added]. Available online: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx> (accessed on 2 June 2015).

The views of UN treaty bodies on mental health law, and the implications of each of the various Articles noted previously have been discussed in detailed studies and do not warrant elaboration here.¹⁴⁸ This brief summary is instead meant to elucidate the call under international human rights law to rethink mental health laws, and (potentially) to use mental capacity as a replacement for the diagnostic criteria.

As well as the generalized human rights concerns raised above, we also wish to comment on specific elements of the draft Additional Protocol.

Participation of People with Disabilities

The development of the Additional Protocol appears to have occurred without the significant input of persons with lived experience of mental health crises, psychosocial disability, mental illness, and so on. This is a matter of process, but relates also to compliance with substantive requirements of the CRPD. Art 4(3) CRPD states:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Although laws that enable involuntary psychiatric intervention are ostensibly designed to safeguard the rights of those who are subject to involuntary treatment, it appears that this same cohort has been historically (and contemporaneously) excluded from the development of these law reform processes. This historical trend ought not be repeated at the international level in the development of instruments such as the Additional Protocol.

Recommendation: DH-BIO, in developing any materials related to psychosocial disability, particularly those with a focus on the CRPD, ought to actively consult disabled peoples organisations, particularly those representing people with psychosocial disability.

References to Risk to Others

In the working document it is stated that “that restrictions on the rights set out in the Convention on Human Rights and Biomedicine are permissible only if prescribed by law and are necessary in a democratic society in the interests of public safety, crime prevention, protection of public health or the protection of the 33 rights and freedoms of others” (lines 30-31). The various justifications for restricting rights in the above statement deserve careful consideration.

It is true that domestic and regional law may prescribe intervention. However, even *if* human rights concerns are set aside, the justifications identified at lines 30-31 of the Additional Protocol are not well supported by the evidence base. For example, the claim that detention and involuntary treatment in the mental health context is necessary to prevent risk to others rests on views that are scientifically unfounded. Typically, violence against others in the mental health context is associated with those diagnosed with schizophrenia. Yet there is limited evidence to justify this claim. In what is perhaps the largest study to date on the correlation between schizophrenia and rates of violent crime, 8003 people diagnosed with

¹⁴⁸ A Nilsson, ‘Objective and Reasonable? Scrutinising Compulsory Mental Health Interventions from a Non-discrimination Perspective’ (2014) 14 *Human Rights Law Review* 459.

schizophrenia in the USA were compared with general population controls (n = 80 025) in terms of criminal convictions for violent crimes.¹⁴⁹ For the vast majority of those with the diagnosis who had committed a violent crime, the acts were attributed to drug use.¹⁵⁰ Where other factors were controlled, those diagnosed with schizophrenia who had not abused drugs were only 1.2 times more likely to have committed at least one violent crime than the control group.¹⁵¹ However, when unaffected siblings were used as controls compared to their siblings, even where drug use had been a contributing factor, ‘substance abuse comorbidity was significantly less pronounced... suggesting significant familial (genetic or early environmental) confounding of the association between schizophrenia and violence.’¹⁵² Despite this limited evidence for a causative relationship between mental impairment and violent crime,¹⁵³ the notion of ‘risk-of-harm to others’ has remained a strong focus in justifications for detention and involuntary treatment in the mental health context. This skewed focus has arguably contributed to prejudice and discrimination towards people with psychosocial disability. This institutional discrimination is compounded given that other groups (such as young men drinking alcohol or known domestic abuse perpetrators, whose propensity to violence compared to others is empirically established) do not face similar restrictions on rights to liberty and consent to healthcare.

As such, we conclude that there is sufficient evidence to echo calls to abandon the risk criteria in mental health legislation.¹⁵⁴ Risk assessment tests used in mental health laws are prejudicial, as they only apply to people with psychosocial disability. Such tests are misguided, given that a diagnosis of mental illness per se is marginally significant in indicating the likelihood of violence, and – in any case – they are ineffective. On this latter point: even *if* sufficient evidence exists to establish a causative link between mental illness and violence, there remains little evidence showing that risk assessment under mental health law reduces violent crimes and other risks to the public.¹⁵⁵ Douglas Mossman has undertaken a meta-analysis of studies that look retrospectively at risk-categorisation criteria in the lead up to violent acts and argues that no satisfactory balance between specificity and sensitivity in identifying risk could be found.¹⁵⁶ ‘Hindsight,’ Mossman concludes, ‘makes “warning signs” clear, but before violent tragedies occur we cannot efficiently distinguish the signs that point to violence from those that will turn out to be false positive signals.’¹⁵⁷ Indeed, it remains an open question in the literature on psychiatric coercion and violence, whether the range of civil commitment and legal involuntary treatment measures – including

¹⁴⁹ S Fazel, N Långström, A Hjern, M Grann and P Lichtenstein, ‘Schizophrenia, Substance Abuse, and Violent Crime’ (2009) 301(19) *JAMA* 2016.

¹⁵⁰ *Ibid.*

¹⁵¹ *Ibid.*

¹⁵² *Ibid.*

¹⁵³ See A Nilsson, ‘Objective and Reasonable? Scrutinising Compulsory Mental Health Interventions from a Non-discrimination Perspective’ (2014) 14 *Human Rights Law Review* 459.

¹⁵⁴ See for example, C Ryan, ‘Capacity as a Determinant of Non-consensual Treatment of the Mentally Ill in Australia’ (2011) 18(2) *Psychiatry, Psychology and Law* 248; C Ryan and S Callaghan, ‘Rising to the human rights challenge in compulsory treatment – new approaches to mental health law in Australia’ (2012) 46(7) *Aust N Z J Psychiatry* 611.

¹⁵⁵ See, eg, D Mossman, ‘The imperfection of protection through detection and intervention. Lessons from three decades of research on the psychiatric assessment of violence risk’ (2009) 30 *Journal of Legal Medicine* 109, 139-140; P Appelbaum, ‘Violence and Mental Disorders: Data and Public Policy’ (2006) 163 *American Journal of Psychiatry* 1319.

¹⁵⁶ Mossman, ‘The imperfection of protection through detection and intervention. Lessons from three decades of research on the psychiatric assessment of violence risk.’

¹⁵⁷ *Ibid* 139-140.

as applied by mental health courts, terms of sentencing, and inpatient and outpatient commitment orders – are effective in reducing the risk of violence.¹⁵⁸

Given the concerns outlined in this section, we recommend that the Additional Protocol does not include content which would support scientifically unfounded claims about the capacity for involuntary psychiatric intervention to increase “public safety, crime prevention, protection of public health or the protection of the 33 rights and freedoms of others.” Such claims have the potential to reinforce longstanding and destructive stereotypes, which promote the view that restraints and rights limitation are the natural course in responding to mental health crises.

Recommendation – Remove any reference to ‘risk of harm to others’ criteria in justifying detention and involuntary treatment in the mental health context. Alternatively, a statement could be made which highlights the limited scientific evidence to support the view that risk assessment and subsequent detention and involuntary treatment can prevent harm to others.

“Involuntary Placement”

The term “involuntary placement”, which is used throughout the Additional Protocol, is not a commonly understood term and has the potential to obfuscate the seriousness of involuntary psychiatric interventions which result in a deprivation of liberty. In contrast, the word ‘detention’ is simple, direct, and has been used in longstanding legal instruments that ensure procedural safeguards for those deprived of their liberty. These instruments include the European Convention on Human Rights¹⁵⁹ and the Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment.

Recommendation: Replace ‘involuntary placement’ with the term ‘detention’ in all DH-BIO references to deprivations of liberty in mental health settings under the powers of mental health legislation.

