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For an ethics the medical and social-education assistance and intervention for persons with disabilities

Iolanda TOBOLCEA¹

Abstract

In the present study we aimed at presenting the image that the present-day Romanian society has formed on the way in which disabled persons correspond to the ethical norms, in view of their integration and normalisation within society. The group of subjects considered in the research was composed of higher education graduates: 250 specialists (doctors, psycho-pedagogues, social workers) that work in institutions for the recovery and rehabilitation of persons with various disabilities (intellectual, sensorial, motion disabilities) and 250 non-specialists (engineers, economists). The questionnaire used during the research comprises five insulating negative items and five integrating positive items. The results of the study showed differences between the specialists' and non-specialists' perception on the application of ethical norms in the medical and social-educational activity (hospitals, recovery institutions) as well as in the educational activity (schools) in the treatment of persons with disabilities, while the factors and means for improving the interaction with these people showed direct correlations in the subjects' view. The conclusions of the study emphasised a better perception of the specialists compared to the perception of the non-specialists concerning the application of ethical norms in the medical-educational activities involving persons with disabilities. The perception of the subjects regarding the methods and the factors for improving the interaction with the persons with disabilities indicates on top position the development and the realisation of some joint programs, considering that every member in the community has to be actively involved in the successful integration of these persons.

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Keywords: medical; social-educational intervention; disability; ethics; attitude; perception.

Introduction

The medical and social-educational perspective, for a personalised rehabilitation of the persons with disabilities registered great progresses in the past few years by the adaptation to the present-day requirements and standards of society. The medical intervention is not limited only to the therapeutic aspect, involving also the surveillance and security of the intervention and care provided by education, so that in the recovery activities we are witnessing a mixture between “treatment, healing” and “care, education” (Davidson, 2005). These two approaches (treatment and care) are compatible, since they contribute to ensuring the respect, the development and the promotion of persons with disabilities. Referring to this aspect, Ionescu, S. (1990) considers that ethics provides a set of actions outside the person, that are likely to radically change the situation in which the person lives and these interventions can be medical, psychological, pedagogical, educational, social or religious. These considerations confirm the ethics’ mission to deal with the theoretical study of the human values from a moral point of view and with their role in the social life; the sum the corresponding moral conduct norms. The bioethics general principles, such as: autonomy, care, avoiding all the actions likely to have negative effects on the person, all constitute the basis for the decisions concerning the health and protection of the person with disabilities. Constant respect of the ethical principles is an ongoing process, based on the new concepts in healthcare, on the social and cultural aspects and on their application to the clinical situations by conceiving appropriate policies, by developing protection ethical alternatives (Harding, 2000). *Disability* is a generic term for deficiencies, comprising all the intellectual and physical impairments likely to affect the life of an individual to various extents (Rusu, 1997). Naturally, medical research and action are first of all directed to the *defect*, term designating the injury, the deterioration or even the absence of an organ or segment of the body. The defect determines the apparition of the disability, when it disturbs significantly the individual’s relationship with the social environment, when the defect prevents the individual to reflect accurately enough the objective reality, to perform at normal level activities characteristic to his/her age, together with the other members of the community. The defect is thus approached in medical terms, while the disability is tackled in social terms, as a consequence of defect (Beatson, 2001). In specialised literature, there are many argumentations in favour of humanistic approaches (Varekamp, 2004) that demonstrate various methods for dealing with disabilities, using medications and therapies varying from patient to patient. Therefore, the goal of the Convention on the Rights of the Persons with

Disabilities (2007) is “to promote, protect and ensure 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”(Art.1). The Convention mentions that “the persons with disabilities are considered to be the persons with long term physical, mental, intellectual or sensorial deficiencies” and that those persons “with disabilities should enjoy legal capacity on an equal basis with others in all aspects of life”. (Art. 12). As far as healthcare is concerned, it will be the same for the persons with disabilities as for others, “including the specification that it will only be administered on the basis of their free and informed consent” (Art.25).

