

CHAPTER 2

LEGAL RELATIONS: FROM THEORY TO PRACTICE

THE RIGHT TO MAKE A DECISION: HUMAN RIGHTS OF PATIENTS WITH MENTAL DISABILITIES

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Abstract. *One of the consequences of mental disabilities is the possibility of a guardianship proceeding that will deprive patients of the legal capacity to taking decisions and manage their assets. The article aims to study the legal capacity issues and guardianship proceedings in patients diagnosed with dementia. The provisions of the Convention on the Rights of Persons with Disabilities, the Convention for the Protection of Human Rights and Fundamental Freedoms, the ECHR's practice on the protection of human rights to liberty and security, the provisions of the legislation of Ukraine concerning incapable people's rights are studied. The methodology of this article is based on comparative and legal analysis techniques and includes a system-structural method, method of generalization, method of analysis, and synthesis as well. The provisions of the Convention on the Rights of Persons with Disabilities, the Convention for the Protection of Human Rights and Fundamental Freedoms, the ECHR's practice on the protection of human rights to liberty and security, the provisions of the legislation of Ukraine concerning incapable people's rights have been examined. New approaches for human rights protection concerning patients with dementia have been established. The acts of legislation of the United Nations and the European Union as well as national legislation show that legal issues concerning disabled persons are problematic. Persons with cognitive disabilities are particularly affected.*

Keywords: *dementia, mental disabilities, capability, decision-making ability, human rights.*

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Introduction. All through history, individuals with mental disabilities have not been recognized as subjects of the same rights and obligations as everybody else. Many of them have been deprived of the exercise of their rights based on assumptions of their lack of capacity to understand or perform certain acts, and, more deeply, based on the poor social understanding of the diverse ways in which humanity manifests itself. As a result, legal systems all around the world have systematically restricted persons with disabilities from exercising their legal capacity, often by putting them under substitute decision-making regimes such as guardianship or curatorship. While this practice has been justified as necessary to protect persons with disabilities, it has proved the contrary; it renders them completely defenseless,

takes away control over their lives, and reduces their opportunities to participate and contribute to society.

Aims. The present work aimed to: study the provisions of the Convention on the Rights of Persons with Disabilities, the Convention for the Protection of Human Rights and Fundamental Freedoms, the ECHR's practice on the protection of human rights to liberty and security, the provisions of the legislation of Ukraine concerning incapable people's rights prevalence of guardianship actions in patients diagnosed with dementia in a neurological outpatient clinic; (ii) evaluate in which period of Alzheimer's disease (AD) the interdiction of the patient was determined and any difficulties in obtaining guardianship; (iii) in the case of absence of the guardianship, to evaluate how families resolve the legal problems in practice.

Methods. The provisions of the Convention on the Rights of Persons with Disabilities, the Convention for the Protection of Human Rights and Fundamental Freedoms, the ECHR's practice on the protection of human rights to liberty and security, the provisions of the legislation of Ukraine concerning incapable people's rights are studied. The methodology of this article is based on comparative and legal analysis techniques and includes a system-structural method, method of generalization, method of analysis, and synthesis as well.

Literature review. On a global scale and in every group of society, there are people with disabilities. Their number is significant and continues to grow. One billion people, or 15 percent of the world's population, experience some form of disability [1]. One-fifth of the estimated global total, or between 110 million and 190 million people, encounter significant disabilities, one in ten of all disabled people has a significant intellectual disability - over 50 million in the world which is up to 1 % of the population [2]. Taking into account their family members, the topic of disability directly affects a quarter of the world's population.

As it is stated in the World Report on Disability by the World Health Organization and the World Bank disability is a human rights issue when people with disabilities are denied equal access to health care, employment, education, or political participation; when they are subjected to violence, abuse, prejudice, or disrespect; when they are subjected to involuntary sterilization, or when they are confined in institutions against their will, or when they are regarded as legally incompetent because of their disability [3; p.9].

Recently, the priorities of international cooperation on disability issues have changed dramatically. The recognition of the problem of ensuring the rights of persons with disabilities as an international problem, as well as the need to improve cooperation between states in this area of public relations, was due to the adoption in 2006 of the United Nations Convention on the Rights of Persons with Disabilities and the Optional Protocol to it [4]. The Convention enshrines international standards in the field of protecting the rights of this category of the population, giving them a legally binding character. Moreover, in 2013, the UN General Assembly took into account the interests and needs of persons with disabilities in the list of measures to implement the development goals formulated in the United Nations Millennium Declaration [5].

