

HEALTH CARE DECISIONS IN SOCIAL CARE **SETTINGS: GENERAL REGULATION AND** INTERPRETATION IN CPT'S JURISPRUDENCE

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Abstract The Committee for the Prevention of Torture and Inhuman Treatment is a body of the Council of Europe that organises visits to places of detention such as social care homes in order to assess how persons deprived of their liberty are treated. This means that in practice people are not free to leave the institution and are therefore de facto deprived of liberty. In such situations, people with disabilities are particularly vulnerable and have limited capacity to make decisions about medical treatment and care. As the number of such persons increases, and in order to ensure protection under international law, the results of the empirical study indicate the need to provide immediate assistance to residents in safeguarding their rights to self-determination or private autonomy and legal interests in making health care decisions in social care settings. For example, involving the resident in consenting to treatment or establishing a decision-making assessment procedure.

Keywords

decision making capacity, legal capacity, CPT. informed consent, people with disabilities



1 Introduction

Residents in social care settings make a range of decisions on a daily basis. First, there are decisions regarding the placement of a person in this type of institution, day-to-day decisions related to their care, as well as decisions about medical treatment. Notably, decisions in social care. Health related decisions within the scope of this article should be distinguished from decisions on placement in social care homes, as well as other decisions such as the right to contact with others, the right to a fair trial, including the right to a lawyer and the right to appeal against decisions taken in relation to the person.

Social care establishments are not typical heath care institutions. Therefore, decision-making in social care is unequivocally distinct from decision-making in healthcare, at least in its classical concept. However, health care, alongside personal and support services, is provided in long-term social care institutions; principally in relation to decisions concerning treatment and general healthcare. Therefore, residents in social care settings must be given the opportunity to make their own decisions about themselves and their bodies, i.e., to accept as well as to refuse care, treatment or other decisions in social care. This article will focus on health care decision-making in social care settings.

Undoubtedly, people with learning disabilities and/or chronic mental disorders (such as schizophrenia), children, adolescents or elderly with dementia (including those suffering from schizophrenia)¹ can be cared for in social care institutions. Such persons with impaired decision-making will be limited in their abilities, so they may not be able to consent. Consequently, they are vulnerable to having their rights and legal interests compromised.

In circumstances where a person's capacity to decide is limited, it is necessary to ascertain whether such a person is guaranteed protection under the general legal principle of self-determination or private autonomy. Specifically, it also must be established whether the rights to information, to self-determination and to make autonomous decisions, both with regard to placement in care homes and to medical

¹ Council of Europe. European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT). Factsheet. *Persons deprived of their liberty in social care establishments*. Retrieved June 21, 2022, from https://rm.coe.int/1680a0cc19

decisions, as essential prerequisites of the internationally and nationally established principle of informed consent, are guaranteed to these persons in social care homes. In turn, in circumstances where persons lack the capacity to decide and are found to have limited capacity, it must be determined whether the necessary legal protection of the health and safety of all persons deprived of their liberty in such settings is guaranteed. Therefore, the aim of this article is to explore how limited capacity is addressed in assessments of the Committee for the Prevention of Torture and Inhuman Treatment (hereinafter-CPT) and its recommendations to the Council of Europe (hereinafter - CoE) Member States in the context of the reports carried out in the EU Member States.

Legal research was done using the normative legal research methods. In doctrinal legal research, documentary materials such as case law and policy documents were reviewed. Empirical *legal* research for the study involved collecting and reviewing publicly accessible CPT reports and documents pertaining to social care settings. The study also included collecting and analysing data regarding adult capacity and incapacity from the CPT's reports and documents published in social care settings since 2012. Altogether, 267² CPT's visit reports and 9³ CPT's annual reports were collected and analysed.

After a systematic selection of the reports, the information was collected, extracting the needed information from the text of CPT's annual and visit reports. The text was interpreted and organized into categories. The identified topics in relation to the residents' legal capacity and decision-making capacity as prerequisites for informed consent, including the legal safeguards relating to informed consent, were studied in depth, assessed and obtained. The scope of this article will not cover topics such as ill-treatment, residents' living conditions, staff and means of restraint.

² Human Rights Documentation. European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT). Retrieved June 24, 2022, from

 $https://hudoc.cpt.coe.int/eng\#\{\%22sort\%22:[\%22CPTDocumentDate\%20Descending,CPTDocumentID\%20Ascending,CPTSectionNumber\%20Ascending\%22], \%22CPTDocumentType\%22:[\%22vr\%22], \%22CPTPersons\%22:[\%22psz\%22], \%22CPTPlaces\%22:[\%22psz\%22], \%22CPTPublicationDate\%22:[\%222012-08-17T00:00:00.0Z\%22, \%22022-08-17T00:00:00.0Z\%22]\}$

³ Council of Europe. *Annual Reports*. Retrieved June 24, 2022, from https://www.coe.int/en/web/cpt/annual-reports

The study concludes that the informed consent, consent to treatment and legal capacity are addressed in CPT's jurisprudence regularly. However, decisional capacity for social care decisions is rarely addressed. The CPT strongly supports the informed consent principle without scrutinizing capacity as the ability to make health care decisions in social care settings. The study provides us with knowledge allowing us to develop recommendations embracing human rights as an integral part of providing patient-centred, systemic, and value-based social care in line with the international legal framework.

