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**SOCIAL AND PEDAGOGICAL ADVOCACY OF THE RIGHTS OF
CHILDREN WITH DISABILITIES¹**

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Abstract

The article focuses on social and pedagogical advocacy of the rights of children with disabilities (CWD). We analysed the specifics of social pedagogics in Russia and determined the following tendencies: parents community takes a proactive approach; there is a high demand for qualified help; it is rather difficult to protect the rights of CWD, when they attend a regular school. School counsellors are responsible for social and pedagogical support and protection of children's rights, and it is, therefore, very important to develop tools for social and pedagogical protection of the rights of CWD. We also analysed the Russian legislation on the rights of CWD to determine and describe the most problematic legal issues. Studying the specifics of protection of the rights of CWD in Russia allowed us to determine the latest tendencies. We also considered the notion of advocacy itself as an activity aimed at protection of the rights of certain groups of people in the form of self-advocacy, case advocacy, and cause (public) advocacy. Based on this analysis, we suggest a description of the specific features of social and pedagogical advocacy of children's rights according to the following parameters: the legal status of the agents, source and initiators of advocacy, and the possibility of combined implementation of social support and social education.

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1. Introduction

School counsellors are responsible for protection of children's rights, and therefore, the scope of their activities includes the following: implementation of the methods of social protection of people coming to various municipal institutions; agency between a child and their parents, as well as institutions, social services, and local authorities; organising social activity.

Social and pedagogical service is a facility provided by the education system. School counsellors, being members of educational institutions, represent the system of social and pedagogical protection. Therefore, they are the first to see any social and legal problems that children face with. Their job is to solve such problems in collaboration with local authorities. The local authorities, in turn, follow the state legislation.

The problem is that quite a number of cases do not fit within the framework of any of the existing laws or legal norms, in which situation school counsellors are not able to help, and parents (or guardians) have to seek solutions themselves.

In such cases advocacy of human rights can be successfully applied.

Social and legal system in Russia regulates the development of legal culture and promotes social and legal protection of certain groups of people, including children with disabilities (CWD). The rights and interests of CWD can be protected by means of social and pedagogical advocacy. Human rights advocacy is an effective tool used by various social organisations and human rights groups. This tool can also be successfully applied to various problems in the sphere of social pedagogics. Hence, it is important to study its theoretical basis and the ways it can be used by social pedagogics. Taking into account the rising awareness of parents community and the growing demand for advocacy services, social workers and teachers feel the need for research-based recommendations on how this advocacy should be implemented. The results of such a research will help to improve the standards of social and pedagogical services, and, consequently, the standard of living of CWD.

2. Research Questions

Considering the need for a research-based model of social and pedagogical advocacy of the rights of CWD, on the one hand, and the lack of theoretical works on social and pedagogical advocacy (and advocacy of the rights of CWD, in particular), on the other hand, it is vital to answer the following questions. What is the current state of theory and practice of advocacy in Russia? What is the specifics of social and pedagogical advocacy of the rights of CWD? To answer these questions we analysed the current state of theory and practice of advocacy, determined the specific features of social and pedagogical advocacy, and then, modelled social and pedagogical advocacy of the rights of CWD.

3. Purpose of the Study

The objective of our study was to determine the specific features of social and pedagogical advocacy of the rights of CWD.

4. Research Methods

The research methods included analysis, generalisation, and interpretation of various studies in law, sociology, psychology, and pedagogics, as well as analysis of existing laws and cases of rights protection. We also modelled certain situations, where social and pedagogical advocacy of the rights of CWD can be used.

5. Findings

Human rights advocacy has been successfully implemented all over the world for over 20 years. The term “advocacy” is not easily translated into Russian, which results in a certain degree of confusion about what it means.

The meaning of the English noun “advocacy” is quite similar to the meaning of the Russian verb “to champion, to advocate”. The English verb “to advocate”, however, means “to protect”, “to recommend”. Thus, advocacy is an act or process of promoting something. Quite often people confuse advocacy with practice of law. “Lawyer activities is the qualified legal aid given on professional basis by persons who received the status of the lawyer according to the procedure, established by this Federal Law, to physical persons and legal entities (further principals) for the purpose of protection of their rights, freedoms and interests, and also ensuring access to justice” (FL, 2002).

