

DISABILITY, POVERTY, AND VULNERABILITY: LEGAL AND ETHICAL CONSIDERATIONS BASED ON A CASE ANALYSE

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Abstract

As a result of a media information regarding the activities of the Equality and Human Rights Action Centre (ACTEDO) from Cluj-Napoca, Mrs. C.A. has addressed to this organization to obtain judicial assistance, pro bono, in the case of her husband, C.I., on the cancellation of the disability certificate that was issued by the Romanian competent authorities. The organization accepted the case and sent it to the associate lawyers, following the legal procedures. We have accepted this case as the Romanian reality shows the need of a prompt judicial intervention in the area of social protection, being necessary to involve in the recognition and protection of the rights of the persons with disabilities. In many cases, they find themselves in vulnerable situations which prevent them to defend legally, therefore the broad rights the legislator concluded to offer them remain only on paper.

Key Words: *disability, vulnerability, poverty, discrimination.*

JEL Classification: [K38]

1. Case report

Mr. C.I. and his wife C.A. live in a city from Romania. C.I. was born in 1948, has 67 years, and he is suffering of bipolar affective disorder (diagnosed at the age of 28). As he gets older, his health has progressively degraded, being diagnosed also with the Parkinson disease (in 2010), the disease developing through a mixed dementia (since 2011). C.A., his wife, is a pensioner, aged 65. As a result of his precarious health, C.I. has no autonomy, he needs permanent care and supervision from another person, which may be a risk both for him and the others. His wife is the only one charged with his supervision. Specifically, he has severe behavioral problems, he cannot properly relate to others, has difficulty in moving, loses his balance, had two suicide attempts, eats uncontrollably, is incontinent, confuses his clothes with his wife's, walks barefoot and illogical on the streets, does not turn off the water tap and the gas cooker, he cannot take his medicines, being episodes in which he even took an overdose. Medically speaking, in 2012, C.I. was declared by the Commission for the Evaluation of Disabled Adults within a County Council from Romania with the degree of "severe" functional deficiency, receiving a

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disability certificate valid for 12 months. In 2013, he was again declared with the same degree of disability, by the same authority, but with permanent validity. The same happened in 2014. In 2015, his health got worse. At the written attested recommendation from the specialized doctors, who considered necessary the change of the classification of disability with “severe” functional deficiency with personal assistant, C.I. requested the reevaluation of the disability classification. Following the reevaluation, the same authority issued a certificate of “medium” functional deficiency disability for 12 months. His wife was not allowed by the Commission to be present at his examination. She was verbally announced that if she is going to contest the decision, the already granted rights would be diminished. The last disability certificate was contested by C.I. at the Higher Commission for Adults with Disabilities from Bucharest, however, his appeal was rejected.

His wife was overwhelmed with despair and frustration since no explanation was given for his classification in an inferior disability degree, as her husband’s health worsened. Considering that the Parkinson disease is incurable, an irreversible condition, being medically impossible, as aging, the functional deficiency to diminish, C.I.’s wife considered that it is necessary to contest the Decision before the court. However, the judicial remedies seemed inaccessible due to the costs, and also due to the disappointment the family felt after the Commission’s evaluation. Shortly before the end of the 6 months term for the formulation of the request for legal actions against the disability certificate, C.I.’ wife while listening a radio transmission found out of the existence of a group of Pro Bono lawyers within the Equality and Human Rights Action Centre (ACTEDO) in Cluj-Napoca, an organization which offers free legal assistance through its member lawyers, subject to the fulfillment of the eligibility conditions.

The lady asked for free legal assistance, the case was accepted and taken over by a pro bono lawyer, considering that the eligibility criteria established by the ACTEDO were fulfilled, as follows: C.I. 1) belongs to a vulnerable group (persons with disabilities), 2) was a victim of a discriminatory situation, 3) his fundamental rights were violated and 4) does not have the financial possibility to bear the costs of the lawyer’s fee.

2. The case analysis

We mention that according to the classification of ”severe” functional disability, that person has the right to a personal assistant, in the event that he/she lost its personal autonomy and, in our case, in all medical records has been explicitly stated by the specialty doctors that C.I. needs permanent care and supervision from another person.

