

8th icCSBs 2019
**The Annual International Conference on Cognitive - Social,
and Behavioural Sciences**

**SOCIAL AND PEDAGOGICAL ADVOCACY FOR CHILDREN
WITH DISABILITIES: CONDITIONS AND REQUIREMENTS¹**

Ekaterina Valentinovna Alekhina (a)*, Tatyana Evgenyevna Povetkina (a),
Belozertsev Evgeniy Petrovich (a)
*Corresponding author

(a) Voronezh State Pedagogical University, Lenina St., 86, Voronezh, Russia, 394043, sp320@mail.ru

Abstract

The article describes specific features of advocacy of the rights of children with disabilities (CWD). It also considers the most important requirements for advocacy of the rights of CWD, such as personal data security, psychological and ethical norms, as well as the specifics of social, education, and healthcare systems in the region. The most common problems that need advocacy are described in detail. These problems primarily concern education, medical treatment, social and pedagogical support. Types of advocacy activities are listed. Among the most common activities are face-to-face individual consultations, phone consultations, online, e-mail, or group consultations (both face-to-face and online), on-site counselling, as well as accompanying parents to public institutions and other organisations to solve any arising problems. The article also describes the structure of an advocacy counselling session. In our research, we studied the advocacy activities of the Voronezh regional organisation for the disabled “Iskra nadezhdy”. Having analysed 177 requests from 23 subjects of the Russian Federation, we accumulated statistical data on the situations that require advocacy of the rights of children with disabilities.

© 2019 Published by Future Academy www.FutureAcademy.org.UK

Keywords: Social and pedagogical advocacy, children with disabilities, conditions and requirements for advocacy.

¹ The reported study was funded by RFBR according to the research project № 18-013-00545



1. Introduction

Social and pedagogical advocacy of the rights of children with disabilities (CWD) protects the rights of this particular group of children. It can be initiated either by parents, or by other concerned individuals. The analysis of the actual cases of advocacy demonstrated that this kind of advocacy has certain peculiarities as to its conditions, forms, activities, and the scope of problems it covers.

2. Problem Statement

Social and pedagogical advocacy protects the rights of various groups of children. Advocacy for children with disabilities requires a different approach.

3. Research Questions

What is the specifics of social and pedagogical advocacy of the rights of CWD? What are the major spheres where social and pedagogical advocacy is required?

4. Purpose of the Study

The objective is to determine the conditions under which social and pedagogical advocacy of the rights of CWD takes place and the situations when it is required. The former will help to enhance the advocacy effectiveness. Analysing particular cases, we can determine the problems and classify the situations requiring advocacy.

5. Research Methods

The research methods included analysis and generalisation of existing laws and cases of rights protection. We also modelled certain situations when social and pedagogical advocacy of the rights of CWD can be used.

6. Findings

Social and pedagogical advocacy is a kind of human rights activity that takes place when parents of CWD, public organisations, or concerned individuals organise an advocacy campaign for a particular violation of rights and interests of a minor, if this violation affects successful socialisation and upbringing (Levin, Logginova, Semerik, & Trukhan, 2004; Pishkova & Radichev, 2007; People's advocacy..., 2019).

Social and pedagogical advocacy focuses on various aspects, such as protection of rights and interests, socialisation, and upbringing of a particular child.

Rights and interests protection involves parents of CWD, CWD themselves, representatives of public organisations, and individual champions of human rights. Relations between these people cannot be classified as legal relations, as they most commonly are not regulated by any formal contracts or agreements.

From the social relations perspective, relations occurring during the process of advocacy can be defined as both altruistic and pragmatic.

A specific feature of advocacy is that it protects the rights and interests of the most vulnerable groups of people. In our case, they are children with disabilities. Therefore, the relations between the agents of advocacy (i.e. non-commercial and non-governmental organisations, active individuals, and active members of parent communities) are classified as altruistic. Advocacy is a non-commercial activity, and the agents of advocacy do not aim at gaining any financial profit. In other words, all the advocacy activities are performed on a voluntary basis, i.e. for free (A guide in advocacy... 2019).

At the same time, for the subjects of advocacy, i.e. children with disabilities, restoration of their rights and interests may bring direct (either monetary or non-monetary) and indirect financial benefits (e.g. a chance to attend schools not far from home, rehabilitation and correctional aids provided by the state, etc.). This is why advocacy can also be classified as pragmatic.

To perform advocacy, one has to consider a number of factors, such as:

- personal data security;
- psychological and ethical norms of working with CWD and their families;
- the specifics of social, education, and healthcare systems in the region.

These requirements are set by the Federal Law “On Personal Data” № 152-FZ of 27.07.2006. According to the law, personal data is “any information referring directly or indirectly to a particular or identified individual (hereinafter referred to as “personal data subject”)” (Federal Law..., 2006). The person performing advocacy thus acts as an operator who “independently or in cooperation with other entities organizes and/or processes personal data as well as determines the purposes and scope of personal data processing”.

Social and pedagogical advocacy covers the following issues: education; medical and social service; social and pedagogical support (Egupova, 2012).

The reasons why parents of CWD seek advocacy depend on the age of their child and the type of problem they face. Most often, there is a set of problems they have to deal with. For example, getting the correct diagnosis and choosing an adequate education path come hand in hand.

An accurate diagnosis is of great importance when applying to kindergarten or school. According to the Russian laws, if a child has disabilities or other health issues, the medical, psychological, and pedagogical board requires a precise diagnosis. Otherwise, the board will not issue the documents which entitle the child to the help he or she will need at a particular educational institution, such as special environment and adaptive academic programmes.

Advocacy also focuses on the following problems.

- Negligence of the medical staff performing early screening, or complete absence of screening, which results in the diagnosis being determined too late or established without any standard tests or methods, which means it is not accurate.