2 Role of the Committee for the Prevention of Torture and Inhuman Treatment (CPT) in protection of people in social care institutions – overview

The CPT is an international body, composed of one independent expert per Member State, charged with visiting places of detention such as prisons, juvenile detention centres, police stations, holding centres for immigration detainees, psychiatric hospitals, social care homes, etc., in contracting states in which persons are deprived of their liberty by a public authority. The CPT was created in November 1989, in accordance with Article 1 of the European Torture Convention. Its role is to "examine the treatment of persons deprived of their liberty with a view to strengthening, if necessary, protection of such persons from torture and from inhuman or degrading treatment or punishment".4 The CPT carries out periodic visits to places of detention in the territory of the States Parties. It can also organize other ad hoc or surprise visits if the circumstances seem to warrant them (ibid, Article 7). As of September 2020, the CPT has carried out more than 450 visits to places where people are deprived of their liberty across Europe and has published over 400 visit reports (O'Connell, Aizpurua & Rogan, 2021). The work of the CPT is only made possible due to the commitment of members of the Committee, Secretariat colleagues, experts and interpreters who assist the Committee during visits.⁵ During the visits, the CPT delegation conducts a series of private interviews with the detainees, taking the necessary notes.

⁴ European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, Article 1.

⁵ European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT).
31st General Report of the CPT. Retrieved July 13, 2022, from https://rm.coe.int/1680a63c72

Following every visit, CPT draws up a confidential report on its findings. After each visit, the CPT sends a detailed report to the State concerned. This report includes the CPT's findings, and its recommendations, comments, and requests for information. Moreover, the Committee's job respecting the scope of its recommendations to the State Parties, is to detect the issues and spell out the measures required to ensure the full compliance with Article 3 of the European Convention on Human Rights.⁶ The CPT also requests a detailed response to the issues raised in its report. These reports and responses form part of the ongoing dialogue with the States concerned. Therefore, CPT, like every monitoring body of the CoE, aims to prevent human rights violations. It adds recommendations for further action to the report, which is then forwarded to the member State in question, together with the request to submit a detailed response. Although the recommendations have no mandatory force on States, in accordance with Article 10 of the Convention, if the State "fails to cooperate or refuses to improve the situation in the light of the Committee's recommendations," the Committee may decide to make a public statement on the matter.8 In accordance with what was previously said, the public statement is aimed at motivating and assisting the national authorities in order for them to take decisive action in line with the fundamental values.

For example, public statements in social care settings can be linked to both the issue of deliberate physical ill-treatment of social care residents, appalling levels of hygiene, deplorable shortages of staff, the use of seclusion and mechanical restraint, as well as the lack of progress with de-institutionalisation in social care. The CPT mandate covers both public and private social care establishments.

This article will focus on the reports and findings on social care homes and the conclusions expressed by the Committee during its visits to each Member State, examining the decision-making capacity to treatment, social care and legal safeguards offered to residents in social care institutions. Firstly, the law of informed consent rights in social care institutions will be discussed.

https://www.coe.int/en/web/cpt/about-the-cpt

8 European Convention for the Prevention of Torture and In

⁶ Ibid, 29th General Report of the CPT. Retrieved July 13, 2022, from https://rm.coe.int/16809e80e1

⁷ Council of Europe. *About the CPT*. Retrieved July 14, 2022, from

 $^{^8}$ European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, Article 10.

3 Informed consent rights in social care institutions in general

Prior to examining the CPT's practice regarding the institution of informed consent in social care, it is necessary to answer the question regarding what should be understood by the concept of consent in general.

According to medical geneticist Polani, consent means agreement or approval, especially of something done or initiated by someone else. It implies capable, conscious assent or consent to an action or purpose, and denotes physical and mental strength (Habiba, 2000). The Oxford Dictionary, on the other hand, defines consent as "permission for something to happen or to be done" (Habiba, 2000). Refusal of medical treatment, on the other hand, would be considered a unilateral act and deriving from the Latin word "refundere", meaning "to give back or to pour over" (Ridley, 2001).