Hypotheses and design

Professional ethics governs the way in which the members of a discipline interact with the subjects, as well as the way in which they interact with each other. Generally, in the field of the medical and social-educational intervention, there were few approaches concerning the principles of the professional behaviour involving ethical dilemmas. Lack of instruction and research in the field of ethics was a regrettable omission, since as efficient as intervention can be, as trustworthy the research, the rehabilitation of children with disabilities calls for a complex set of activities confronted with many ethical challenges. Special education policies and ethical justifications for the practical activity require a special attention in creating the medical and social-psychological bases to support the challenges in the field (Gostin, 2001). The *goal* of the study was to analyse the way in which are perceived the existence, the manifestation and the quality of ethical attitudes and behaviours towards the persons with disabilities, both by the persons working in these fields, and by those working in social-educational and medical domains, and specialists in the medical and social-psycho-pedagogical field, working with persons with disabilities.

Within this research we started from the hypothesis that the persons with disabilities have to be not only accepted, but also integrated, practically trained, first of all as far as accessibility, equality, cooperation, tolerance, and assistance are concerned. These approaches develop the personality of the disabled persons and contribute to the accomplishment of a better integration from a psycho-social and professional point of view. In a first stage of our research we established some of the indices, items that are able to present as faithfully as possible the inclusive / insulator attitudes towards the persons with disabilities. On the basis of these items we investigated the specialists' and non-specialists' perception on the way in which the persons with disabilities are looked at, accepted and treated in the social-educational and medical environments, the way in which they interact with the communities members.

The *objectives* of the study are related to emphasizing some differences concerning the perception of the ethical principles applied in the medical and social-educational intervention according to the expertise, and the professional qualification.

1. A first objective of the research was to analyse the perception on the application of the ethical principles in the medical and social-educational intervention according to the field of activity: in the medical field (hospitals, health centres, nursing homes, etc.), or in the educational field (schools, recovery centres).

2. A second objective of our research was to analyse the influence of various means for improving the interaction with the disabled persons within the community, as well as to emphasize the important factors in realising the interaction with these persons. This objective aims to demonstrate that for a better perception on the disabled persons, it is necessary to know the medical and social-educational characteristics, requirements and aspects, to interact and cooperate with these persons, to hold both theoretical and practical information. Among the *hypotheses*, we presupposed that there are differences between the perceptions of the non-specialists and those of the specialists in the medical and social-educational field, concerning the application and the exertion of the ethical norms during the medical and social-educational interventions for persons with disabilities.

Methods

Instruments used. In order to evaluate the variables of this study we created a questionnaire that measures the perception on the ethical principles application in the medical and social-educational intervention for the persons with disabilities. The items selected for the questionnaire were the ones that highlight the main aspects of the ethical norms applied during the medical and social-educational intervention. The questionnaire contains 18 questions with 4 answer options, the subjects being asked to mark by "X" the option they consider to be the most appropriate. On the basis of specialised studies, according to the Convention on the Rights of the Persons with Disabilities (UNO, 2007), the results showed 5 insulating, negative items: non-acceptance, discrimination, inequality, intolerance, non-assistance, and 5 inclusive, positive items: acceptance, non-discrimination, equality, tolerance, and assistance. The antinomic position of the 5 positive items and the 5 negative ones is situated within the two dimensions of our research: insulating and inclusive. According to the Convention on the Rights of Persons with Disabilities (UNO, 2007), the previous items were conceptualised as follows: a) acceptance/non acceptance of the persons with disabilities – part of human diversity and humanity; b) non-discrimination/discrimination of the persons with disabilities – full and efficient participation within the society; c) equality/inequality of rights for the persons with disabilities – the right to preserve their own

identity; d) tolerance/intolerance towards the persons with disabilities, understanding the capacities and the limitations of these persons, their actions and moral and ethical behaviours; e) assistance / lack of assistance for the persons with disabilities – without injuring these persons' dignity, autonomy, freedom and independence in making their own decisions.

The pilot research. Initially, the questionnaire had to be applied to a sample (90 subjects), according to the conditions of the research, in order to check if the items' formulations presented problems with understanding the concepts. Based on the data obtained, a final revision of the questionnaire was carried out, in order to check the validity and the accuracy of the questionnaire. The Alpha Cronbach coefficient was calculated with the SPSS program. The value 0.8008 of the Alpha Cronbach indicated a high accuracy of the questionnaire.