Conclusion

The use of involuntary treatment and detention in the mental health context remains the subject of wide ranging critique, with some commentators charging that such powers create more problems than they solve. Mental health law – and the powers to detain and treat involuntarily – has been variously described as anti-therapeutic, ineffective on its own terms, and discriminatory.¹⁶⁰ Perhaps most importantly, detention and involuntary treatment under mental health laws have struggled to provide substantive rights to persons with mental

¹⁵⁸ P Appelbaum, ‘Violence and Mental Disorders: Data and Public Policy’ (2006) 163 *American Journal of Psychiatry* 1319.

¹⁵⁹ The European Convention on Human Rights and Fundamental Freedoms, (ECHR), 1950, Art 5.

¹⁶⁰ A Nilsson, ‘Objective and Reasonable? Scrutinising Compulsory Mental Health Interventions from a Non-discrimination Perspective’ (2014) 14 *Human Rights Law Review* 459; A Dhanda, ‘Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?’ (2007) 34 *Syracuse Journal of International Law and Commerce* 429; T Minkowitz, ‘The United Nations Convention on The Rights Of Persons With Disabilities and The Right To Be Free From Non-consensual Psychiatric Interventions’ (2007) 34(2) *Syracuse Journal of International Law and Commerce* 405; SJ Morse, ‘Crazy Behavior, Morals, and Science: An Analysis of Mental Health Law,’ (1997) 51 *Southern California Law Review* 653; T Campbell, ‘Mental Health Law: Institutionalised Discrimination’ (1994) 28 *Australian and New Zealand Journal of Psychiatry* 554, 556.

impairments—that is *access to support and healthcare*. Indeed, there is even some evidence showing that the introduction of human rights advocacy within mental health law has led to an *increase* in detention and involuntary treatment.¹⁶¹ The partial recognition of human rights in mental health legislation and policy is yet to achieve the type of deep integration of human rights – in theory, everyday practice, and the law – to which this submission is aimed.

Therefore, we recommend that the DH-BIO withdraw the current additional protocol, with a view to shifting the focus from restraining rights to liberty and consent to healthcare, and instead to a focus on facilitating access to support. The DH-BIO is in a unique position to promote a legal and ethical framework for the delivery of these emerging systems of support.

Partnership to Ensure Reform of Supports in other Nations (PERSON)

We welcome the commitment in the Convention on Human Rights and Biomedicine, as defined in Article 1, to *protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine*. We welcome the inclusion of the aspiration to be guided by the UN Convention on the Rights of Persons with Disabilities (hereafter CRPD) in this Protocol. We welcome the recognition in the preamble to this Protocol: ‘that the use of involuntary placement and involuntary treatment has the potential to endanger human dignity and fundamental rights and freedoms’.

The present submission relies strongly and follows quite explicitly the line in which the matter of personal liberty, prohibition of discrimination and equality, dignity, integrity and human rights in general of persons with disabilities (including persons with psychosocial disabilities) have been so far observed, regulated and interpreted at the levels of United Nations (namely the CRPD and CAT Conventions, Special Rapporteurs for Torture, the Rights of Persons with Disabilities and the Right to Health and the CRPD Committee), the Council of Europe (namely the Commissioner for Human Rights), and in the scholarship of health and medical law. Stances collected within the EU-funded research projects on the given topic has also been incorporated in the submission.

It also grounds its arguments and intentions in the evolving case law within the Council of Europe mandate, namely the European Court of Human Rights and the European Committee on Social Rights. Especially so in their observations regarding the ill-treatment in psychiatric and social care detention (placement without consent), personal liberty of persons with disabilities under Article 5, and the right to private life, under Article 8 ECHR, as well as the Committee’s standing with regard to living conditions and treatment in psychiatric institutions (Article 11 ESC) and the Council’s Committee for the Prevention of Torture in its work of observing treatment, placement and non-consensual measures imposed on persons with disabilities.

Finally, strong arguments for the opinion formed within the present submission can be found within the International Covenant of Economic, Social and Cultural Rights, more prominently in its absolute prohibition of discrimination, particularly in the domain of the right to health (Article 12 ICESCR).

Compliance with UN Convention on the Rights of Persons with Disabilities

¹⁶¹ See D Nahon, I Pugachova, R Yoffe, and Itzhak Levav, ‘The Impact of Human Rights Advocacy, Mental Health Legislation and Psychiatric Reform on the Epidemiology of Involuntary Psychiatric Hospitalizations’ (2006) 25 *Med. & L.* 283–96.

The present Protocol contravenes the emerging jurisprudence on the CRPD, especially General Comment number 1 on **Article 12 CRPD** which states that people with disabilities, including mental health conditions (hereafter referred to as psychosocial disabilities in line with the CRPD) are to be recognized as equal subjects before the law and that to discriminate against such people solely on the basis of a diagnosis is prohibited.

Article 25 CRPD on the right to health protects the rights of people with disabilities to the highest attainable standards of health without discrimination on the basis of disability. **Article 25 (d)** requires healthcare professionals to provide care 'on the basis of free and informed consent'. **Article 5 CRPD** asserts that people with decision-making support needs are equally entitled to the benefits and protections afforded by the principle of free and informed consent.

In addition, the UN Committee on the Rights of Persons with Disabilities (2011: para 36) has called for measures to ensure that healthcare services, including all mental-health-care services: '... are based on the informed consent of the person concerned'. **Article 14 CRPD** prohibits deprivation of liberty on the basis of disability. **Article 17 CRPD** requires respect for the physical and mental integrity of persons with disabilities on an equal basis with others, which has been interpreted to include freedom from forced psychiatric treatment.

Also, the CRPD prohibits decisions taken about people with disabilities by others on outdated patronising concepts such as 'best interests' rather than respect for people's own decisions informed by their will and preference. People may need support in decision-making in times of distress, and the CRPD asserts that people have the right to support to exercise legal capacity, i.e. supporting people to make their own decision based on their will and preferences rather than others' determination of their best interests.¹⁶²

Also, **Article 5 of the European Convention on Human Rights** guarantees the right to personal liberty and provides that no-one should be deprived of their liberty in an arbitrary fashion. *We hold that mental health laws are arbitrary and unjust and not based on best available evidence on mental health treatment. The labelling of persons as being of 'unsound mind' or having a 'mental disorder' as a basis for psychiatric detention is inherently subjective, value-laden and therefore arbitrary*¹⁶³.

Not only does this protocol fail to implement Articles of the UN CRPD, it also upholds a medical model of disability, long discredited in other areas of disability law and policy.¹⁶⁴ The reliance on doctors alone to make decisions about detaining and treating people is not in accordance with human rights norms.¹⁶⁵

¹⁶² Gooding P, 'Supported decision-making: A rights-based disability concept and its implications for mental health law' (2013) 20 *Psychiatry, Psychology and Law* 431

¹⁶³ See for example *Stanev v. Bulgaria [GC]* App No 36760/06(17.1.2012 [GC])

See also Pilgrim D, 'Some implications of critical realism for mental health research' (2013) 12 *Social Theory & Health* 1; Rose N, 'What is Diagnosis For' (2013) 4 *Lecture given at the Institute of Psychiatry (London) on Conference on DSM---5 and the Future of Diagnosis* 4 June 2013.

¹⁶⁴ Stein MA, 'Disability Human Rights' (2007) 95 *California Law Review* 75

¹⁶⁵ See for example *X and Y v. Croatia, App No 5193/09 (EC 03.2.2012.)* In para 85. the Court explicitly states that "it is the judge and not a physician, albeit a psychiatrist, who is to assess all relevant facts concerning the person in question and his or her personal circumstances" when referring to issues of deprivation of legal capacity. This shows that European Court of Human Rights also departs from exclusive medical approach.