The major difference between advocacy and practice of law is that the former can be performed by anyone who is interested, and the latter - only by qualified professionals.

In Russian, the term “advocacy” refers to a certain type of activities concerning mainly social issues (Deshko, 2005).

Advocacy itself appeared in Russia in the late 1990s and quickly became popular with various human rights organisations. At that time advocacy reached its high. A large number of guidebooks on advocacy were published (Levin, 2004; Pishkova & Radichev, 2007). However, after 2010, there have been very few papers on advocacy. Yet, advocacy is a valuable tool, as it gives people an opportunity to be heard. It can influence public opinion and raise awareness and activism in society. Advocacy also encourages the government to actively introduce international laws, protect constitutional rights and provide for state guarantees.

In Russia advocacy is most often done by non-governmental organisations, which work in collaboration with international human rights organisations. They usually promote the rights of people with AIDS, LGBT community, drug addicts, and, in some cases, certain groups of women and children.

There are three general types of advocacy:

- self-advocacy;
- case advocacy;
- cause advocacy.

Self-advocacy is speaking for, representing the interests of, or defending the rights of oneself.

Case advocacy is speaking for, representing the interests of, or defending the rights of another person or specific group of people who are not in a position to defend their rights at that very moment.

Cause or public advocacy is speaking for, representing the interests of, or defending the rights of a general category of people, or the general public (People's advocacy, <http://mognovse.ru/viw-advokaciya-vlaste-i-uchastie-naroda.html>).

Advocacy usually aims to influence government and municipal bodies, organisations and institutions, and initiate legislative and structural changes to meet the interests of individuals or groups of people. Advocacy focuses on social problems, ill-being, and the lack of effective solutions to these problems. It often aims to change the society, policy, or position of certain groups of people. There are two major approaches to advocacy - the Needs-Based Approach and the Rights-Based Approach (A guide in advocacy, <http://docplayer.ru/26941723-Uchebnik-po-advokasi-prakticheskiy-gid-po-razvitiyu-navykov-deystviya-dlya-osushchestvleniya-obshchestvennyh-peremen.html>).

The first one focuses on the identification of people's needs, and the intervention is based on what a community really needs.

The second approach is based on universal human rights. Violation of human rights is the point where advocacy groups start to analyse the issue in order to determine the ways of addressing it.

The definition of advocacy also presupposes that the process includes two parties - an agent and a counter agent.

Advocacy agents usually include

- non-commercial and non-governmental organisations, which are the most active part of the society;
- initiative individuals who are aware of other people's rights;
- initiative members of communities, whose rights are being violated.

The counter agents to advocacy are

- representatives of the government or local authorities (politicians, public figures, lawmakers);
- executive authorities;
- administration of various organisations and institutions.

Social and pedagogical advocacy, or advocacy of the rights of minors, can be considered a separate type of advocacy due to its specific characteristics. It has a number of differences from the other types of advocacy:

- minors are not able to do self-advocacy until they come of age (i.e. until they are 18 years old), and they can only indirectly act as agents within the other types of advocacy;
- the initiative usually comes from parents community;
- it may be rather difficult to determine, whether there is an advocacy issue, as children often do not admit that there is a problem and may be unwilling to solve it;
- apart from the community members, social and pedagogical advocacy may be initiated by a school counsellor;
- besides protecting human rights, social and pedagogical advocacy focuses on social education.

Social and pedagogical advocacy is based on the following principles:

- humanism;

- lawfulness;
- feasibility;
- precision;
- completeness.

The humanism principle presupposes respect for human dignity of any individual in need for advocacy.

The lawfulness principle determines legal methods and ways of action.

The feasibility principle means that advocacy is done only when a problem can really be solved.

The precision principle implies that advocacy focuses on certain individuals or social groups and communities whose rights and interests need to be protected.

The completeness principle means that advocacy is a finite action both in terms of its duration and the result obtained.

Social and pedagogical advocacy may be done to promote the interests of any group of minors. The group whose rights and interests are neglected most often are children with limited health capacities or with disabilities.