To analyze this case, to show out authorities’ errors, and to identify the ethical and legal aspects that should be taken into consideration in these situations, we will punctually answer to the following sets of questions:

- i. What does disability mean?

- ii. Which are the rights of persons with disabilities?
- iii. Who are the persons with mental disabilities?
- iv. Which is the legal framework regarding rights of people with mental disabilities?
- v. What are the duties of authorities regarding the qualification degree of disability?
- vi. Which is the judge's decision on the case?
- vii. What are the ethical issues related to the case?

i. What does disability mean?

The International Classification of Functioning, Disability and Health (ICF), adopted by the World Health Organization in 2001, defines 'disability' as the interaction between an individual (with a certain health condition) and contextual factors (Leonardi, 2010, p. 40), which can be environmental or personal factors. This document proposes a series of changes at the cultural level regarding the concepts of health, functioning and disability.

For a long time, the health concept was superimposed to the one of the absence of disease, a strict model of medico-organic matrix. Health is not the absence of disease, but it can be synthesized as a state of well-being of the whole person; therefore the well-being state is strictly related to the human functioning at all levels: biological, psychological and social (Leonardi, 2010, p. 39).

The United Nations Convention on the Rights of Persons with Disabilities (2006) defines disability as an evolving concept that results from the interaction between the persons with deficiencies and the barriers that impede their full and effective participation in the society on an equal basis with others (Preamble of the United Nations Convention on the Rights of Persons with Disabilities (2006), lit. e)). Any person, at any time of life, can have a health condition that in an unfavorable context becomes a disability (ICF) (Aluaș, 2010, p. 73), therefore, any of us can find in a similar situation as the one described in our case.

The disability is a complex, broad and evolving concept, very debated through the history, which has led to increased attention of the society in the recent years, with legislative consequences (Aluaș, 2010, p. 74). The Law no. 448 from 2006 on the protection and promotion of the rights of persons with disabilities (republished), defines in article 2 align. 1) the persons with disabilities as those whose social environment misfit to their physical, sensorial, psychic, mental and/or associated deficiencies, totally prevents or limits the access to equal chances to the life of society, requiring protection measures in support of social integration and inclusion. Further, the law defines disability as the generic term for impairments/deficiencies, activity limitations and participation restrictions, defined according to the ICF adopted and approved by the National Organization of Health, and which reveals the negative aspect of the interaction between the individual and the social context he lives in. The Law no. 48/2006 regulates, in reality, the rights and obligations of the persons with disabilities granted for their social integration

and inclusion. Unfortunately, due to the new trends worldwide, the Romanian legislation still retains the phrase “disabled person”, instead of “person with disability”. There is no person with disability, but just a person who has an impairment and who in relation to the environmental or personal factors leads him/her in a condition of disability (Dumitrescu, 2011).

According to the Romanian legislation in force in matter, respectively art. 86 from the Law 448/2006, the notion of disability is classified in the following typologies: physical, visual, auditory, deafblind somatic, mental, psychic, HIV/AIDS, associated, rare diseases and the degrees of disabilities are: mild (low), medium and severe. Within the meaning of the Law 487/2002, respectively art. 5 let. a) and b), by person with psychic disorders is understood a person with mental imbalance or insufficiently physically developed or addicted to psychoactive substances, whose manifestations fall within the diagnostic criteria in force for the psychiatric practice, and by person with severe psychic disorder is understood a person with psychic disorders who is not able to understand the significance and the consequences of his behavior, and therefore he needs immediate psychiatric help.

ii. Which are the rights of the persons with disabilities?

According to the dispositions of art. 3 of Law no. 448 from 2006 on the protection and promotion of the rights of persons with disabilities, they have the rights to: health protection – prevention, treatment and rehabilitation; education and personal training; employment and job adaptation, career orientation and reconversion; social assistance, such as social services and benefits; house, environmental arrangement, transportation, access to the physical, informational and communicational environment; leisure, access to culture, sport, tourism; judicial assistance; fiscal facilities; evaluation and reevaluation through home examination of the persons unable to move by the members of the evaluation commission, at a period of 2 years.

iii. Who are the persons with mental disabilities?