Dementia is a term for the loss of cognitive abilities such as memory, language, problem-solving, and other thinking abilities that are severe enough to interfere with daily life. In this regard, the ability to perform daily activities and contact others is gradually decreasing. Among other things, the patient suffers from confusion, anger, suspicion, and even outbursts of aggression. Over time, in addition to impairing cognitive functions, physical capabilities are also impaired.

Dementia is not a single disease; it is a syndrome (a group of related symptoms) associated with an ongoing decline in brain functioning. This general term covers a wide range of specific medical conditions, including Alzheimer's disease. Disorders grouped under the general term "dementia" are caused by abnormal brain changes. These changes trigger a decline in thinking skills, also known as cognitive abilities, severe enough to impair daily life and independent function. They also affect behavior, feelings, and relationships.

Dementia is one of the main factors leading to limited opportunities for older people. It is considered one of the most serious illnesses for the patients themselves, their families, and society. Stigma and discrimination heighten the already significant psychological, social, emotional, and financial impacts that dementia has on individuals, their carers, families, and communities [6]. Dementia is a major cause of disability and dependency among older adults worldwide, affecting memory, cognitive abilities, and behavior, ultimately interfering with one's ability to perform daily activities. The impact of dementia is not only significant in financial terms but also represents substantial human costs to countries, societies, families, and individuals [7].

It is estimated that about 10% of people aged 65 and over suffer from dementia. Dementia increases with age: among people in the 65 to 74 age group, about 5%, and among people aged 85 and over, about 30% of people suffer from dementia [8].

Due to the gradual nature of the disease, it is customary to divide its course into several stages. Mild dementia is characterized by patient independence. The symptoms at this stage appear as common signs of old age: mild memory disorder (difficulty remembering words, placing objects in the wrong place, etc.), difficulty in performing complex tasks, and changes in mood (chaotic thoughts, the tendency to depression, aggressiveness, etc.). Then comes the moderate stage with the loss of short-term memory, loss of the thread of conversation and difficulty making decisions, sleep disturbances, suspicion, delirium, hallucinations, and aimless wandering. And the advanced stage of dementia causes so significant loss of memory that patients hardly recognize family members. As dementia progresses, memory loss and difficulties with communication often become severe. In the later stages, the person is likely to neglect their health, and require constant care and attention. Dementia at the last stage causes a total loss of independence, and patients need caregiving. Legal issues concerning financial administration and managing assets arise.

A state that is minimally necessary for an individual to be able to maintain personal decision-making ability is called capability. It is legally defined as the ability to acquire rights and take on duties. Article 30 of the Civil Code of Ukraine

lays down that a natural person who can perceive and control their actions shall have a legal capability [9].

Legal incapacity is, therefore, a restriction or constraint upon civil acts. The concept of legal capability differs from the medical concept of capacity, which defines a set of skills required such as memory, judgment, and decision-making, to manage affairs and carry out daily tasks. Mental capacity is not universal. The absence of the capacity in a given situation may not imply its existence in other situations; it may therefore change.

Results. The legal entity of incapacity aims principally to protect individuals who are significantly impaired, from a legal standpoint, and the forms of protection are graded.

For decision-making capacity, it is important to clarify what form the legal procedure of declaring a patient incapable will take. According to the legislation, guardianship proceedings – the declaration of incapacity – is a judicial measure using which an authority deprives an individual who is of age – in other words over eighteen – of the right to manage their affairs and engage in the activities of civil life. This measure presupposes that the person is incapable. The declaration of incapacity involves the appointment of a guardian who administers the individual's life and the affairs they are unable to manage by themselves. The guardian is responsible for carrying out all those civil acts that embody the conservatee's rights [8].

As it is noted in the Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities (by the Department of Economic and Social Affairs of the United Nations) many persons with disabilities can make decisions, sign contracts, vote, defend rights in court or choose medical treatments is often taken away. When individuals lack the legal capacity to act, they are robbed of their right to equal recognition before the law and their ability to defend and enjoy other human rights. Guardians acting on behalf of persons with disabilities sometimes fail to act in the interests of the individual they are representing; worse, they sometimes abuse their positions of authority, violating the rights of others [10].