In-depth research into the meaning of informed consent and its ethical implications in medicine, research, law and philosophy only began around 1972 (Beauchamp, 2011). It was not until the end of the 20th century that the concept emerged in health law. The concept of informed consent only at the end of the 20th century encompassed three components or elements: 1) providing information about the nature and purpose of the proposed treatment or procedure, its potential benefits and risks, as well as the available alternatives (Grisso & Appelbaum, 1998); 2) providing information in a way that allows for a voluntary choice; 3) the decision is made by someone, who has the capacity to make the decision. In circumstances where any of the above elements are deficient, any consent to treatment is deemed not to have been legally valid (Grisso & Appelbaum, 1998).

The concept of informed consent is a well-established principle of law in international law. It is first and foremost enshrined in the Convention of Biomedicine.⁹ Article 5 of the Biomedicine Convention sets forth the requirement of obtaining free and informed consent. Article 5(1) of the Convention emphasizes consent to medical treatment as a well-established international rule, i.e., that in principle no person may be forced to undergo medical treatment without consent.

⁹ Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine.

Therefore, every person must be able to freely consent to and refuse any medical treatment in which they are involved (ibid, Article 5(1)). The Explanatory Report to the Convention indicates that in the discussion during the drafting of the treaty consent was envisaged as an informed, voluntary and competent act. 10

As stated in Article 5(2)¹¹ of the Convention, for a person to be able to give free and informed consent to medical treatment, the person must have received adequate prior information about the purpose and nature of the act, as well as about its consequences and risks. For consent to be valid, the persons concerned must be informed of the essential facts relating to the planned intervention.

While Article 5(2) of the Convention lists the most important aspects of information prior to a medical intervention, the enumerated factors should not be regarded as an exhaustive list, as informed consent may, depending on the circumstances, contain additional elements. The information should include the purpose, nature and consequences of the intervention and the risks involved. Information on the risks or alternatives associated with the intervention should include not only the risks specific to the type of intervention, but also any risks related to the individual characteristics of each patient, such as age or the presence of other pathologies. In addition, requests for additional information from patients should be listened to appropriately.

The importance of informed consent in protecting persons' rights is also highlighted by the European Court of Human Rights (hereinafter - ECtHR). The ECtHR has repeatedly referred to the Oviedo Convention in its judgments, in particular on the application of Articles 2 and 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms. 12 As the ECtHR has emphasised in one of its judgments, namely Botoyan v. Armenia¹³, it is important for individuals who face risks to their health to have access to information that would enable them to assess those risks. Personal inviolability of the individual, his/her physical, moral

11 Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application

of Biology and Medicine: Convention on Human Rights and Biomedicine, Article 5(2).

¹⁰ Secretary General of the Council of Europe. Explanatory Report to the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine, paras 34-35.

¹² Judgment of the ECtHR of 5 June 2015 in Case of Lambert and Others v. France, para 59; Judgment of 8 November 2011, in Case V.C. v. Slovakia, paras 76-77, 108, 115 and 152; Judgment of 8 July 2004, in Case Vov. France, para. 35; Judgment of 10 April 2007, Evans v. the United Kingdom, para. 50., et.al.

¹³ Judgment of the ECtHR of 8 February 2022 in Case of Botoyan v. Armenia, para 93.

and psychological integrity, and personal autonomy are the inherent elements of the rights enshrined in the Convention. Private autonomy is the principle of selfdetermination of legal relationships by the will of the individual (Flume, 1992). In the sphere of medical assistance, this principle is embodied, inter alia, in the requirement to obtain consent of a person to any, even minimal, medical intervention. 14 Such an assessment can be burdensome in the absence of a common procedure, as will be argued in chapter 5.1. of this article.

Thus, as established in the legislation, informed consent is recognised as a prerequisite before treatment can be undertaken, unless an exception is provided for in the law. Medical intervention without consent is an extreme measure that should be taken only if a less intrusive alternative is not available. In circumstances where treatment has been carried out without the person's consent, it must be regarded as a violation of the patient's physical integrity, which is permissible from a human rights perspective only if carried out in accordance with the national law. The next chapter will assess and examine the CPT committee's implementation of this legal institute in its reports.

4 Informed consent rights in social care institutions in CPT's reports

Clearly, the CPT strongly supports the principle of informed consent. The CPT in its reports underlines that informed consent is seen as a fundamental principle such that all residents should be provided the opportunity to give their free and informed consent to treatment. Any derogation from this fundamental principle should be based upon law and only relate to clearly and strictly defined exceptional circumstances. 15 Under the following conditions, it is necessary to limit and prevent any situations in which the consent to treatment is being denied for any residents who had been deprived of their legal capacity. 16 This is due to the fact that not all decisions require a person to have certain capacities. In particular, if a person's legal capacity is limited by a judgment that has entered into force, this does not mean a priori that the person is incapable of giving informed consent in social care, and vice

¹⁶ Russian Federation: Visit 2018, para 123.

¹⁴ Judgment of the ECtHR of 22 July 2003 in Case of Y.F. v. Turkey, para 33.