We should note that there is no universal terminology in Russian legislation. There are several groups of children with certain health problems who need advocacy, but the government offers different amount of assistance to these children, according to the group they belong to. The best support is offered to children officially given the status of the disabled. The Federal Law “On Social Support for Persons with Disabilities in the Russian Federation” determines a disabled person as “a person who has the violation of health with permanent disorder of functions of organism caused by diseases, consequences of injuries or defects, leading to restriction of activity and causing the necessity of its social protection” (FL, 1995).

Activity restriction is “complete or partial loss by person of capability or opportunity to perform self-service, to independently move, be guided, communicate, to control the behaviour, to study and be engaged in labour activity” (FL, 1995).

But the term “persons with disabilities” is not the only one used in the Russian laws to refer to groups of people with health issues who need state support. Thus, the Federal Law “On the Foundations of Providing Social Services to Citizens in the Russian Federation” determines the legal norms and standards of social services and support to citizens “qualified as individuals who need social support” (FL, 2013).

According to article 15 of this law, an individual is entitled to social support and social services if there exist certain circumstances that are or may be interfering with their activity, including;

- complete or partial loss by person of capability or opportunity to perform self-service, to independently move, and provide for basic needs due to illnesses, injuries, age, or disabilities;
- one or more family members, including children, being disabled and in need for constant nursing care.

Thus, the ground for state social support is not the citizenship, but the existence of a difficult life situation.

The Federal Law “On Education in the Russian Federation” uses the term “children with limited health capacities - individuals with violations of physical or psychological health, as confirmed by the medical, psychological, and pedagogical board, restricting the access to education unless special conditions are created” (FL, 2012).

Regional laws also use various terms such as, for example, “other persons with restricted activity”. Such individuals also need social support. The Law of the Voronezh Region “On Social Support of Certain Groups of Citizens of the Voronezh Region” determines the following groups of citizens as requiring social service:

- people with disabilities;
- individuals with socially significant diseases, individuals with dangerous diseases, and individuals with mental disorders, who are in a difficult life situation.

As we can see, some documents refer to people with disabilities and people with limited health capacities as the same groups, while in others they are considered separately. Russian laws imply that state support is provided only to a limited number of specific individuals or groups. Thus, the Federal Law “On the Foundations of Providing Social Services to Citizens in the Russian Federation” grants social services only to people with disabilities, and the Federal Law “On Education in the Russian Federation” - only to children with limited health capacities, etc.

Not all children with health problems are officially declared disabled, and this happens both because of objective and subjective reasons. The objective reason is that quite often their condition and activity restrictions do not fit within the official medical parameters. The subjective reason is that such children are afraid of being discriminated because of their disabilities, or are simply unwilling to undergo all the formal procedures in order to acquire the official status. Thus, in order to confirm the status of a “pupil with limited health capacities” a child has to take several medical and psychological tests. This may be rather problematic, so parents quite often do not want to put their children through all the formal procedures.

Moreover, the group of children with various health problems who need advocacy is actually much wider. For instance, these are children who have no disabilities or any serious medical issues, but still face constant learning and communication difficulties. The number of such children has become significantly larger recently and exceeds the number of children with disabilities. All these children need regular professional help. Current legislation in Russia does not cover the problems of this group of children, and it is rather difficult to find any legal norms referring to them.

Another and probably the most problematic issue is the right of children with mental and psychological disorders to rehabilitation and education. Such children constitute 75% of the disabled children and 2% of all children in Russia.

In our study, we use a general term children with disabilities (CWD) to refer to children who need advocacy as a consequence of violations in physical or mental health and illnesses restricting their activity, and who tend to have difficulties in learning, communication, and socialisation.

Protection of the rights of CWD, as a social movement, has been developing gradually. Back in 1990s, the Russian government tried to reform the existing Russian legislation in order for it to comply with the international standards. Thus, it adopted several laws based on international rules and laws and

protecting the rights of CWD - the law “On education” (1992) and the law “On social protection of persons with disabilities in the Russian Federation” (1995). These were the first laws in Russia that set the basis for social rights and determined how CWD could enjoy their rights and integrate into society. However, there was not enough practice of applying these laws, the officials were unwilling to do anything, and parents of CWD did not pay enough attention to their rights. As a result, most CWD did not get the necessary rehabilitation and education services guaranteed by the government.