General Comment no. 1 issued by the UN Committee on the Rights of Persons with Disabilities, on Article 12 of the UN CRPD Convention, has offered an authoritative interpretation on both the content of the right to legal capacity of persons with disabilities and States' duties in this regard.¹⁶⁶ Article 12 CRPD is the main bearer of the "paradigm shift" brought in this revolutionary universal human rights treaty. It is insistent on full equality regarding the right to universal legal capacity and 'recognizes that persons with disabilities enjoy legal capacity on an equal basis with others in all areas of life'.¹⁶⁷

'Article 12, paragraph 3, recognizes that States parties have an obligation to provide persons with disabilities with access to support in the exercise of their legal capacity. States parties must refrain from denying persons with disabilities their legal capacity and must, rather, provide persons with disabilities access to the support necessary to enable them to make decisions that have legal effect.'¹⁶⁸

The very next paragraph of the General Comment reads that 'support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making.'

The concept of legal capacity as a human right of persons with disabilities (including psychosocial) does not only refer to legal status and the official recognition of legal capacity before the law. It moreover emphasizes the importance of giving impact, effect and recognition to actions, decisions and will and preference of a person, regardless of her/his disability and especially detached from his or her given medical diagnosis. This right also includes rights of persons to take risks and make mistakes.¹⁶⁹

The CRPD, as seen in the authoritative interpretation of the CRPD Committee in the General Comment no. 1, foresees that States have a duty to refrain from any action that deprives persons with disabilities of this right. They also have a duty to prevent other actors from endangering or limiting this right.

Persons with disabilities must not be subjected to any form of substitute decision making where their will and preference are not respected fully, but should be given an option of supported-decision making, in line with choices of the persons in question. These kinds of support in exercising the right to legal capacity must not be used as justification of limiting other rights of persons with disabilities.¹⁷⁰ Also, States must abolish all provisions and practices that are discriminatory in the sense that they deny persons with disabilities the right to make legally effective decisions, based on their disability (e.g. state of mental health).¹⁷¹

¹⁶⁶ Committee on the Rights of Persons with Disabilities, General Comment No.1 – Article 12: Equal Recognition Before the Law (April 2014) UN Doc. No. CRPD/C/GC/1, adopted at the 11th Session

¹⁶⁷ 'Legal capacity includes the capacity to be both a holder of rights and an actor under the law. Legal capacity to be a holder of rights entitles a person to full protection of his or her rights by the legal system. Legal capacity to act under the law recognizes that person as an agent with the power to engage in transactions and create, modify or end legal relationships.' (GC no.1, para.12)

¹⁶⁸ *ibid*, para.25

¹⁶⁹ *ibid*, para.22

¹⁷⁰ *ibid*, para. 29f

¹⁷¹ *ibid*, para.25

The right to legal capacity is also read in light of Article 5 CRPD, where discriminatory action would mean “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms”.¹⁷²

Such a paradigm shift has as the main objective of restoring the autonomy and respect of dignity of persons with disabilities in all areas of their lives, and as such, the right to legal capacity is indivisibly interrelated with the freedom to make one’s own choices and decisions.

The CRPD Committee, in its interpretation of Article 12 in General Comment no.1, has established a legally binding stance regarding the involuntary actions against persons with disabilities in health care and social care setting. It has urged States to abolish all practices and grounds of arbitrary and discriminatory deprivation of liberty by placing persons with disabilities in a residential setting without their express consent. Paragraph 40. of the General Comment no. 1 reads as follows:

‘The denial of the legal capacity of persons with disabilities and their detention in institutions against their will, either without their consent or with the consent of a substitute decision-maker, is an ongoing problem. This practice constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention. States parties must refrain from such practices and establish a mechanism to review cases whereby persons with disabilities have been placed in a residential setting without their specific consent.’

Probably the most evident prohibition of involuntary placement and treatment is given in reading of Article 12 CRPD in conjunction with Article 25 CRPD on the right to health, through insisting that no treatment shall take place without prior informed consent of the person with disabilities. Paragraph 41 of the General Comment no. 1 reads as follows:

‘The right to enjoyment of the highest attainable standard of health (art. 25) includes the right to health care on the basis of free and informed consent. States parties have an obligation to require all health and medical professionals (including psychiatric professionals) to obtain the free and informed consent of persons with disabilities prior to any treatment. In conjunction with the right to legal capacity on an equal basis with others, States parties have an obligation not to permit substitute decision-makers to provide consent on behalf of persons with disabilities. All health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities.’

The Council of Europe Commissioner for Human Rights has quite eloquently and expressly addressed the urgent need for European States to identify and amend laws and measures regarding compulsory psychiatric care and treatment of persons with disabilities, in light of the adopted international standards, with particular reference to CRPD Article 12.¹⁷³

¹⁷² *ibid*, para.32

¹⁷³ Council of Europe Commissioner for Human Rights, “Who gets to decide? Right to legal capacity of persons with intellectual and psychosocial disabilities”, Recommendations, para. 2.

Furthermore, again in an explicit manner, he has called States to ensure that persons with disabilities enjoy the right to consent to or reject medical interventions, on an equal basis with others.¹⁷⁴

He moreover stated that placement of persons with disabilities in any residential setting without their true consent should always be seen as a deprivation of liberty under Article 5 of the European Convention on Human Rights.¹⁷⁵

Finally, he urges the States to put in force means of supported decision making with full respect for a person's will and preferences, while abolishing forms of substitute decision making in their national systems.¹⁷⁶

Comments and findings vis-à-vis particular provisions of the Draft Protocol

Article 2 – Scope and definitions

Definitions

-“ ‘mental disorder’ is defined in accordance with internationally accepted medical standards.”

Comment: Accepting and incorporating solely *international medical standards* and terminology thereof is problematic and inadequate in a human rights source such as this Protocol to the Convention, especially bearing in mind that human rights standards and sources/treaties relevant in that particular area have been proclaimed as important in drafting of the present Protocol (e.g. the UN CRPD). Therefore, a suggestion is made that human rights terminology should replace this terminology, especially by avoiding the term “mental disorder” and replacing it with the term “psychosocial difficulties (disability)”, or alternatively “mental health problems/difficulties”, as used in the UN discourse on disability rights.

Article 3 – Legality

- “Measures for involuntary placement and involuntary treatment shall only be applied in conformity with the provisions set out in domestic law, and in accordance with the safeguards established in this Protocol.”

Comment: To base the Protocol's provisions' legality solely on standards in domestic legal systems and the present Protocol will not suffice. Namely, given the rising standards in international law and the international community, and that the achievements of the CRPD (a treaty with binding force, with the official support of a vast majority of EU countries, including the European Union itself) have inspired the principles underpinning the present Protocol, the article in question should explicitly include a formulation “standard adopted in international law”, which would strongly and explicitly state the intentions of the Protocol to have its provisions and values in line with universal human rights standards which are legally binding.

Article 4 – Necessity and proportionality

¹⁷⁴ Ibid, para. 4

¹⁷⁵ Ibid, para. 6.

¹⁷⁶ Ibid, para. 8.

- “Measures for involuntary placement and involuntary treatment shall only be used in accordance with the principles of necessity and proportionality. Persons subject to involuntary placement and/or involuntary treatment shall be cared for in the least restrictive environment available and with the least restrictive or intrusive treatment available, taking into account their health needs and the need to protect other persons from harm.”

Comment: It is of utmost importance to differentiate, in the most comprehensive way possible, “*health needs*” and “*needs in an urgent situation*”.