¹⁵ Hungary: Visit 2018, para 153; Azerbaijan: Visit 2013, 56.

The medical staff assumed that informed consent to was not required for any of the residents who had been deprived of their legal capacity. In accordance with that, the treatments were prescribed, with little or no information provided to the resident.

versa. No one should be automatically deprived of these rights because of an impairment or disability, or due to being subjected to guardianship.¹⁷ This interpretation is consistent with the previously discussed understanding of the CRPD Convention and the resulting and internationally fundamental principles of protection of individuals, and in this context, also for residents. *Moreover, the* restriction of a person's rights should not be based solely on the fact that the person has a mental disorder and is placed in a closed institution. The deprivation of legal capacity should require additional grounds and a separate procedure.¹⁸ In the light of the CPT reports, the deprivation of legal capacity procedures should be strengthened in favour of the person concerned.¹⁹ In addition, it is necessary to ensure that all decisions on deprivation of legal capacity are subjected to a regular court review and can be challenged by the person concerned.²⁰

It should be stressed here, however, that the resident's consent should, in the CPT's view, be distinguished from consent to treatment and consent to admission.²¹ It considers that consent to admission or stay and consent to treatment are two distinct issues and residents should be requested to express their position on both of these issues separately. Therefore, even in circumstances where residents wish to leave the social care establishment, i.e., those who did not wish to stay there, such rights must be ensured. Otherwise, it may be held that residents were *de facto* deprived of their liberty, without benefiting from any legal safeguards.²²

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¹⁷ Council of Europe. Commissioner for Human Rights. Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities. Retrieved July 25, 2022, from https://rm.coe.int/16806da5c0

¹⁸ Bosnia and Herzegovina: Visit 2011, para 127.

¹⁹ Serbia: Visit 2021, executive summary.

²⁰ Serbia: Visit 2021, para 174; Serbia: Visit 2015, executive summary; Serbia: Visit 2015, para 204, 205; Azerbaijan: Visit 2013, para 66.

²¹ Cyprus: Visit 2017, para 150.

Within this visit report, residents in Cyprus social care homes were asked to sign an admission agreement. By signing the agreement, the resident explicitly and generally consented to all medication prescribed. The delegation was informed that in circumstances where the residents refused their medication, the permit to leave the establishment could be withdrawn.

²² Ukraine: Visit 2019, para 41; Moldova: Visit 2020, paras 182, 185; Bosnia and Herzegovina: Visit 2019, executive summary; Bosnia and Herzegovina: Visit 2019, paras 168, 169; Hungary: Visit 2018, paras 151, 152; Lithuania: Visit 2016, para 121. A violation of such a right has also been established by physically preventing a resident from leaving a social care establishment by locking the exit door with a key code. From: Liechtenstein: Visit 2016, executive summary.

The CPT recommends that the practice of linking the requirement to take medication with consent to admission and stay by means of the admission contract should be reviewed.²³ Therefore, CPT recommends that a person should not be able to give consent for both medication and admission by signing a single consent form, which is still a common practice and exists in several Member States, including Latvia. It can be recognised that the resident's expression of will is the most important thing that is being considered. As to the form in which such consent should be given in either case, the CPT has not reached any specific conclusions as regards social care homes.

In order to ensure that such rights are guaranteed for residents, it is necessary to guarantee their rights to information. The right to information requires that the resident's expression of will is a fundamental prerequisite for the undertaking of medical care. Without a freely given expression of will, which is necessary for the assessment of decision-making capacity for informed consent to medical treatment, practitioners would not be entitled to take any action in the course of medical treatment.

The CPT reiterates its recommendation that all residents (and, if they are incompetent, their legal representatives) be provided systematically with information about their condition and the treatment prescribed for them, and that doctors be instructed that they should always seek the resident's informed consent to treatment prior to its commencement.²⁴ This could be done by means of a special form for informed consent to treatment, signed by the resident or (if he/she is incompetent) by his/her legal representative. Relevant information should also be provided to residents (and their legal representatives) during and following treatment.²⁵ It is therefore particularly relevant to keep the patient properly informed, since the burden of responsibility may fall on the doctor if the patient was unaware of a certain matter. However, the informed consent forms provided in some of the visited homes did not always describe all of the detained persons' rights to their full extent. Accordingly, the practice of including the resident's right to information only in written form, without providing additional information and without allowing the resident to be heard, is not permissible. Such practices must not be tolerated. A mere

²³ Ibid

²⁴ Ukraine: Visit 2019, executive summary; ibid, para 42.