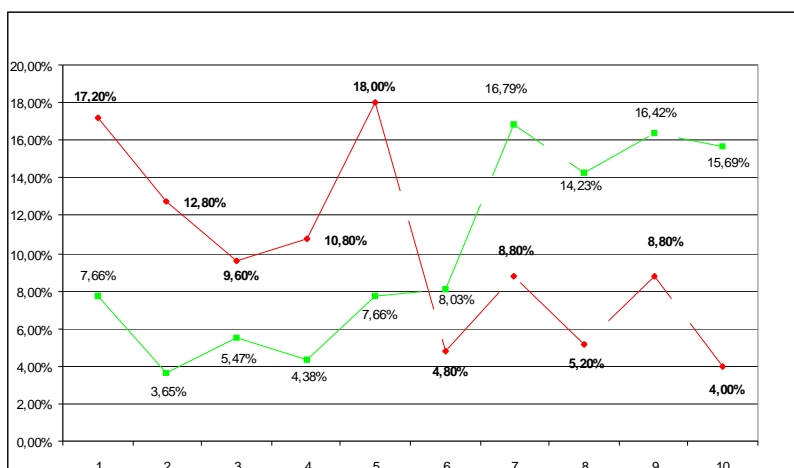
The experimental group was composed of higher education graduates: 250 engineers, economists and 250 doctors, social workers, psycho-pedagogues, working in institutions for the recovery and rehabilitation of the persons with various disabilities (intellectual, sensorial, motor) in the counties of Iași, Vaslui, Suceava and Neamț. The age of the subjects ranges from 30 and 35 years, and gender distribution is uniform in both groups. Using the aleatory probabilistic method, 500 subjects were selected according to the following characteristics: a) specialists in the medical and social -educational field (doctors, social workers, psycho-pedagogues); b) non-specialists in the medical and social-educational field (engineers, economists, other professions outside the medical and social-educational field); c) higher education graduates; d) age comprised between 30 and 35 years.

Results and discussions

General hypothesis. There are differences between the perception of the specialists and the non-specialists in the medical and social-educational field on the ethical norms application within these activities.

Specific hypothesis 1. The perception of the specialists concerning the application of the ethical norms in the social-educational environment (schools, recovery centres) in the activities involving persons with disabilities is more favourable than the perception of the non-specialists.

Fig.1. Perception on the application of the ethical norms concerning the persons with disabilities in the social- educational environment (schools, recovery institutions).



Perception of people without speciality studies in the activity involving people with disabilities

in schools-negative elements — / positive elements - - -

Perception of people with speciality studies in the activity involving people with disabilities in

schools-negative elements — / positive elements - - -

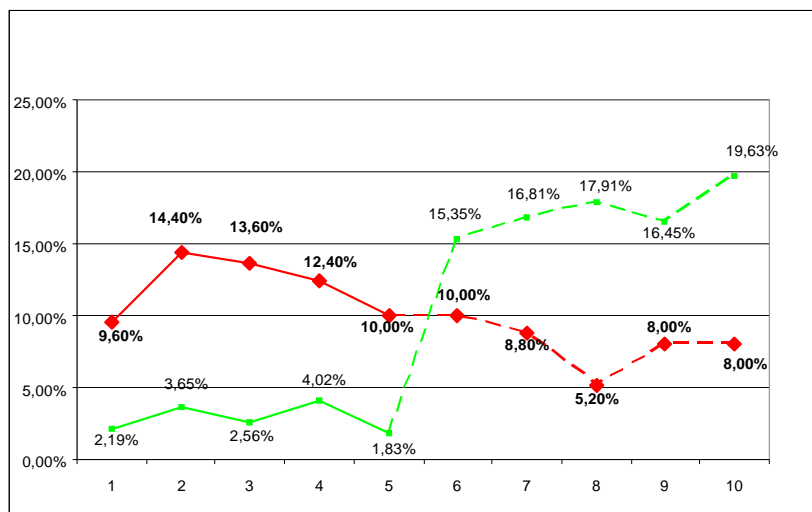
In order to check this hypothesis, the Independent Samples T-Test was used. The hypothesis was confirmed, with a significance threshold of $p = 0,00$ ($p < 0,05$); the value is significant at a trust level of 99%. In fig.1 and fig. 2 on the horizontal line from 1 to 10 are given the negative and positive items representing the perceptions of the two groups: 1- non-acceptance; 2 - discrimination; 3 - inequality; 4 - intolerance; 5 - helplessness; 6 – acceptance; 7 – non-discrimination; 8 - equality; 9 - tolerance; 10 – helping. Also, the legend from fig. 1 is the same for fig.2. The differences in perception between the two groups (group 1 – specialists in the medical and social-educational field and group 2 – non-specialists in the medical and social-educational field) are around 10% on each item analysed. The results interpretation is carried out differently for the 5 negative items, compared to the 5 positive items. Considering that the first 5 items are negative, the smaller their values are, the better the perception of the subjects is, and for the 5 positive items, the bigger the obtained values are, the better the perception of the subjects. Therefore, it can be noticed that for the negative items, the perception of the specialists is significantly positive of 7,66% for the items non-acceptance and non-assistance, compared to the significantly negative values