The latter holds its scope over situations where danger is immediate and where danger is to be avoided through some form of intervention aimed at averting immediate danger to the person or others. It includes the doctrine of medical necessity, which allows for emergency intervention in certain situations, for example, where a person is unconscious, and no informed consent can be given. However, it is important to note that the doctrine of medical necessity has also given rise to the violation of the rights of persons with disabilities, including its use to justify forced sterilisation. Therefore, this doctrine requires careful scrutiny to ensure that it is not abused to justify the violation of the rights of persons with disabilities. The use of the term ‘health needs’ to justify intervention has a wider scope and transcends to all medical treatments including, but not limited to compulsory placement – i.e. every medical intervention and treatment while a person is in compulsory placement due to a prior urgent situation. This can lead to multiple violations of the individual’s human rights. A person may be subjected to other forms of treatment without respecting the person’s right to consent in health care. Therefore, the formulation “health needs” should be removed from this article. Otherwise, a person in question will be deprived of his/her right to consent or refuse other medical or other treatment while kept against her/his will.

As noted in the introductory paragraphs, the right to informed consent is valued as a norm of high importance in the area of human rights of persons with disabilities, as it embodies personal autonomy, physical and mental integrity and prevents persons from being subjected to involuntary treatment, coercive measures of different kinds and abuse and ill-treatment. Furthermore, as a means of self-determination, this right is to preserve dignity of patients. From the perspective of medical law and patients’ rights, all recent literature and studies conducted regarding conditions of involuntary placement/treatment of psychiatric patients emphasizes the importance of the right to consent, and preserving that right to the highest attainable extent, regardless of diagnosis, mental state or other circumstances.¹⁷⁷ Regardless of any specific circumstance that would imply limited capacity to understand or participate in decision making regarding health treatment, medical professionals should continuously make efforts to inform the patient fully and obtain consent to any treatment in involuntary conditions.¹⁷⁸

*There is strong evidence of limited therapeutic effects and benefits of involuntary treatment and coercive approach in psychiatry. Building a strong network of community-based services and support networks brings more benefit even to those in distress, in urgent situations and need of help and assistance.*¹⁷⁹

¹⁷⁷ See Méndez JE, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, 2013); McSherry B and Freckelton I, *Coercive Care: Rights, Law and Policy* (Routledge 2013); Newbigging K and others, *Independent Mental Health Advocacy-The Right to Be Heard* (Jessica Kingsley 2015)

¹⁷⁸ Even the European Commission funded EUNOMIA study on coercive measures in psychiatry insists that one of the main principles in this context has to be preservation of informed consent. See

¹⁷⁹ See Allen and Smith, “Opening Pandora’s Box: The Practical and Legal Dangers of Involuntary Commitment”, in *Psychiatric Services*, 52/3, 2001

The UN Special Rapporteur on the Prohibition of Torture has taken a strong stance that coercive and involuntary actions undertaken by health professionals and masked as “good intentions” (e.g. protecting the interests of a person) fall under the prohibition of torture from the UN CAT Convention.¹⁸⁰

Article 5 – Alternative measures

Comment: The present article needs to be illustrative of alternative options and manners of using alternatives to compulsory placement and / or treatment. Namely, insisting on employing an existing support network, services within the out-patient facilities, counselling and other available less intrusive options should be illustrated as a guidance to the State parties.

While we also welcome Article 5 of this Protocol which asserts that alternatives to involuntary detention and treatment should be developed, we draw your attention to the fact that routine and widespread practice is to deny funding and resources for research on alternative responses, which address social/emotional and other environmental conditions that cause, or otherwise play significant roles in the development of psychosocial distress.¹⁸¹ There is emerging and robust evidence of the role that prior trauma plays in causing distress and indeed psychosis, which require different responses than those proposed by biopsychiatric aetiology.¹⁸² In addition, the new paradigm shift of the CRPD calls for a re-imagining of supports offered to people.¹⁸³ We suggest that the Protocol could support this direction by endorsing the diversion of resources towards supporting alternatives, which can reduce the need for involuntary detentions. Examples of practices which have been demonstrated to support people and reduce hospitalisations and the reliance on medication could named in this Article as guidance for mental health services.

Some of the alternatives which could be listed in Article 5 include the following non-exhaustive list. Crisis houses operating with an alternative ethos (little or no medication, or prescribed medication used as demanded by the individual) have been found to be just as effective as inpatient units, and result in reports of higher patient satisfaction.¹⁸⁴ Additionally many projects focusing on widening communication networks beyond the individual, (for

¹⁸⁰ See Interim report of the Special Rapporteur on Torture, A/63/175, at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N08/440/75/PDF/N0844075.pdf?OpenElement> section B and A/HRC/22/53 at <http://109.74.198.40:8087/jspui/bitstream/123456789/294/1/UN%20Special%20Rapporteur%20on%20Torture.pdf> para. 61-62

¹⁸¹ See Muñoz RF and Ying Y-W, ‘The prevention of depression: Research and practice’ (JHU Press 2002); Fava GA, ‘The Intellectual Crisis of Psychiatric Research’ (2006) 75 *Psychotherapy and Psychosomatics* 202; Faulkner A, ‘Being There in a Crisis: A report on the learning from eight mental health crisis centres’ (2002) Mental Health Foundation

¹⁸² See Read J and Dillon J (eds), *Models of Madness: Psychological, Social and Biological Approaches to Psychosis* (Second edn, Routledge 2013); Read J and others, ‘Childhood trauma, psychosis and schizophrenia’ (2005) 112 *Acta Psychiatrica Scandinavica* 330.

¹⁸³ Bartlett P, ‘The United Nations Convention on the Rights of Persons with Disabilities and the future of mental health law’ (2009) 8 *Psychiatry* 496; Mégret F, ‘The Disabilities Convention: Towards a Holistic Concept of Rights’ (2008) 12 *The International Journal of Human Rights* 261.

¹⁸⁴ Doughty C And Tse S, ‘Can Consumer-Led MHS be Equally Effective? An Integrative Review of CLMH Services in High-Income Countries.’ (2011) 47 *Community Mental Health Journal* 252; Solomon P, ‘Peer support/peer provided services underlying processes, benefits and critical ingredients’ (2004) 27 4 *Psychiatric Rehabilitation Journal* 392; Johnson S and others, ‘Acute in-patient psychiatry: residential alternatives to hospital admission’ (2007) 31 *Psychiatric Bulletin* 262.

example, 'open dialogue' as practiced in Finland); social inclusion through education¹⁸⁵ and/or fulfilling employment (for example Ontario Council of Alternative Businesses)¹⁸⁶ have been found to reduce hospitalisations, as well as improving the quality of life of people with psychosocial distress.¹⁸⁷ None of these alternatives are given due weight and fair trials in mental health systems focused on involuntary detention and treatment, as this becomes the default system response.¹⁸⁸

Many alternative projects can be classified as supported decision-making regimes, in that various strategies are used to support people in crisis to make choices that can help avoid hospitalisation. The UN Committee on the CRPD describes various forms of supported decision-making as:

Those assisting a person may communicate the individual's intentions to others or help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/ her legal capacity . . . The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual.^{189 190}

Supported decision making programmes have been implemented through developments such as the PO Ska ñe in Sweden¹⁹¹, or the use of Advance Healthcare Directives (AHD).¹⁹² Many people with mental health difficulties have the experience to know what helps their recovery and want their advance decisions respected. Advance Healthcare Directives would ensure that people are treated in the manner they chose, and which they have found helpful in the past. A submission made on the topic of AHD by the Centre for Disability Law and Policy NUIG outlines how they may be incorporated into capacity and mental health legislation.¹⁹³

¹⁸⁵ Delman J, Delman, D.R., Vezina, B.R., & Piselli, J., 'Peer led Recovery Learning Communities: Expanding Social Integration Opportunities for People with Lived Experience of Psychiatric Disability and Emotional Distress' (2014) 5 Global Journal of Community Psychology Practice 1

¹⁸⁶ Diamond S, 'What Makes Us a Community?' in LeFrançois B MRaRG (ed) *Mad Matters: A Critical Reader in Canadian Mad Studies* (Canadian Scholars Press Inc 2013) at 65

¹⁸⁷ Delman J, Delman, D.R., Vezina, B.R., & Piselli, J., 'Peer led Recovery Learning Communities: Expanding Social Integration Opportunities for People with Lived Experience of Psychiatric Disability and Emotional Distress' (2014) 5 Global Journal of Community Psychology Practice 1; Stastny P and Lehmann P (eds), *Alternatives Beyond Psychiatry* (Peter Lehmann Publishing 2007); Seikkula J and others, 'Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies' (2006) 16 Psychotherapy Research 214.