This was followed by a reform in social welfare and a new law “On Benefits Monetisation” (2004), which made the position of CWD much worse. The reform resulted in greater activity on the part of socially vulnerable groups, as they did not want to put up with their position any longer and began protecting their rights. Parents community became more active, which led to a significant improvement in the sphere of children’s rights protection and rehabilitation, and education for CWD. Nevertheless, the need for advocacy of the rights of CWD was still very high, and it was extremely difficult to find social support and obtain rehabilitation, medical, and education services.

There have been significant changes in legislation concerning persons with disabilities over the past ten years. The changes began in 2008, when the Russian Federation ratified the UN Convention on the Rights of Persons with Disabilities. As a result, new laws concerning social issues were adopted, such as the law “On Education in the Russian Federation” (2012).

The terms used to refer to people with disabilities were also reviewed. The UN convention defines persons with disabilities as those “who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (http://www.un.org/ru/documents/decl_conv/conventions/disability).

Disability is thus viewed as a result of interaction with the social environment. When there are no barriers between people with disabilities and the rest of the society, the question of disability does not even arise.

However, the terms used by the legislation in Russia still have certain discrepancies with the UN Convention on the Rights of Persons with Disabilities. The definition of a disabled person remains the same in all the laws. Sufficient social support is only guaranteed to citizens after they undergo the government-set procedure and are declared disabled. In the same way, assistance in learning and education is only available to children whose limited capacities have been confirmed by an official psychological, pedagogical and medical council. The UN Convention, however, does not differentiate between various types of disability. It implies that its provisions should be applicable to any person with permanent health disorders leading to restriction of activity, regardless of whether they have an official status of the disabled.

Conversely, Russian laws require children with health violations to undergo medical and psychological examination. Otherwise they will not obtain any social support from the government. The scope of the social services they obtain also depends on their official status.

This generally explains why a great number of CWD do not get the help and support without which their development and socialisation remains rather problematic.

Another characteristic feature of the kind of social support CWD get in Russia is that the government focuses only on protecting their right to life in the form of medical care, rehabilitation equipment, financial support and in-kind aid, i.e. anything that ensures that CWD eat properly, have a home and access to medical treatment. Financial support to CWD is meant by the law as a compensation for the extra expenditures, but in fact it most often only compensates parents for not being able to work full time.

In most cases, medical and financial support provided to CWD does not serve the purpose intended by the laws, i.e. enhance socialisation and integration of CWD in society.

One of the major objectives of state support to people with disabilities, including CWD, is stated in the UN Convention as follows: “States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes enable persons with disabilities to attain full inclusion and participation in all aspects of life” (http://www.un.org/ru/documents/decl_conv/conventions/disability). In other words, social support should aim at providing CWD with an opportunity to enjoy the same rights as healthy children.

Taking into account the above mentioned discrepancies in the legislation, we defined the major spheres where social and pedagogical advocacy is required:

- education (from pre-school learning to higher education);
- medical care and social services;
- social, psychological, and pedagogical support in learning and rehabilitation (habilitation).

Social rights movement in Russia faces the following obstacles:

- imperfections in the current legislation (confusion and controversy);
- problems related to the implementation of laws (lack of proper instructions on the implementation of laws, insufficient subordinate legislation);
- law enforcement problems (legal ignorance of senior officers and authorities, officials thinking in stereotypes and reluctant to introduce any changes);
- in case of doubt or ambiguity in laws, CWD are less likely to receive help. Another major problem is that stereotypes still prevail in the society and general public tend to regard CWD and adults with disabilities as a burden to the state budget.

6. Conclusion

Advocacy is vital for children with health limitations and special needs. Although the Russian government has adopted a number of progressive laws aiming to promote social rights, the implementation of these laws is a very slow and complicated process. The situation is aggravated by the unwillingness of the officials of various levels to change the current state of affairs, and the need for a dramatic change in the entire social system. Today CWD very rarely receive adequate state support, and it takes a lot of time and effort to obtain it.

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