of the non-specialists, respectively 17,2% and 18%. For all the positive items, the values of the non-specialists' perception are around 6% on every item, compared to the specialists that recorded average values of 16% on every item. Analysing the global results from fig. 1, we can conclude that the perception of the specialists is 3 times more favourable compared to the non-specialists perception concerning the application of the ethical norms in schools and recovery centres with persons with disabilities. Within the social-educational environment, the psycho-pedagogue professionals consider that throughout the activity, the persons with disabilities carry out recovery activities that fulfil the social-educational ethical norms in order to compensate for the deficiencies and to fully integrate them. When the specialists interpret the ethical codes in the educational context of persons with disabilities, they have to answer various low incidence questions. Since the ethical code does not offer a specific orientation concerning the actions that should be carried out in specific situations, the specialists have to apply the guidelines when confronted with ethical dilemmas provoked by a variety of persons and contexts.

Specialists have a better perception than the non-specialists as the former have an adequate social and psycho-pedagogical training and manage to select the working methods corresponding to each individual case. The non-specialists from the social-educational field do not have access to direct information related to the psycho-pedagogical training and they frequently have a distorted and wrong perception of the ethical methods of the recovery activities. For example, very complex issues appear in the case of individuals with severe mental disorders whose birth, life and death are dominated by difficult problems concerning humanity, quality of life and community integration. These examples underline what Ramsey (2002) describes as the "ethics at the edges of life", or dramatic incidents that force people to assess the values when making choices that may support life or cause death. Goodlad (1993), researcher and initiator of the movement for education renewal, approaches issues related to ethics in education and qualifies the teachers as ethics practitioners. Goodlad (1993) supports the idea that education is a fundamentally moral process because it involves the expression of the social values through actions that influence the evolution and the development of a child. Researchers also continue to analyze ethical problems within the special programs for individuals with special needs and state that the classical ethical issues and dilemmas are still present and continue to influence the 21st century.

Specific hypothesis 2. The perception of the specialists is more favorable than the perception of the non-specialists on the application of ethical norms in the medical environment (hospitals, nursing homes, etc.), in the activities involving persons with disabilities. In order to check this hypothesis, the Independent Samples T-Test was used. The hypothesis was confirmed, the value of the significance threshold was $p = 0,00$ ($p < 0,05$); the value is 99% accurate.

Fig.2 The perception on the ethical norms application concerning the persons with disabilities in the medical environment (hospitals)

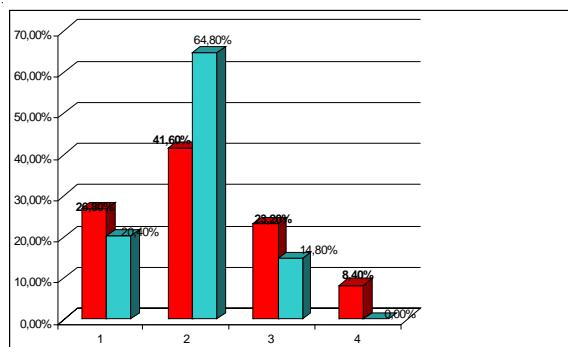


The differences in perception between the two groups are noticeable in the appreciation of the ethical aspects encountered in the medical and social-educational activities with the disabled persons; therefore, the non-specialists consider that as far as the acceptance of these persons is concerned, the percentage is 10% compared to 15.35% in the case of specialists, the non-discrimination is 8.8% compared to 16.81%, equality is 5.2% compared to 17.91%, tolerance is 8% compared to 16.45%, and assistance is 8% compared to 19.63%. Similarly, in the case of the perception on the activities carried out in school, the same difference of about 10% can be noticed on every positive and negative item between specialists and non-specialists. The specialists consider that after the birth of a child with an accentuated disability, the medical treatment must be analysed, and several decisions must be taken concerning the objectives and the corresponding programs with a major impact on their life. During these activities, the specialists are confronted with a variety of ethical dilemmas, since they work with the disabled persons throughout their entire life. In the medical activity, they should rely on careful practices in decision making and on solid ethical principles in order to ensure results likely to promote the interests of every person with severe disabilities. We considered that these perceptive differences at moral and ethical level of the ethical modalities for carrying out the medical and social-educational activities also result from the way in which the informing campaigns on the needs of the disabled persons are organised and carried out within the community.