¹⁸⁸ Thomas P, *Psychiatry in Context: Experience, Meaning & Communities* (PCCS Books 2014)

¹⁸⁹ Cited by Gooding 2013 at 432

¹⁹⁰ The Vulnerable Persons Living with a Disability Act (Manitoba C.C.S.M. c.V90), s 6(1).

¹⁹¹ Morrissey F, 'The United Nations Convention on the Rights of Persons with Disabilities: a new approach to decision-making in mental health law' (2012) 19 European journal of health law 423; Donskoy A-L and Pollard K, 'Interprofessional working with service users and carers' (2014) *Interprofessional Working in Health and Social Care: Professional Perspectives* 35

¹⁹² Council of Europe, European Committee on Legal Co-operation, CM (2009) 1073, December 9, 2009, available at <https://wcd.coe.int/ViewDoc.jsp?id=1529977&Site=CM> [Last Accessed October 19, 2015].

¹⁹³ A Submission to the Department of Health on the Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013 <available at >

Article 10 – Criteria for involuntary treatment

- “Involuntary placement of a person with a mental disorder may only be used if the following criteria are met:

- i. a) the person’s mental health condition represents a significant risk of serious harm to his or her health and his or her ability to decide on placement is severely impaired or
- b) the person’s mental health condition represents a significant risk of serious harm to others;
- ii. the placement has a therapeutic purpose; and
- iii. no less restrictive means of addressing the risk are available.”

Comment: The formulation contained in the present Article is discriminatory as a whole *on the basis of psychosocial disability*, and contrary to UN CRPD Convention standards (as described in Introductory observations). To foresee a possibility for involuntary placement by making an explicit connection to persons with mental disorder and disorder itself is discriminatory and therefore prohibited by the standards contained in the abovementioned document.

The formulation that reads “the person’s mental health condition represents a significant risk of serious harm to his or her health or her ability to decide on placement is severely impaired” is *discriminatory in its language and spirit*. Namely, the given formulation foresees that a medical condition, a diagnosis or a label of a mental health problem suffices for involuntary placement. It does so by explicitly (i. a) and b)) proclaiming person’s “mental health condition” as basis for legitimate involuntary placement. UN CRPD Convention prohibits discrimination on the basis of disability and therefore prohibits that disability is used as grounds for differing treatment of any sort.

A person’s mental disorder or health problem does not have a potential to present harm or threat to anyone or anything on its own, without the occurrence of tangible consequences. Therefore, the current proposal of the given Article is both discriminatory and contrary to common human rights reasoning. The same argumentation should be applied to Article 11 on involuntary treatment.

Observations of the Special Rapporteur on Torture confirm the same line of thought, relying heavily on provisions in both UN CAT and UN CRPD. Namely, in his Report, the Rapporteur emphasizes the absolute prohibition of discrimination on the basis of disability in health care settings, derived from the provisions of the UN CRPD Convention, and in line with the UN CAT Convention.¹⁹⁴

Article 12: Standard procedures

Comment: Basing the court decision primarily on the results of medical examination is the consequence of employing the medical approach (medical model) to disability and is therefore problematic.

Also in reading of the UN CRPD, no deprivation of liberty regarding a person with disability may be based on the diagnosis given. Such a practice is outdated, discriminatory, and not in line with human rights standards. Again, we are facing exclusion and compulsion based solely on medical views of a disorder, not on someone’s behavior or real/objective circumstance or consequence and means of protection, or objective evaluation of potential danger or harm. Even in situations where the person is in grave danger, or causing harm to others, we contend that involuntary detention and forced treatment are not proportionate

¹⁹⁴ See A/63/175 at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N08/440/75/PDF/N0844075.pdf?OpenElement>

responses. Alternative methods must be used, and as illustrated above, these are more effective than involuntary treatment at preventing harm. Where the person is causing harm to others, this requires an engagement of the criminal justice system, which must also be reformed to ensure that effective access to justice is provided to persons with disabilities. The same argumentation applies to Article 13 and 14 on procedures for taking decisions and termination of placement/treatment.

Article 16 – Appeals and reviews concerning the lawfulness of involuntary placement and/or involuntary treatment

Comment: States must ensure that mechanisms of effective rights protection (e.g. through an instance for patients' rights protection) is easily accessible to the person in question, and that no procedural or obstacles of other nature exist regarding the person's right to easily and effectively approach these mechanisms, in order to challenge a deprivation of liberty. In order to ensure that persons with disabilities have effective access to justice, legal aid and representation must be made available to challenge unlawful and arbitrary deprivations of liberty, including any detention in psychiatric hospitals, social care homes, or other congregated settings.

Article 18 – Right to communication of persons subject to involuntary placement

Comment: If a person is unlawfully and arbitrarily deprived of liberty, there may be no restrictions whatsoever in any means of communication of the person with the outside world.¹⁹⁵ The extent of inclusion of other persons in the process of decision-making concerning healthcare treatment should depend solely on the will of the person. Safeguards should be foreseen however, to honour and include the relationships of trust created for this purpose, based on will and preference of the person in question.

Article 20 Monitoring

Comment: A new paragraph should be inserted stating that any monitoring body must have full and active involvement of persons with psychosocial disabilities. The active and informed participation of individuals, communities and populations is an integral component of the right to the highest attainable standard of health enshrined in Article 12 of the International Covenant on Economic, Social and Cultural Rights. This right includes participation in identifying overall health strategy, agenda-setting, decision-making, prioritization, implementation and accountability.¹⁹⁶ According to Article 4 (3) and Article 33(3) of the CRPD, direct involvement of persons with disabilities and their representative organizations should also be ensured. This is further endorsed by the EU Framework on the CRPD, which has identified monitoring of implementation as one of three strategic priorities.¹⁹⁷ There is active and resourced involvement of civil society organizations of people with disabilities. In accordance with this provision this needs to be made explicit under Article 20 of this protocol.

¹⁹⁵ **This is also set out as an absolute standard within the results of the EUNOMIA study:** "The contacts of the patient with people outside the ward cannot be limited by anyone; in particular, letters written by the patient cannot be censored." See in Fiorillo et al. "How to improve clinical practice on involuntary hospital admissions of psychiatric patients: Suggestions from the EUNOMIA study", *European Psychiatry*, 26/4, 2011, section 3.3

¹⁹⁶ Potts H, *Participation And The Right To The Highest Attainable Standard Of Health* (Human Rights Centre, University of Essex 2008)

¹⁹⁷ 'Seventh Disability High Level Group Report On The Implementation Of The Un Convention On The Rights Of Persons With Disabilities' (2015) <available ec.europa.eu/social/BlobServlet?docId=14328&langId=en> see pages 110-113

PRO MENTE SANA ROMANDIE

Reply by Pro mente sana Romandie to the consultation on the draft Additional Protocol to the Convention on Human Rights and Biomedicine concerning the protection of persons with mental disorder with regard to involuntary placement and treatment

Introductory comment

Pro mente sana Romandie's opinion is based on the working document concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment. Our comments include the numbers of the articles and lines referred to. Proposed changes are underlined.