In Ukraine as in many other countries guardianship laws for individuals with mental disabilities dominate. It means that the legal capability of an individual may be restricted if the mental disorder materially influences their capability to perceive and (or) control their actions According to the Civil Code of Ukraine, an individual may be declared incapable by a court if, due to a chronic, persistent mental disorder, they are unable to realize the significance of their actions and (or) manage them; an individual is declared incompetent from the moment of entry into force of a court decision; guardianship is established over an incapable natural person; an incapable natural person has no right to commit any transaction; transactions on behalf of an incapacitated individual and in their interests are performed by their guardian; the responsibility for the damage caused by an incapable natural person is borne by their guardian (part one of Article 39, part one of Article 40, Article 41) [9]. Guardianship proceedings are regulated by the Civil Procedure Code of Ukraine (articles 236-241) [11].

The Constitution of Ukraine enshrines that an incapable person does not have the right to vote in elections and referendums (Article 70) [12]. In this regard, the restrictions provided for in Articles 72, 76, 81, and 103 of the Basic Law of Ukraine are applied to these persons. In the opinion of the Constitutional Court of Ukraine, declaring a person incapable cannot deprive him of other constitutional rights and freedoms or restrict them in a way that eliminates their essence [13].

The subject of the right to a constitutional petition - the Commissioner for Human Rights of the Verkhovna Rada of Ukraine - appealed to the Constitutional Court of Ukraine to declare the provisions of the sixth sentence of part one of Article 13 of the Psychiatric Medical Assistance Act [14] unconstitutional.

According to the petitioner, the procedure of hospitalization of these incapacitated persons without a court decision deprives these persons of constitutional guarantees for the protection of their rights and freedoms established by Articles 29 and 55 of the Basic Law of Ukraine.

An analysis of the legislation of Ukraine gives grounds to claim that incapable persons are a special category of people (individuals) who due to chronic, persistent mental disorders temporarily or permanently can not independently exercise property and personal non-property rights, perform duties and bear legal responsibility for their actions. Incapable persons should be provided with legal opportunities to meet individual needs, and exercise and protect their rights and freedoms.

Although incapacitated persons are not able to personally exercise certain constitutional rights and freedoms, including the right to liberty and security of persons, they cannot be completely deprived of these rights and freedoms, so the state is obliged to create effective legislative mechanisms and guarantees for their maximum implementation. According to the first part of Article 29 of the Constitution of Ukraine [12], everyone has the right to liberty and security of person.

Among the fundamental values of an effective constitutional democracy is freedom, the existence of which is one of the prerequisites for the development and socialization of the person. The right to liberty is an inalienable constitutional human right and provides for the possibility to choose one's behavior for free and comprehensive development, to act independently by one's own decisions and intentions, to set priorities, to do everything not prohibited by law, without hindrance and at one's discretion move around the country, choose a place of residence, etc. The right to liberty means that a person is free in their activities from outside interference, except for restrictions established by the Constitution and other laws of Ukraine.

Article 5 § 1 of the Convention for the Protection of Human Rights and Fundamental Freedoms [15] sets out the grounds for lawful deprivation of liberty by the procedure established by law, including the lawful detention of a mentally ill person, and § 4 of this article provides for the review of the lawfulness of such detention in court.

Discussion. The European Court of Human Rights has identified the requirements to be met during the lawful detention of mentally ill persons under Article 5 § 1 of the Convention. Except in emergency cases, the individual concerned should not be deprived of his liberty unless they have been reliably shown to be of

"unsound mind". The nature of what has to be established before the competent national authority - the presence of a mental disorder - calls for objective medical examination by a procedure prescribed by law. Further, the validity of compulsory confinement depends upon the persistence of such a disorder "(paragraph 39 of the Case of Winterwerp v. the Netherlands, 24 October 1979). In the Court's opinion, no one may be confined as "a person of unsound mind" in the absence of medical evidence establishing that his mental state is such as to justify his compulsory hospitalization [16].