²⁵Azerbaijan: Visit 2013, para 56; Ukraine: Visit 2019, para 42; Azerbaijan: Visit 2011, para 138.

signature on the form issued cannot, standing alone, confirm that informed consent has actually been given. This is indeed illustrated by the ECHR's Chatterrton v Gerson judgment, which held that a signature, for example on an informed consent form, does not in itself confirm that a person has duly consented to medical treatment (Bell, 2013, p. 103).²⁶

In addition, it is important to consider how this information is disclosed to persons. This is particularly important for people with communication and cognitive²⁷ impairments. It is relatively common for extremely low communication skills to be associated with a lack of ability. Although many residents have comprehension and communication difficulties, whenever possible, they should be informed of their rights, if necessary, using repeated, simplified, individualised, verbal formats.²⁸ As indicated in one of the reports, good practice should include the identification of a person, independent of the establishment, who will effectively ensure the process of granting consent and defend the interests of the resident.²⁹ The following arrangements will support and shift the process towards community-based care and independent living for social care home residents.³⁰

Appropriate information tailored to a specific group of persons can not only help to improve the quality of decision-making for those who are able to give such consent but also strengthen decision-making capacities in general, thereby crossing the threshold of capacity to give consent themselves, as well as involving persons with limited decision-making power more closely in decision-making where acceptable measures are specifically relevant to them. Furthermore, the provision of relevant information tailored to the individual patient provides the capacity assessor with a

²⁶ Court's judgment highlights the need to look beyond the signature on the form. In particular, all aspects must be considered cumulatively, as well as whether the person has given valid consent. The judgment further concludes that once the patient has been widely informed of the nature of the procedure envisaged and has given his consent, it must be accepted that the consent was valid. This of course leads to the next issue of the difficulty of proving what the person has actually expressed to the practitioners.

²⁷ Cognitive impairment is defined as a disorder that significantly impairs an individual's cognitive function to the point where normal functioning in society is impossible without treatment. Se: Dhakal & Bobrin, 2022. Cognitive impairment is the impairment in memory, decision-making and comprehension that predominates in people with age-related dementia or delirium.

²⁸ Kosovo: Visit 2020, para 176; Bulgaria: Visit 2020, para 83.

²⁹ Russian Federation: Visit 2018, para 121. The report stated that residents were not aware of the name of the medication taken, nor of their possible side effects.

³⁰ European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT).
30st General Report of the CPT. Retrieved July 13, 2022, from https://rm.coe.int/1680a25e6b

credible basis to be able to assess the patient's inability to consent in each case.³¹ To this effect, an information brochure, setting out the establishment's routine and residents' rights – including information on legal assistance, review of placement (and the resident's right to challenge this), and complaints procedures should be drawn up and issued to all residents on admission, as well as to their families. Residents unable to understand this brochure should receive appropriate assistance.³² This again ties in with the provision of rights information to residents in social care.

The communication framework between residents and care givers was particularly important during the pandemic. In this time of pandemic transition, when the absolute prerequisite of informed consent can be seen as burdensome and resourceconsuming, this not only guarantees the right to information, but also reduces the growing number of health care negligence cases. This not only protects the rights of the residents, but also of healthcare professionals when providing healthcare services in a way that avoids liability. It is no coincidence that the World Health Organisation has also acknowledged the decade 2020-2030 as the decade of patient safety. Moreover, the pandemic has shown the importance of patient safety as well as protecting the well-being of all healthcare workers, as demonstrated by the WHO's World Patient Safety Day in 2020 (O'Brien, Durkin & Lachman, 2021). Concerns have also been raised about the impact of the pandemic on the human rights of residents with impaired mental capacity (Kuylen et al., 2022). On March 20, 2022, the CPT issued a statement and reminded all actors of the absolute nature of the prohibition of torture and inhuman or degrading treatment of persons deprived of their liberty in the context of the pandemic, 33 even in circumstances where countries have been forced to adopt and implement more restrictive Covid-19 measures. There is no standardized information on the way care homes have managed the competing risks of protecting these vulnerable residents' overall health and wellbeing, while also protecting them and the whole care community against COVID-19 (Liu et al., 2021).

³¹ Deutsches Ärzteblatt. Hinweise und Empfehlungen der Bundesärztekammer zum Umgang mit Zweifeln an der Einwilligungsfähigkeit bei erwachsenen Patienten. Retrieved July 29, 2022, from

https://www.aerzteblatt.de/archiv/208054/Hinweise-und-Empfehlungen-der-Bundesaerztekammer-zum-der-Bu

Umgang-mit-Zweifeln-an-der-Einwilligungsfaehigkeit-bei-erwachsenen-Patienten

³² Kosovo: Visit 2020, para 176; Serbia: Visit 2021, para 175; Armenia: Visit 2019, para 104; Bosnia and Herzegovina: Visit 2019, para 171.