Article 2

Line 62 A measure must be regarded as involuntary not only when the person concerned objects to it but also when he or she does not consent to it. Persons subject to placement without their consent must also be protected by the Protocol. It should not be essential to object to a measure formally or within a certain deadline for it to be regarded as involuntary. It should be enough for the measure not to stem from the person's wish.

Proposal amend to: (...) who has not requested the measure him or herself or objects to it.

Lines 64 and 65 The definition of treatment must be expressly confined to inpatient treatment provided during placement. Compulsory outpatient treatment is a long-term infringement of a person's personality and cannot be compared to inpatient treatment, which will necessarily be limited to the time span of the placement. Pro mente sana Romandie objects to the legalisation of compulsory outpatient treatment, especially as Article 11 of the Draft Protocol does not expressly protect the rights of persons subjected to compulsory outpatient treatment.

Proposal add: "treatment" means an intervention (physical or psychological) on a person with mental disorder during placement, which has a therapeutic purpose in relation to that mental disorder;

Line 68 "Cure" is not an appropriate word in psychiatry because the aim of neither the placement nor of the treatment is to cure the patient. There is no scientific means of effecting the cure of mental disorders as they constantly evolve. It is preferable to talk of recovery.

"Rehabilitation" should not be the therapeutic purpose of involuntary placement or treatment as the use of this vague notion would make it possible to prolong placement indefinitely.

Proposal amend to: "therapeutic purpose" includes the management or medical treatment of a disorder.

Line 69 It must also be possible for the representative to be appointed by the person concerned if he or she is capable of discernment.

Proposal add: “representative” means a person provided for by law or appointed by the patient to represent his or her interests and take decisions on behalf of, a person who does not have, according to law, the capacity to consent.

Article 4

Lines 88/89 The text proposed goes beyond the criminal law, which does not allow anyone to be imprisoned for an offence they have not yet committed. The abstract protection of others must never be used as a reason to justify compulsory placement or treatment.

Proposal amend to: taking into account their health needs and the need to protect the life or physical integrity of others.

Article 9

Line 105 The Convention should express a clear view on whether establishments for the enforcement of sentences are appropriate. They should be expressly ruled out for the execution of civil measures.

Proposal add: Prison establishments are not appropriate.

Article 10

Line 111 The notion of a “significant risk of serious harm to his or her health” leaves too much scope for the wrongful confinement of persons who will not benefit from the support measure for want of being able to understand the therapeutic process in operation and consent to it. Negligence towards oneself can only warrant an authoritarian measure in the event of danger to life or physical integrity. Pro mente sana is in favour a narrow definition of health.

Proposal amend to: the person’s mental health condition represents a significant risk of serious harm to his or her life or physical integrity and his or her ability to decide on placement is severely impaired.

Line 113 See comment on lines 88/89: civil placement must not be used to prevent a crime or an offence.

The notion of a “significant risk of serious harm to others” leaves too much scope for the wrongful confinement of persons who will not benefit from the support measure for want of being able to understand the therapeutic process in operation and consent to it. Involuntary placement must not be justified by a risk of harm to others unless there is simultaneously a risk of serious harm for the persons concerned themselves. The subjective opinions of others should not be allowed to play too great a part in decisions to place patients. It is unacceptable to place a person because of behaviour prompting another person to think that they are running a risk, because there is no fundamental right not to be exposed to risk. Pro mente sana is in favour of a narrow definition of health.

Furthermore, it has to be questioned whether it is wise to protect irresponsible persons from criminal punishment by authorising preventive civil measures. Pro mente sana Romandie is against this idea. However, if this has to be the case, then the possibility of placing mentally ill persons should be restricted to cases where damage has occurred but criminal proceedings have been abandoned.

Proposal delete Article 10 i b or:

Amend Article 10 i b to: the person's mental health condition has caused physical harm to others.

Article 11 Same comments as for lines 111 to 113.

Pro mente sana refuses to accept the prescription of compulsory outpatient treatment outside criminal proceedings. The treatment referred to in Article 11 must only ever be inpatient treatment.

Proposal amend the title to: Criteria for involuntary inpatient treatment

Lines 121/122 There is no risk to others if persons are given medical care and kept secured within an appropriate environment. It would be unacceptable to force persons to undergo care on the ground that they pose a threat to the medical team treating them.

Proposal add: involuntary inpatient treatment may only be used for a limited time span and with the aim of restoring the person's discernment so that he or she can take a decision.

Article 12

Line 143 It is unwise to leave the decision on involuntary treatment to a single doctor. Past experience has shown that leaving patients in one-to-one discussions with doctors can give rise to inappropriate measures leading patients to their deaths. Only an emergency situation can justify such an arrangement.

Proposal add: Decisions on treatment made by doctors acting alone shall be subject to approval by a court within 24 hours.

Article 13

Line 151 On "to others", see the comments above on Article 10, lines 111 to 113, and Article 11.

Proposal amend to: because of the imminent risk of serious harm, either to the health of the individual concerned or to the life or physical integrity of others ...

Article 15

The draft Protocol takes no account of the role that close relatives can play in protecting patients' rights. This gap has to be filled. Furthermore, as placement can only be justified if the patient is undergoing severe

suffering, it should be possible for the often changeable circumstances on which the decision to deprive the person of their liberty is based to be reviewed by a court at any time.

Add a 4th paragraph worded as follows: The person concerned and his or her close relatives may request at any time that the measure be lifted.

Article 16

Lines 186/187 It should be possible to make an appeal “at any time”. The mental state of the persons concerned is changeable so they should be able to request that the lawfulness of the placement measure is checked as soon as they believe that it is no longer appropriate. Unless such a guarantee is established, there is a risk that persons will be kept in the establishment in which they have been placed by well-meaning doctors on the ground that continued treatment is desirable without, however, satisfying the criteria set out in Articles 10 and 11.

Proposal add: An appeal may also be made and a review requested by the person’s representative, where appropriate, by his or her close relatives and ...

Article 17

Line 205 Patients subject to placement must be given full information. The use of the word “appropriate” leaves room for interpretation making it possible not to provide patients and/or their close relatives with all the information needed for their rights to be protected.

Proposal amend to: Full information, adjusted to the persons’ mental status, about their rights in respect to ...

Line 207 Information concerning rights must also be given to close relatives and persons of trust.

Proposal add: their lawyers, their representatives, their persons of trust and, in so far as possible, their close relatives.

Line 209 See comment on line 207. Line 209 becomes superfluous.

Proposal Delete.

Article 18

Line 211 The right to communicate with a person of trust must not be restricted.

Proposal add: their lawyers, representatives, persons of trust ...

Line 214 The Protocol should take account of the role of close relatives in protecting the rights of persons subject to placement.

Proposal add: Their right to communicate with their person of trust, their close relatives and other persons ...

Article 19 It is important to provide that anonymised data are used to produce national statistics on the frequency and length of placements.

Transgender Europe

Summary

Being transgender or having a variety in gender expression is not a mental condition. Gender identity and gender expression must not be accepted as criteria for involuntary placement or treatment.

However, the International Classification of Diseases, which is currently being updated, still places the diagnosis of trans persons' identities as that of a mental disorder.