Besides the right to liberty and security persons with disabilities under guardianship lose their capacity to exercise other rights, such as voting, parenting, giving consent to medical treatment, including invasive procedures, deciding where and with whom to live, signing a work contract, opening a bank account or marrying. Substitute decision-making regimes perpetuate discrimination and exclusion against persons with disabilities, limit every aspect of their lives, and legitimize harmful practices such as involuntary placement and involuntary treatment.

The Convention on the Rights of Persons with Disabilities has introduced a paradigm shift, which means new approaches toward the human rights protection of persons with disabilities. According to article 12, all persons with disabilities are equal rights holders and have the right to recognition everywhere as persons before the law; they enjoy legal capacity on an equal basis with others in all aspects of life; they should be supported with exercising their legal capacity; they should be provided with appropriate and effective safeguards to prevent abuse by international human rights law should; the equal right of persons with disabilities to own or inherit property, to control their financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit should be ensured, as well as the provision that persons with disabilities should not be deprived of their property [4].

The provisions of the Convention on the Rights of Persons with Disabilities presume the supported decision-making that can take many forms, including, among others, formal and informal networks, support agreements, support networks, peer and self-support groups, support for self-advocacy, and independent advocacy. To provide the realization of these conditions, existing legislation to prohibit discriminatory denial of legal capacity based on the condition of the person with disabilities, their functional abilities or the expected outcomes of their decisions should be reformed. The existing practice of substitute decision-making should be replaced with a supportive decision-making model, considering persons' universal legal capacity without discrimination. The legalization of a supportive decision-making model based on the rights, wishes, and preferences of the recipients of assistance, and not on the idea of their best interests should be carried out. The presumption always favors the person with a disability who will be affected by the decision. The individual is the decision maker; the support person explains the issues, when necessary, and interprets the signs and preferences of the individual.

In all matters related to persons with disabilities, even when an individual with a disability requires total support and when it is not possible to accurately know their wishes and preferences, instead of being guided by the concept of the best interests,

the support persons should try to understand these wishes and preferences as accurately as possible and should enable the individual to exercise their legal capacity to the greatest extent possible, according to the wishes of the individual. Besides, high-quality free legal advice and legal aid services, which must respect the wishes and preferences of these people and protect their procedural rights (right to legal capacity) should be carried out. This distinguishes supported decision-making from substituted decision-making, where the guardian has court-authorized power to make decisions on behalf of the individual without necessarily having to demonstrate that those decisions are in the individual's best interest or according to their wishes [10].

A Resolution on Mental Health and Human Rights by the United Nations Human Rights Council also calls upon States to “abandon all practices which fail to respect the rights, will and preferences of all persons, on an equal basis” with others and to “provide mental health services for persons with mental health conditions or psychosocial disabilities on the same basis as to those without disabilities, including based on free and informed consent” [17].

In Latin America, Costa Rica, Peru, and Colombia the legal capacity of persons with disabilities have been recognized and the restrictions to their rights have been removed and provided support to allow them to take their own decisions.

In Europe, the significant efforts to remove legal barriers prevent the full enjoyment of all human rights by people with disabilities, although it is worth noting that challenges remain and still several legal frameworks include some degree of substitute decision-making schemes [17].

The Province of British Columbia in Canada is one of the leading jurisdictions in incorporating supported decision-making. An individual with disabilities can enter a “representation agreement” with a support network. The agreement is a sign to others, including doctors, financial institutions, and service providers, that the individual has given the network the authority to assist them in making decisions and represent them in certain matters [10].

Conclusions. However, more than ten years after the Convention on the Rights of Persons with Disabilities entered into force, despite the ongoing changes in the international regulation of the legal status of persons with disabilities, the problem of promoting and protecting the rights of this socially vulnerable group of the population does not cease to be relevant. Many groups have been denied their legal capacity. Among them, persons with psychosocial disabilities, as well as persons with intellectual disabilities, autistic persons, and persons with dementia (also called “cognitive disabilities”) are particularly affected. The international legal aspects of the promotion and protection of the rights of persons with disabilities, including the legal status of persons with disabilities in society, need to be rethought and re-evaluated in connection with the global changes taking place at present [18]. There is still a need to fulfill the duty and implement supported decision-making systems for people with disabilities to receive the full recognition they deserve that means promoting, protecting, and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

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