According to the data supplied by the Ministry of Labor, on September 30, 2015, in Romania lived 759,019 persons with disabilities, of which 97.7% were under the care of their families or lived independently.

The studies concluded that the number of persons with disabilities is increasing, the disability being most common among low-income countries than the high-income ones, and the persons from the poorest areas, the women and the elders have a higher prevalence of disability (World Health Organization, 2011).

iv. Which are the legal framework regarding rights of people with mental disabilities?

At present, in Romania, the most important normative documents that frame the rights of persons with mental disabilities are the Law no.448 from 2006 on the

protection and promotion of the rights of persons with disabilities and the Law no. 487 from July 11, 2002 of mental health and protection of the persons with mental disorders – republished, the United Nations Convention from December 13, 2006 on the rights of persons with disabilities, also applicable once it has been ratified by Romania through Law no. 221 from November 11, 2010.

The classification of the persons with mental disabilities is based on Order no. 762 from August 31, 2007 for the approval of the medico-psycho-social criteria based on which the classification on a certain degree of disability is established.

The actual reality leads to the idea that the disability is a matter closely related to the human rights domain, since the persons with disabilities are often wronged by being denied the right to medical services, access to justice, employment, education, ownership of property; they are subject to violence or abuse and due to their vulnerability, they are not treated as human beings in the true sense of term.

v. What are the duties of authorities regarding the qualification degree of disability?

The evaluation procedure of adult persons for the qualification of a degree and type of disability can be found in Annex II of the Order no.2298 from August 23, 2012 on the approval of the Frame-Procedure of the evaluation of adult persons, issued by the Ministry of Labor, Family and Social Protection.

The evaluation of adult persons is done by the Complex Evaluation Service of adult persons with handicap (SECPAH), structure within the General Direction of Assistance and Child Protection (DGASPC). SECPAH consists of people who have at least the following specializations: social assistant with superior studies, specialty doctor, psychologist, psycho-pedagogue, physiotherapist, education instructor, recovery pedagogue. The necessary documents for the complex evaluation are stated in art. 7 from the Procedure, constituted in a file that will be the basis of the person's evaluation. The required documents for the complex evaluation, provided in the Government Decision no. 430/2008 for the approval of the Methodology regarding the organization and functioning of the evaluation commission of adult persons with disability, are the following: a) application-type of complex evaluation; b) a copy of the identity documents; c) medical documents: 1. a report of the actual medical situation, issued by the specialty doctor 2. medical - type letter from the family doctor, only at the first presentation to SECPAH; 3. copies of the discharge tickets, if needed; 4. the para-clinically investigations requested by SECPAH; d) the social investigation carried out by the specialized social service within the town hall the person with disability resides; e) a certificate showing the quality of the employee, if employed, a copy of the retirement decision and a pension coupon, if retired, a certificate stating that the person has no income, in the situation of those without income. SECPAH verifies and analyzes the file of the person concerned, which must contain the documents stated in art. 7 of the law and notifies the person concerned the date to present for the evaluation. The evaluation activity involves the file analysis, the verification of the documents that

must contain relevant information for the establishment of the deficiency, the severity, type and the estimated duration, the dependency, the activity limitation and participation restrictions, as well as the carrying out of the evaluation by the multidisciplinary team of the person concerned, and by case, in the presence of its legal representative. At this stage, the information from the file will be correlated with the ones resulted from the evaluation, and SECPAH also elaborates the proposal regarding the individual rehabilitation and social integration program, following the discussions with the person concerned or both, with the person and its legal representative. The file of the person who requested the qualification of the degree and type of disability and the complex evaluation report is submitted to the secretariat of the evaluation commission for adults with disabilities, which records it into their own register and that ensures its transmission to the evaluation commission to establish their classification or non-classification.

In this case, the reevaluation procedure of adult persons for the qualification of type and degree of disability was not respected by SECPAH. When the disability qualification certificate was issued on August 31, 2017, SECPAH did not respected the medico-psychic-social criteria for the classification, the file submitted by C.I., was not realized and studied properly and the change made by the commission was not motivated and justified by a legal act. It was impossible that C.I.'s deficiency to diminish and to return to a "medium" degree, given that all three conditions he suffered and which are evidenced by the medical records in the SECPAH file produce irreversible effects, evolve and are incurable. In all medical records the express mention was inserted by the specialty doctor and the psychologist: "needs permanent care and surveillance from another person", and from all medical records results his lack of personal autonomy.