Therefore trans people suffer from forced pathologisation of their identities, even though they do not have a mental illness.

In Europe today, trans people's human rights and fundamental freedoms continue to be regularly violated by involuntarily placement and involuntary treatment in a psychiatric hospitals on basis of their gender identity. Trans people have to provide for an often unwanted and medically unnecessary mental health diagnostic process in order to access legal gender recognition procedures or necessary trans-related health care. Also, trans people are still admitted against their will to "cure" or "correct" their gender identity or expression.

Three specific aspects of the Draft Explanatory Report should therefore be amended to reflect the following:

Paragraph 9:

"Mental disorder" is defined broadly in accordance with internationally accepted medical standards.

The World Health Organization's International Statistical Classification of Diseases and Related Health Problems (ICD) is currently under review, and the new, 11th, version will be released in the coming years. The review foresees that mental health codes relating to gender identity in Chapter V are deleted.

The pathologisation of identities of transgender and gender variant persons in the current ICD version 10 is highly criticized by international human rights groups, including the Council of Europe Parliamentary Assembly (see Resolution 2048(2015) and the European Parliament (See Article 91 of the EP Resolution of 8 September 2015 on the situation of fundamental rights in the European Union (2013-2014)).

Following from the above we suggest the following changes (in bold) to the Explanatory Report:

9. "Mental disorder" is defined broadly in accordance with internationally accepted medical standards. **However, for the purpose of this Additional Protocol it does not include mental health diagnoses related to the gender identity of a person, such as Gender Identity Disorders (ICD-10 F64.x), F65.1 Fetish Transvestism, Disorder sexual maturation (F66.0), Ego-dystonic sexual orientation (F66.1), Disorder of sexual relationship (F66.2), Gender Dysphoria in DSM-5 or similar diagnoses.**

Paragraph 10:

“An example of an internationally accepted medical standard is that provided by Chapter V of the World Health Organization’s *International Statistical Classification of Diseases and Related Health Problems (ICD)*...”

As mentioned under Paragraph 9, the current ICD, which is under review, should not be used as a guideline for classification of mental disorders on issues pertaining to the gender identity of a person.

In the current ICD, Trans identities are still affected by a wide range of ICD-codes, such as Transsexualism (F 64.0), Gender Identity of Childhood (F 64.2), Other Gender Identity Disorders (F 64.8), Gender Identity Disorder, unspecified (F 64.9), Fetishistic Transvestism (F 65.1) or Dual – Role Transvestism (F 64.1). These diagnoses have been criticized by human rights activists as stigmatizing and actively pushing for social exclusion of trans people, while not adding to their physical or mental well-being. Sweden, Norway and Finland removed Dual-role transvestism (F.64-1), Fetishism (F.65.0), Fetishistic transvestism (F65.1) and Multiple disorders of sexual preference (F65.6) from their national catalogues for a lack of therapeutic value.

As mentioned under Paragraph 9, the ICD is under review and the proposed new version will delete mental health codes related to gender identity.

Following from the above we suggest the following changes (in bold) to the Explanatory Report:

10. An example of an internationally accepted medical standard is that provided by Chapter V of the World Health Organization’s *International Statistical Classification of Diseases and Related Health Problems*, which concerns *Mental and Behavioural Disorders (ICD-10)* **except for diagnoses relating to the gender identity of a person, such as F64.x, F65.1, F66.0, F66.1 or F66.2.** This method of defining mental disorder aims to prevent idiosyncratic approaches to diagnosis. It also follows the jurisprudence of the European Court of Human Rights, for example in its judgement in the *Winterwerp* case, that: "... Article 5.1e [of the European Convention on Human Rights] obviously cannot be taken as permitting the detention of a person simply because his views or behaviour deviate from the norms prevailing in a particular society."

Chapter III Article 10, Criteria for Involuntary Placement:

Trans and gender variant people, as a group, should be explicitly excluded from meeting the criteria for involuntary placement. Gender identity must not be used as justification of involuntary placement or treatment.

In the text which follows, please find background material to substantiate these references.

Following from the above we suggest the following changes (in bold) to the Explanatory Report:

Article 10 – Criteria for involuntary placement

50. This Article stipulates that a person with a mental disorder may be subject to involuntary placement only under certain circumstances: when the person’s mental health condition represents a significant risk of serious harm to the person himself/herself or to a third party, when the placement has a therapeutic purpose, and when no less restrictive means of

addressing the risk are available. Involuntary placement is in general only considered appropriate with regard to certain types of mental disorder, for example psychoses or other severe mental disorders. **In no case should personal characteristics of a person, such as gender identity, be an eligible criterion for involuntarily placement. Also, administrative requirements stemming from legal gender recognition procedures or trans-specific health care protocols must not result in involuntarily placement. [...]**

Chapter III Article 11, Criteria for Involuntary Treatment:

As suggested by paragraph 61 of the Explanatory Report the above changes would apply similarly to involuntarily treatment.

Background

Involuntary psychiatric treatment in Legal Gender Recognition procedures

In many European countries access to change of documents (legal gender recognition) depends on a mental health diagnosis, such as Gender Identity Disorder (F. 64.0). Independent of an individual's need for therapy legal instruction might force them undergo therapy.

Procedure	Country	Explicit requirement		Implicit requirement	
		Diagnosis (X)	Therapy (O)	Diagnosis (X)	Therapy(O)
Legal regulation	Austria		*		
	Azerbaijan	n/a	n/a	n/a	n/a
	Belgium				
	Bulgaria		n/a		n/a
	Croatia		n/a		n/a
	Czech Rep.				
	Denmark				
	Estonia				
	Finland				
	France				
	Germany				
	Greece	n/a	n/a	n/a	n/a
	Iceland				
	Italy				
	Ireland				
	Latvia				

	Lithuania				
	Luxembourg				
	Malta				
	Moldova				
	Montenegro				
	Netherlands				
	Norway				
	Poland				
	Portugal				
	Romania				
	Russia ¹⁹⁸				
	Slovakia				
	Spain				
	Slovenia				
	Sweden ¹⁹⁹				
	Switzerland				
	Turkey				
	UK				
	Ukraine				
No legal measure, but procedures in practice	Cyprus				
	Georgia				
	Hungary				
	Serbia				
No legal gender recognition	Albania, Andorra, Armenia, Bosnia-Herzegovina, Kosovo, Liechtenstein, Macedonia, Monaco, San Marino				

Key

198 The national law refers to an inexistent official form which leads to intransparent and inconsistent proceedings.

199 Current practice was changed by an administrative court (Stockholm) judgement (16th of May 2014); psychiatric diagnosis cannot be mandatory for obtaining legal gender recognition

- = required
- = required due to interpretation of law
- = needed to undergo sterilization/ hormone therapy/ other gender reassignment measures
- = likely to be needed to undergo sterilization/ hormone therapy/ other gender reassignment measures
- = likely to be needed to get a diagnosis
- * = recommended by institution
- n/a = data not available

Forced Sterilisation

It is still the case that 23 states in Europe require by law the trans people undergo sterilisation before their gender identity is recognized. This is a clear violation of their human rights and unacceptable form of state-sanctioned involuntarily treatment.

Access to Trans-specific Care

Coverage of costs for gender reassignment treatment hinges on obtaining a GID diagnosis or equivalent.