³³ European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT).
30st General Report of the CPT. Retrieved July 13, 2022, from https://mm.coe.int/1680a25e6b

Alongside the right to consent to medical treatment, including the right to information, it is noteworthy that, unlike patients in psychiatric settings³⁴, where the CPT's opinions imply a right to withdraw patient's consent at any time as an essential cornerstone of informed consent, there are no direct references to social care settings in this respect. As has been found previously in several reports from psychiatric establishments, it is essential that all patients who have given their consent to treatment are continuously in a position to withdraw their consent at any time.³⁵

Notwithstanding the above, there have been no such references in the social establishment parts of the reports obtained. Indirectly, however, it is acknowledged that there may be circumstances where residents may refuse medical treatment. Accordingly, in any case where a resident does not agree with treatment proposed by the establishment's doctors, it is required to provide a second psychiatric opinion (i.e., from a psychiatrist not involved in the treatment of the resident concerned). This applies even if the guardian consents to the treatment. The above, however, points to the possibility and right of residents to disagree with the treatment offered. It has been further stated, that residents should be able to challenge a compulsory treatment decision (or the consent provided by the guardian) before an independent outside authority and should be informed in writing of this right. During this visit, the delegation raised concerns about whether social care is provided on the basis of patients' self-determination and free consent. Such doubts were raised because the delegation was informed that the doctor may withdraw the authorisation for the resident to leave the establishment if the residents refused the medication.

In the light of the above, it can be seen that, in circumstances where residents enjoy the right to informed consent to medical treatment, it does not follow from the CPT reports that residents also have a guaranteed right to withdraw their previously given consent. On the contrary, if a resident refuses, opposes or resists the treatment

³⁴ CPT recognises the right to withdraw patient's consent at any time as an essential cornerstone of informed consent. As we can see from the wide range of CPT reports, it is essential that all patients who have given their consent to treatment are continuously informed about their condition and the treatment applied to them.

³⁵ Bosnia and Herzegovina: Visit 2019, para 143; Bulgaria: Visit2020, para 49; Kosovo: Visit 2020, para 145, Serbia: Visit 2021, para 149, Moldova: Visit 2020, 147, North Macedonia: Visit 2019, 154.

³⁶ Moldova: Visit 2020, para 147; Bosnia and Herzegovina: Visit 2019, para. 143; Czech Republic: Visit 2018, para 116.

³⁷ Hungary: Visit 2018, para 153.

offered (wishing to withdraw from it), there has been concern on the part of the delegation that, in such circumstances, the individual's liberty is being restricted.

In order to assess the legal nature of the consent given and its legal consequences, decision-making capacity is a prerequisite for informed consent.

4.1 Decision making capacity a prerequisite for the existence of the institute of informed consent

As outlined above, a decision to deprive a person's legal capacity should not be considered to automatically mean the person concerned should not and cannot give informed consent to treatment. In circumstances where the resident is limited in their abilities, the resident may not be able to make decisions in social care on their own - not at all or only in part. In such circumstances, the resident is subject to the will of the attending physicians as to what steps should be taken to ensure the resident's right to health in social care. The capacity to consent should therefore be assessed on an individual basis and, even for persons from whom fully informed consent cannot be ensured, efforts should be made to provide some understanding of the treatment received, including the nature of the treatment, its purpose and possible side-effects.³⁸

Every national legal system establishes regulations concerning legal capacity in general, as well as concerning natural and legal persons. Exercising legal capacity is something all human beings must enjoy on an equal basis with each other and is fundamental to the enjoyment of all other rights.³⁹

The right to legal capacity is guaranteed by Article 12 of the CRPD. Article 12(2)⁴⁰ CRPD requires that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." In order to interpret this right, CRPD Committee General Comment No. 1 draws a distinction

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³⁸ Russian Federation: Visit 2018, para 121, 123.

³⁹ Committee on the Rights of Persons with Disabilities. General Comment No 1 (2014) Article 12: Equal recognition before the law. CRPD/C/GC/1. Retrieved May 20, 2022, from

https://digitallibrary.un.org/record/425041/files/E_C.12_2000_4-EN.pdf?ln=en

⁴⁰ Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Article 12(2).

between "legal capacity" and "mental capacity".⁴¹ Legal capacity refers to the right to make decisions for oneself, within the constraints of the law, which must then be recognised as being legal. It could directly or indirectly apply to an everyday matter such as deciding what to wear or what to have for dinner. This could also include decisions like moving into a care home or having a risky operation. Therefore, the ability to be a holder of rights and expresser of preferences must be given effect and respected. Mental capacity (also referred to as decision-making capacity), on the other hand, refers to a person's decision-making skills, which may vary from time to time and between individuals. Decision-making capacity is fundamental to the respect for autonomy and is a key component of informed consent to medical treatment. *Decision-making* capacity should always be considered in relation to a particular decision, at a particular moment in time. This is particularly important in cases where, as shown in the CPT report, the resident is receiving medication for a long period of time without any interruption, during which such abilities are not reevaluated.