In relation to the evolution of the medical conditions must be mentioned that according to the current medical studies, the Parkinson disease is classified as a neuro-degenerative disorder that affects both dopaminergic neuronal activity and the non-dopaminergic one. There are no treatments to improve the symptoms associated to the non-dopaminergic functionality (Schapira at al, 2014). As the disease progresses in time, the motor disorders especially, but also the parkinsonian symptoms worsen and will affect the quality of daily life and of the patient's independence in performing current activities. Under treatment, the disease continues to evolve and with the help of medication it can be slowed down (Annex 9 to Order no. 1223, 2010).

Dementia is classified as neuro-degenerative disorder and is one of the non-dopaminergic manifestations of the Parkinson disease. Moreover, the presence of dementia among patients with Parkinson is a sign of the advanced stage of disease. It must be mentioned that the "neurodegenerative" term involves a progressive degradation. The treatments do not eliminate the symptomatology, do not prevent the progressive degradation, but just slows it down. The progressive degradation is inexorable (Klingelhoefer&Reichmann, 2014).

The bipolar disorder is classified as mental disorder. Even under treatment, a 37% of patients relapse into depression or manic episodes within 1 year, respectively 60% of patients relapse within 2 years. The aim of the treatment is not to cure, but to stabilize and to maintain the state of existence (Duffy et al., 2014).

The illegality of the certificate released by the SECPAH has derived from the fact that they were not communicated the reason for which in 2012 and in the next 2 years C.I. was classified with severe disability and later it was changed to an inferior degree, since the patient's medical conditions deteriorated by the time.

The legislation in force in Romania obliges the authorities to motivate their decisions, their motivation being a guarantee against the arbitrariness of the public administration and essential, especially in the case of those documents by which is modified or suppressed the individual or subjective rights or judicial situations¹ (High Court of Cassation and Justice, 2012), as in our case (reducing the degree of disability and the social rights deriving from this act), precisely so that their recipients to have the opportunity to know and evaluate the basis of the decision and to be able to subsequently exercise the legal right to contest them.

The Convention on the Rights of Persons with Disabilities (2006) states in its preamble at let. x) that the family is the society's basic cell and it has the right to be protected by the society and state, and that the persons with disabilities and their family should be protected. C.I.'s family was deeply prejudiced by the conduct of the concerned authority's representatives. Therefore, the family confronted serious financial problems to cover the costs of medicines, of the annual medical investigations for reevaluation, as well as the remuneration of various persons who supervised C.I. when his wife couldn't. The authorities in question refused the wife's request to participate at the reevaluation and did not consulted with her, since she knew the best her husband's condition.

vi. Judge's Decision on the case

After the contest of the qualification in lower degree of disability to the competent authorities, which maintained the same classification, the application was brought to court in March, 2016. After almost 2 years of procedures against the State's authorities (The Commission for the Evaluation of Adults with Disabilities within the Mureș County Council, the Superior Commission for Evaluation of Adults with Disability within the Ministry of Labor, Family, Social Protection and the Elderly and the Mureș County Courts), the competent Court of Appeal of Romania granted C.I. definitive gain in November, 2017. The Court decided not only the change of the disability degree to "severe", but also the right to a payed personal assistant and the retroactive payment from 2015 of the indemnity he

¹ High Court of Cassation and Justice, Decision no. 5271/2012. Refusal of accordance of social protection rights (people with disabilities, child protection). Appeal on points of law, available at: <https://legeaz.net/spete-contencios-inalta-curte-iccj-2012/decizia-5271-2012>, last accessed on 03.12.2018.

deserved. Unfortunately, shortly after the definitive gain of the process, which took place on November 06, 2017, C.I. died before he could benefit from the rights recognized by the court decision.

vii. Ethical Issues

Which was the difficulty for the authorities to issue a disability certificate according to the real situation, as long as the medical and judicial history of Mr. C.I. was well known and faithfully supported by the complex and recent medical documents? There are only two versions of answers to this question, namely: either there was a legal act to motivate this classification, or an abuse of those who released the act. The fact that the court gave the claimant gain of cause, it means that the abuse hypothesis is the one left. Our question is the following: is this a unique case or there are many such cases in Romania in which people as Mr. C.I. have their rights denied?