The 'mental disorder' label reinforces psychopathologisation driving stigma, making prejudice and discrimination more likely, and rendering trans people more vulnerable to social and legal marginalisation and exclusion. The mental health diagnosis thus contributes to increased risks of deteriorated mental and physical well-being. 63% of trans respondents to a German quantitative study felt that the GID diagnosis is a source of significant distress for them. In view of the revision process of the ICD-10 (WHO) a group of international transgender health experts has been developing different alternative models, to facilitate access to healthcare coverage without stigmatizing diagnoses. The global campaign Stop Trans Pathologisation - STP 2012 demands the removal of the categories of "gender dysphoria" / "gender identity disorders". The World Professionals Association of Transgender Health – WPATH has called for the depsychopathologisation of gender variance and urges "governmental and medical professional organizations to review their policies and practices to eliminate stigma toward gender-variant people".

Involuntarily placement as part of Legal Gender Recognition

In some countries trans people are still exposed to involuntarily placement as they need to provide such a mandatory mental health diagnosis.

For instance, Order No 60 of the Ukrainian Ministry of Health foresees that a person is institutionalised for 30 – 45 days as a pre-condition for establishing a trans-specific mental health diagnosis. This diagnosis is mandatory for accessing trans related health care and legal gender recognition. Those trans people who do not undergo the institutionalisation are not recommended by the relevant medical commission to obtain access to gender reassignment treatment and ID documents that correspond with their gender identity.

Ukrainian NGO *Insight* documented in its report *Documentation of cases of discrimination in the field of access to health in the process of gender recognition procedure in Ukraine* (2015) from page 62 onwards the discriminatory practices and institutional limitations trans persons experienced during the mandatory hospitalisation, such as:

- Dehumanizing medical procedures
- Placement in ward not corresponding to the individual's gender identity
- Disrespect for the person's preferred name/pronoun
- Prohibition to use a restroom according to gender identity; non-secured restrooms
- Prohibition to use personal belongings, technical and communicational devices
- Limitation of freedom of movement

- Misdiagnosing and/or unlawful involvement of the third party, namely, parents

Being transgender as reason for committing to a psychiatric institution

French initiative group *STS - Support Transgenre Strasbourg* highlight that as being trans is still considered a mental diagnosis in France, a third party can have the right to commit a trans person against their will to a psychiatric institution.

“Conversion” therapies and admission by parents/ family members

TGEU has anecdotal evidence of cases when parents, partner or other family members commit a trans person against their will to a psychiatric institution to “cure” their gender identity or to socially isolate them.

In a particular violent case, a young Kazakh trans woman was first brutally physically and verbally assaulted by her family. In an attempt to socially isolate her they locked her up and brought her against her will to a psychiatric clinic:

“...in the morning they all came back, and began to address the question of how to close and isolate me in a mental hospital, I was not given breakfast. Then they took me, battered, in a terrible state in a psychiatric clinic. I begged them to let me go, but no one listened to me, I continued to listen insults in my address. They told that I'm crazy, mentally ill, does not deserve to live in this society that they want to isolate me no one has ever seen.” (trans woman, 22, Kazakhstan)

Source: Human Health Institute, Astana

Mental health practitioners have a special responsibility to act ethically and ensure that no one is held against their will because of their gender identity in a psychiatric institution. Practitioners in mental institutions should particularly refuse to engage in involuntary placements if these are required for other reasons, such as legal gender recognition or access to trans-specific care.

UN Special Rapporteur on Health Dainius Pūras recently critiqued in an interview on the psychopathologisation of variances in gender identities and expression that medicalization of diversities may lead to grave human rights violations: “It is absolutely unacceptable that in the 21th century we are witnesses of such harmful practices [Conversion therapies] that have no scientific grounds and further violate human rights.”²⁰⁰

About the submitting organisation

Transgender Europe - TGEU is a European human rights NGO working for the human rights and equality of all trans people with member organisations in 42 countries in Europe and beyond. TGEU is registered as a charity under German law.

Governments have sought after TGEU’s competence in regard to trans specific health care across the continent. TGEU regularly consults European institutions, such as the European Parliament, the European Commission and the Council of Europe’s Commissioner for Human Rights. More Information can be found at www.tgeu.org

We are available for further comment:

200 Interview with Dainius Pūras, October 2015, UN Special Rapporteur on the Highest on the right of everyone the highest attainable standard of health. Available at:

<http://wp.me/a1djE5-aq>

Annex: Documentation of cases of discrimination in the field of access to health in the process of gender recognition procedure in Ukraine

OTHERS

Edmund Schönenberger



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ⁱ See also, Human Rights Committee General Comment no. 35, para. 18: "The individuals must be assisted in obtaining access to effective remedies for the vindication of their rights, including initial and periodic judicial review of the lawfulness of the detention, and to prevent conditions of detention incompatible with the Covenant." Oxford Pro Bono Public study: In regard to preventive detention proceedings, there is a very strong trend toward guaranteeing the right to be heard and to legal representation (p. 97). Further, there is a significant trend in the practice of States toward guaranteeing the right to information and to legal representation to a person with a mental illness during detention proceedings (p. 99).

ⁱⁱ Committee on the Rights of Persons with Disabilities, General Comment No. 1, para. 17: "Support" is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication. Support to persons with disabilities in the exercise of their legal capacity might include measures relating to universal design and accessibility. Support can also constitute the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences.

ⁱⁱⁱ Committee on the Rights of Persons with Disabilities, General Comment No. 2, para. 37

^{iv} Committee on the Rights of Persons with Disabilities, General Comment No. 2, para. 20.

^v HRC General Comment no. 35, para. 19: "States parties should make available adequate community-based or alternative social care services for persons with psychosocial disabilities, in order to provide less restrictive alternatives to confinement".

^{vi} This includes deprivation of liberty based on disability or perceived disability, particularly on the basis of psychosocial or intellectual disability or perceived psychosocial or intellectual disability.

vii

Endnotes:

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x "Does your child really have a behaviour disorder? A shocking book by a leading therapist reveals how millions of us – including children – are wrongly labeled with psychiatric problems," *Daily Mail*, 6 May 2013, <http://www.dailymail.co.uk/health/article-2320493/Does-child-really-behaviour-disorder-A-shocking-book-leading-therapist-reveals-millions--including-children--wrongly-labelled-psychiatric-problems.html#ixzz2SciDb8UA>

xi Allen Frances, "Does DSM-5 Have a Captive Audience?" *Huffington Post*, 4/14/2013, http://www.huffingtonpost.com/allen-frances/does-dsm-5-have-a-captive_b_3080553.html

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- xii Thomas Insel, "Transforming Diagnosis," NIMH Website, 20 Apr. 2013, <http://www.nimh.nih.gov/about/director/2013/transforming-diagnosis.shtml>
- xiii "Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez," UN Human Rights Council, 1 Feb. 2013, Twenty-second session, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf
- xiv** "Study finds young people on antidepressants more prone to violence," Reuters, 15 Sept. 2015, <http://www.reuters.com/article/2015/09/15/us-health-antidepressants-crime-idUSKCN0RF2BB20150915>
- xv Thomas J. Moore, Joseph Glenmullen, Curt D. Furber, "Prescription Drugs Associated with Reports of Violence Towards Others," Public Library of Science ONE, Vol. 5, Iss. 12, Dec. 2010, <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0015337>
- xvi Matthew M. Large, Christopher J. Ryan, "Disturbing findings about the risk of suicide and psychiatric hospitals," Soc. Psychiatry Psychiatr Epidemiology (2014), 49: 1353-1355.
- xvii Paul Andrews, "Things Your Doctor Should Tell You About Antidepressants," Mad in America: Science, Psychiatry and Community, 12 Sept. 2012, <http://www.madinamerica.com/2012/09/things-your-doctor-should-tell-you-about-antidepressants/>
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- xix Per Maegaard Poulsen, *Tvang i psykiatrien*. 1997.