In particular, the report acknowledges that a large number of residents received benzodiazepines in combination with other sedating drugs for years without a clear objective indication. The CPT considered that such indiscriminate use of medication is unacceptable and should be stopped immediately.⁴² Given that decision-making capacity is linked to the performance of a specific function, it would be wrong to assume *a priori* that a person is completely incapable of making all decisions. To exercise these rights, any person should be able to understand, retain, analyse and communicate the information and their decision (Appelbaum & Grisso, 2020).

Decision-making capacity is the ability to make autonomous and informed decisions about medical care. As stated in legal doctrine, a patient possesses medical decision-making capacity, if the understanding of the situation, the consequences of the decision to be taken and reasoning in thought process, and communicating the wishes can be demonstrated (Appelbaum & Grisso, 2020). The capacity to make decisions about medical care is essential for the recognition that the individual has autonomy and the right to it. This recognition of autonomy is also ethically

⁴¹ Committee on the Rights of Persons with Disabilities. General Comment No 1 (2014) Article 12: Equal recognition before the law. CRPD/C/GC/1. Retrieved May 20, 2022, from https://digitallibrary.un.org/record/425041/files/E_C.12_2000_4-EN.pdf?ln=en

⁴² Hungary: Visit 2018, executive summary.

important, supporting the ethical right of individuals to make decisions in medical care.

Although the law relating to decision-making capacity is not mentioned, as indicated above, the nature of the "other capacities" referred to in the report would, by the description given, be considered to be decision-making capacity as a prerequisite for informed consent. While informed consent is essential for the exercise of autonomous decision-making, informed consent is based not only on the information needed for the patient to make a specific decision (as discussed above), but also on the patient's own capacity to make a health care decision. Therefore, in order to exercise the right of patients to make autonomous decisions about their social care, individuals must posess decision-making capacity (Derse, 2022, p. 95).

In light of the findings expressed in the CPT visit reports, it can be concluded that the reference to such capacity assessment or recording procedures has not been considered as a prerequisite for informed consent. Moreover, there is not even a reference to such an assessment of capacity having been carried out, nor any explanation of the concept.

Notwithstanding the absence of a defined concept, it can be inferred that the CTP, in their reports to the authorities, require an evaluation of certain capacities of persons when providing social care in establishments. Moreover, during a separate visit, the CPT has recognised that there should be a personal medical file for every resident, containing diagnostic information (including the results of any special examinations which the resident has undergone), as well as an ongoing record of the resident's mental and somatic state of health and treatment.⁴³

Record keeping also plays an integral role with respect to gaining informed consent. The purpose of medical records is to provide documentary evidence of a person's medical assessment and the direction of their treatment, as well as changes in their state of health. Their clarity and accuracy are paramount for effective communication between healthcare professionals and patients. The maintenance of good medical records ensures that a patient's assessed needs are met comprehensively (Abdelrahman & Abdelmageed, 2014). In addition, it is important

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⁴³ Azerbaijan: Visit 2013, para 58.

that the resident's medical records contain complete and accurate information about the resident's condition and events during the treatment process, as only the medical records and the information they contain are evidence of the resident's condition and treatment. When completed adequately, record keeping can promote continuity of care through clear communication (Davidson & Devlin, 2013) and later supply, if necessary, the evidence for any legal proceedings.

Conversely, poor records may have a negative effect on care delivery, with pertinent information not being documented or relayed to the right people. When carrying out a determination of consent, it is important to document this in the medical records. Accurate answers to questions are useful, as is a brief summary of the interview conducted when assessing the consent. The information should also be included in the medical record if a formal capacity assessment tool is used. In most cases where legal action is taken, inadequate record-keeping by the treating physician is a significant deficiency. The doctor may have made great efforts to obtain information, involve the resident or ensure that the resident has made an informed decision, but if this is not clearly documented in the medical records, the effort may have been wasted. Some guidance on what should be documented could include how to record the date, names of relatives, relationship with the resident, concerns raised and solutions offered, medication, dosage, side effects if any, diagnosis and follow-up dates (Hegde & Ellajosyula, 2016).

On the few occasions when medication issues were recorded during one of the CPT visits, there was no indication of dosage, or sometimes even to whom it had been administered. Further, it was clear that residents were not always consenting to being medicated. 44 To record the impairment of the patient's decision-making capacity, the practitioner must make precise and accurate entries in the patient's medical records, which must indicate the patient's decision-making capacity. In such circumstances, a clear statement of intent, its assessment and entry in the medical record, as well as other notes about the resident, would operate as a protecting tool for the rights of both the resident and the caregivers.

⁴⁴ Azerbaijan: Visit 2013, para 56.

The contents of the medical record must be sufficiently detailed and organised not only to help protect the interests of the patient, but also to protect the physicians and the social care institution from potential liability.