Therefore, it was necessary to monitor the perception of the two groups of specialists/non-specialists concerning the roles and the important functions in assuring the optimal conditions for developing recovery activities, as well as the important role in carrying out the information campaigns about the disabled persons. The specialists have emphasised the idea that the involvement in the private life of an individual requires high quality treatments and recovery programs. Specialists recognize that training, the patient's involvement in the recovery process and forced medication are often perceived as an extreme and traumatic experience (Bindman, Maingay and Szmukler, 2003). A number of researches indicate that the respect for the integrity and dignity of individuals with disabilities is considered an ethical obligation, but also a recovery method. Also, the results of some studies refer to persons with disabilities who admitted that, after hospitalisation, treatment was necessary in some situations, but compulsory treatment did not lead to improvements. Thus, the coercive measures have a negative impact on the interpersonal relations and on the therapeutic results. Since the recovery of the persons with disabilities involves the staff vocational training for solving inherent ethical dilemmas, the specialists must be prepared to interfere efficiently in each particular case (Davidson, 2005). Therefore, the specialists have to rely on careful decision making practices and on solid ethical principles in order to ensure results able to promote the interests of every person with severe disabilities.

Specific hypothesis 3. The perception of the professionals on the ways of improving the interaction with disabled persons correlates with the non-professionals' perception. In order to verify this hypothesis, the Pearson correlation was used, the significance treshold resulting from the statistical analysis is $p = 0,00$ ($p < 0,05$), showing a direct correlation.

Fig.3 Perception on the ways of improving the interaction with the disabled persons



1 - cultural programs (tv, radio, etc.); 2 - common projects with people with disabilities; 3 - non-discrimination campaigns; 4 - none

perception of people without speciality training

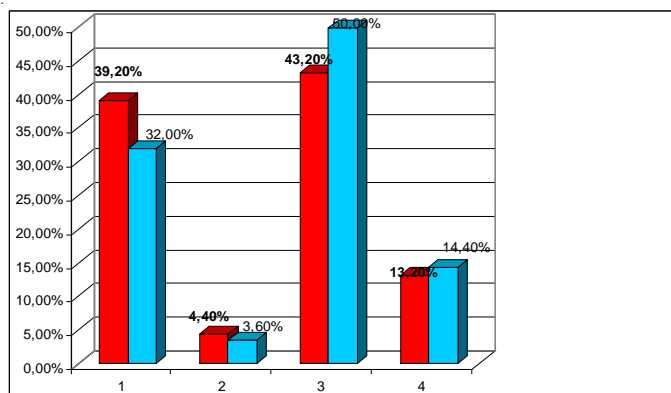
perception of people with speciality training

It can be noticed (fig.3) that both the perception of the specialists and that of the non-specialists presents maximum values (64,8% și 41,6%) concerning activities in common projects with disabled persons. For the cultural informative programs (20,4% specialists and 26,8% non-specialists), and anti-discrimination campaigns (14,8% specialists and 23,2% non-specialists), the proportions obtained show that they have a helping role, additional in realising the interaction with these persons in activities within the community. From the data obtained it results that, due to the fact that they perceive negatively the application of the ethical norms in the therapeutic interventions, the non-specialists, wish to participate in programs, projects developed together with the disabled persons, in order to contribute to their integration. The non-specialists state that they are less or even at all familiarised with the disability phenomenon, that throughout their life they had little interaction with the persons with disabilities, that their integration is difficult, that is, at the end of the specific therapies, these persons have troubles in carrying out their professional, social, entertaining activities within the community, together with the normal persons. This lack of information influences the different perception of the specialists / non-specialists on the ethical behaviours and the quality of the services in the medical and social-educational field. Once again, we notice the role of information in rendering the society sensible to the problems of the persons with disabilities. Among the non-specialists we did not find any volunteers who activate within centers or associations. This system should be introduced and developed also within the Romanian society (not only students in psychology, social assistance or medicine should perform volunteer activities), in order to develop collaboration with the persons with disabilities, as well as with local authorities, and the families of the persons involved. Both groups consider that the development of some common projects with the persons with deficiencies is extremely indicated for mutual understanding, by the common development of the various activities in which each person should be involved according to their capacities and abilities, creating thus optimal conditions for cooperation. Especially the non-specialists express the desire that, in the future, the persons with disabilities benefit from better integration conditions, and enjoy a better life, according to the capacities and real professional qualities they have. Some researchers emphasise the fact that within this context, the instruction programs in the field of special education concerning collegial relationships, research projects and the processes involved in the creation of some policies place only superficial attention on a better answer to the ethical problems (Harding, 2000). Cooperation with local authorities is extremely important for paediatricians, social workers, nurses, therapists, and other professionals working with children with special needs. The education of the child with disabilities in normal schools, kindergartens, inclusion in a normal group, is important for the child and family's rehabilitation, for avoiding social exclusion and it gives the feeling that the child's deficiency is acceptable. The results of various studies