The end of the case emphasizes that “the quality of life of the persons with disabilities is, generally, low, not only for financial reasons, but also because their integration in the society is understood as an individual or family responsibility. To these barriers is added a bureaucratic institutional system, which, contrary to its purpose, is against the most vulnerable ones and a lack of the culture of social justice (...). Although, the access to justice is a fundamental right protected by the European Convention for Human Rights, the European Union right and the Romanian law, the multiple barriers vulnerable persons face in their everyday life increase their marginalization and their susceptibility to abuse” (Columban&Drăgan, 2018). It is important that the state and authorities to respect the persons with disabilities and their families and to grant them the rights they are entitled.

The present case is just an example of a family from Romania that has struggled to obtain the rights guaranteed the by legal norms in force, most of these families do not have the necessary knowledge and support to seek justice in court against the abuses and the neglect of the authorities’ representatives. Their attitude raises serious questions about the ethics of the cares in a person’s life, as the responsibility for the care of persons with disabilities cannot be left exclusively to the family, this responsibility being a social one, and not an individual one (Aluaș, 2017, p. 567).

The social responsibility is not just a moral one, but also legal. The Law no. 448/2006 mentions in art. 7 align. (1) that the promotion and respect of the rights of persons with disabilities mainly belong to the local public administration authorities the person resides and, complementary, to the central public administration authorities, the civil society and family or to its legal representative.

The law is created to protect, and its role can be achieved only by giving it to those needing it. Therefore, although we are currently in a dynamic and changing context of life, as long as we respect the laws, we prove good faith and show

solidarity with those around us, by supporting them even in exercising their own access to justice, we could create guarantees to a better life.

Final remarks

When we were asked in this case, we have analyzed the opportunity to open a trial, weighted the advantages and the risks of such an action, we asked ourselves what would be his faith, how is going the judge to analyze the case and which will be the direct impact on Mr. C.I.: if the attendance to the court, the public character, the formality and solemnity of the court hearings could be detrimental for his health. In addition, we wondered how much the family's relationship with the authorities would be altered as a result of this step, if it was wise to assume this risk.

From the legal and strategy perspective, the legislation in force allowed us to initiate a trial, the defense being supported by a series of legal text, enforcement rules, regulations including legal and medico-psychologic criteria, so that our position presented to the judge was according to dispositions of the medical practice guidelines. In such conditions, we considered that the conduct of the authorities charged with their implementation was unreasonable, considering that the issuing of the certificate of disability is a procedure they frequently face and the legislation in discussion should be familiar to them.

We consider that each of us, regardless of the field of activity and the social level we are in, we have the task to observe what is happening around us, with our fellows, to help those who are in a vulnerable or disability condition, and not to be passive to these realities. It is a natural conduct based on the coherent functioning of the community, society and world.

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Conflict of Interest. The first author declares her affiliation and collaboration to the Equality and Human Rights Action Centre (ACTEDO) being the main lawyer in this case. The last author has no conflict of interests.

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Legislation

1. Law no. 448 from 2006 on the protection and promotion of the rights of persons with disabilities (republished) in the Official Monitor, Part I no. 1 from 03/01/2008.
2. Law no. 487 from July 11, 2002 on mental health and protection of the persons with mental disorders (republished) in the Official Monitor, Part I no. 652 from September 13, 2012.
3. Law no. 221 from November 11, 2010 for the ratification of the Convention for the rights of persons with disabilities, adopted at York by the General Assembly of the United Nations Organization on December 13, 2006, opened for signature on March 30, 2007 and signed by Romania on September 26, 2007, in the Official Monitor no. 792 from November 26, 2010.
4. Order no. 762 From August 31, 2007 for the approval of the medico-psycho-social criteria on the basis of which the classification of the disability degree is established in the Official Monitor Part I no. 885 from December 27, 2007.