5 Residents with limited capacity or incapacity and the role of safeguards

Undeniably, most care home residents are limited in their abilities. In particular, they struggle to make complex and less complex everyday decisions. Decision-making can be influenced by a variety of circumstances. As recognised by the CPT in one of its reports, residents with severe learning disabilities and not communicative, will present difficulties, including difficulties giving informed consent to medical treatment.⁴⁵

As specified in the UN Convention, in circumstances where the person is incapable of giving consent, Article 6⁴⁶ of the Convention states rules for the protection of such persons. Part 3 of Article 6 states: 'where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorization of his or her representative or an authority or a person or body provided for by law'.

Also as indicated in CPT reports, attention has been drawn to the fact that the decision-maker will not always be the resident himself/herself, given that the person is not capable of making a decision. Most reports explicitly refer to representatives as the persons who are responsible for taking decisions for residents. This applies to cases where residents are found to be incompetent. It should be highlighted here, however, that in some of the reports the limited capacity of the person is recognised as a reference to the legally incompetent⁴⁷ status, in others only as incompetent.⁴⁸

⁴⁶ European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, Article 6.

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⁴⁵ Russian Federation: Visit 2018, paras 121, 123.

⁴⁷ Serbia: Visit 2021, para 173; Armenia: Visit 2019, para 102; Ukraine: Visit 2019, paras 40, 42; Lithuania: Visit 2016, executive summary; Lithuania: Visit 2016, para 122, 123; Serbia: Visit 2015, paras 203, 204.

⁴⁸ Azerbaijan: Visit 2013, para 56; Ukraine: Visit 2019, executive summary.

First, the above highlights the need for the resident's capacity to be assessed. Only if it is established that the resident is not capable of making a decision on their own should the question of appointing a third person to make the decision for them be considered.

Second, as the report points out, effective social care practice requires the identification of a person who would be able to effectively defend the interests of the resident, as well as ensuring participation in the process of granting consent. Significantly, in the CPT's view, such a third party should be independent of the social care establishment so as to avoid any conflict of interest.⁴⁹

Therefore, in order to ensure a multidisciplinary approach to the social care, health care staff should participate, alongside with other categories of staff, in the drawing up and review of the care plans. To this end, social care establishments should employ sufficient numbers of specialised staff trained to carry out both the rehabilitative and therapeutic activities relevant to the needs of residents, including educators, social workers, psychologists and occupational therapists.⁵⁰

6 Conclusions

Decision-making capacity is a necessary component and prerequisite for social care residents to be able to exercise their right to self-determination over their own bodies, enjoying the right to autonomy and identifying who will be the final decision-maker. Decision-making capacity is not recognised in CPT practice, but such practices should be changed to ensure the protection of all, especially residents who are limited in their capacity. By this practice of disregarding the institute, the CPT is acting contrary to an internationally established institute in law and doctrine.

In contrast to the absence of decision-making capacity, the CPT's practice extensively and frequently emphasizes the importance of the institute of informed consent for obtaining the consent of residents to treatment, maintaining that it is to be determined separately and distinctly from the provision of consent to addinission.

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⁴⁹ Russian Federation: Visit 2018, para 121.

⁵⁰ Council of Europe. European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT). Factsheet. *Persons deprived of their liberty in social care establishments.* Retrieved June 21, 2022, from https://rm.coe.int/1680a0cc19

In order to guarantee the protection deriving from international law, all residents, but especially residents with limited capacity, must be given immediate support in securing their rights and legal interests. In circumstances where this is necessary, an additional and independent expert should be called in to assess such capacity.

Any social care, but especially resident-centred social care, based on capacity assessment should aim at safeguarding the vulnerable, in this case the resident as the central element of social care.

Disclamer

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Povzetek v slovenskem jeziku

Odbor za preprečevanje mučenja in nečloveškega ravnanja je organ Sveta Evrope, ki organizira obiske ustanov za pridržanje, kot so socialni domovi, da bi ocenil, kako se obravnava osebe, ki jim je odvzeta prostost. To v praksi pomeni, da osebe ne morejo svobodno zapustiti te ustanove in so zato dejansko prikrajšane za svobodo. V takšnih razmerah so invalidi še posebej ranljivi ter imajo omejeno sposobnost odločanja o zdravljenju in oskrbi. Ker se število takšnih oseb povečuje in zaradi zagotavljanja zaščite po mednarodnem pravu, rezultati empirične študije kažejo na potrebo po zagotovitvi takojšnje pomoči prebivalcem pri varstvu njihove pravice do samoodločanja ali zasebne avtonomije ter pravnih interesov pri odločanju o zdravstveni oskrbi v socialnovarstvenih ustanovah. Na primer vključitev stanovalca v privolitev v zdravljenje ali vzpostavitev postopka glede ocenjevanja odločanja.