suggest that this preoccupation should be materialized by the inclusion and the transfer of the children with special needs in the general educational system (Levinas, 2003).

Specific hypothesis 4. The perception of the specialists on the factors involved in the interaction with the disabled persons correlate with the non-specialists' perception. In order to verify this hypothesis, the Pearson correlation was used, the significance threshold resulting from the statistical analysis is $p \hat{=} 0,00$ ($p < 0,05$), showing a direct correlation.

Fig.4. Perception concerning the role of the factors involved in the interaction with the disabled persons;



Note: 1 - the state; 2 - each person with disabilities; 3 - each individual; 4 - NGOs;

— perception of people without speciality training

— perception of people with speciality training

Every member of the community has an extremely important role in the perception of both groups (between 43,20% non-specialists - 50 % specialists) to be involved in and to activate within the therapeutic programs involving persons with disabilities. According to the average obtained, the state – represented by the government – is regarded as the main body responsible for solving the problems of the persons with disabilities, first of all from an economic point of view (ensuring the financial resources necessary for the development of the medical and social-educational programs in the best conditions). It can be noticed that the subjects mentioned next the role of the centers / associations, the local authorities and the community to which they belong, in involving in and realising the interactions with the disabled persons. It is considered that only education, work and family create a normal life that involves the same rights and obligations in the society in which we develop our daily activities. This research should be followed by an informing and awareness raising campaign for the general public, in order to improve the mentality concerning the persons with disabilities. The information

campaigns intended to raise people's awareness on the persons with disabilities are often carried out only at theoretic level (Barnes, Mercer and Shakespeare, 1999) with no interaction with these persons, failing to understand their problems, possibilities and limits, their needs and the way in which they manage to respond to the demands of society. The ethical principles applied practically on a regular basis (Atkinson, Garner and Gilmour, 2004) should modify the legislation, so that it supports the social aspects related to rehabilitation, health and education protection, with a view to the integration and normalisation of the disabled persons. Social acceptance and equal treatment of the persons with disabilities is the ideal we aim at within our communities, and, more precisely, social-educational and health service providing.

Conclusions

The results of this study present at a global level the perception on the application of the ethical principles to the medical and social-educational intervention according to the field in which it is developed: in the medical environment (hospitals, health centers, nursing homes, etc.) or in the social-educational environment (schools, recovery centers). Moreover, both the analysis of the influence of the various ways of improving the interaction with the disabled persons within the community, and the important factors in realising the interactions with these persons are analysed.

From the analysis of the specific hypotheses, the following conclusions can be drawn:

1. There are important differences between the perceptions of the specialists / non-specialists in evaluating the ethical methods of collaboration with disabled persons in medical and social-educational activities.
2. The specialists and the non-specialists consider that within the ways of improving the interaction with the disabled persons, the development and creation of some common projects should prevail.
3. As far as the role of the factors involved in the interaction with the disabled persons is concerned, both groups appreciate the fundamental role of each member of the community for the success of integrating these persons. The economical and financial problems are attributed to the state bodies in charge of solving the economical situation of the medical and social-educational activities. Through this study we intended to mirror as clearly as possible the image that the current Romanian society created on the way in which the ethical norms are applied in the medical and social-educational interventions for persons with disabilities.

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