- Doctors often lack the information about the education, rehabilitation and other paths of children with cognitive, mental, or severe physical disorders. Being unaware of these aspects, doctors tend to say unprofessional things, such as “send him/her to a care facility and get a new baby”, “s/he is never going to speak”, “s/he is unteachable”, etc.

- The family does not get any systematic, adequate, and guaranteed support (there are just a few voluntary advocacy projects).

- Stigmatisation of the family and the child (actual and expected).

- Lack of easy and state-guaranteed ways to receive any help.

- Parents do not fully trust doctors and are reluctant to follow their prescriptions.

- Medical institutions refuse to give parents their child's medical records.

- Parents do not understand the recommendations given by doctors, which means they cannot use them to develop rehabilitation and education strategies for their child and determine the ways to compensate for particular deficiencies.

- The child does not receive comprehensive medical treatment, as it is difficult to cure physical illnesses in children with mental disorders. Another problem is that a lot of laboratory and other medical tests are not available for free, even though they are included in the medical insurance.

- Most doctors at local hospitals and medical centres know very little about mental disorders and related illnesses and avoid working with children with any mental, cognitive, or behavioural disorders.

- Psychiatrists and neurologists monitoring the child do not provide recommendations for other specialists (for example, on how to deliver dental care, whether or not to use anaesthesia and how to do it, or how to perform any other medical procedures).

- Difficulties occurring while visiting a doctor (long queues, few appointment options).

- Parents are often not allowed to stay with children admitted to hospital. Most often, the refusal is not well grounded, and if any reasons are given, it is not possible to assess their adequacy.

- Doctors are unable to recognise pain syndrome and relieve pain in children who are not able to speak or understand other people.

- Parents of children with autism, mute children, or children who are unable to understand what others say to them, are reluctant to use WAIS to measure their intelligence.

One of the reasons causing these problems is that parents tend to be very reluctant to admit that their child has any developmental disabilities.

Besides advocacy itself, parents living in small towns and villages, which do not have any advocacy groups, require assistance with the following issues:

- creating and registering an advocacy organisation;

- submitting a collective, adequately formulated request to the local authorities;

- finding sponsors to develop a support system in the region;

- organising education process and supervision by specialists;

- monitoring the situation;

- developing various models of inclusive education for children with disabilities.

We would like to point out that according to the Russian laws, it is for the parents to decide whether their child should receive medical treatment or not. The same concerns education: only parents have the right to select the mode and scope of learning. The choice that parents make should be justified. They have to consider all the parameters of the situation in order to make it beneficial for their child. Members of non-commercial organisations provide parents with all the informational, organisational, legal, and any other support they need to make a justified and well-grounded decision.

Non-commercial advocacy organisations have developed certain forms of interaction with parents. One such form are consultations: face-to-face individual consultations, phone consultations, online, e-mail, or group consultations (both face-to-face and online), as well as accompanying parents to public institutions and other organisations to solve any arising problems. Together with governmental and non-governmental organisations, they also perform on-site counselling. Members of non-commercial organisations may also act on behalf of children and protect their interests during the tests performed by the medical, psychological, and pedagogical board, medical and social examination, or during meetings with the heads of education or medical institutions. Support of a qualified specialist is most effective when provided directly on the site where parents or CWD face any problems, i.e. at education, medical, or rehabilitation institutions.

Face-to-face counselling is the most effective form of communication with the family. Due to a number of factors, face-to-face counselling is of primary importance. During the consultation, counsellors help parents to formulate their requirements more clearly or reformulate them completely. To file a correct request, certain level of knowledge and experience is required. Parents most often lack the knowledge they need to make a decision, as the state support system seems rather complicated to anyone who is not experienced in the sphere. Sometimes the request formulated by the end of the consultation appears to be different from the initial one.

A consultation for parents is usually based on the following scenario.

- 1) First, the counsellor lets the parents describe the problem, employing active listening and encouraging them with guiding questions.
- 2) The counsellor tells parents about the child's rights and prospects. It is vital to make parents understand that if they want to get any support from the government, they need to file written requests.
- 3) The counsellor helps parents to select the institution for medical examination and the institutions for further health screening, and tells about the kind of documents they will need.
- 4) The counsellor explains the benefits of the child being officially recognised as disabled and tells about the formal procedure. It is important to encourage parents to tell about their fears concerning this step, and ensure them that there is nothing to be afraid of.
- 5) It is also important to explain to parents why they need a formal resolution of the medical, psychological, and pedagogical board. The counsellor stresses that the resolution will help to protect the child's right to education and special education environment.
- 6) The next stage includes making a list of educational and/or rehabilitation institutions, which fit certain criteria (primarily the criteria of location and qualification level).

Advocacy counsellors should also bear in mind that parents have to admit that their child has intellectual disability. Most parents are reluctant to admit it because of their fears, which result from the lack of information, social myths, and the stigma of mental illness. Parents fear that the diagnosis "intellectual disability" will interfere with successful socialisation and prevent their child from getting education and acquiring a profession. They fear that their child will be rejected by the society.

They also fear that they will get older and eventually die, and there will be no one to take care of their child. At present, this problem is the most difficult to solve in Russia. Various non-governmental

organisations focus most of their attention on the problem and work hard to ensure a decent life for people with mental and intellectual disabilities.

An important part of the advocacy process is assigning the so-called social partners for particular families. A good social partner may help to solve the family's problems efficiently. Upon preliminary agreement, social partners are selected during the first consultation. For example, the counsellor can make an appointment for the family with the medical board, send their case directly to the social welfare service to solve the existing problems, request help from charitable foundations, or recommend parents to go directly to any of the early support services.

Awareness of the existing education institutions, social projects for both teenagers and adults, and the ways to help their child, gives parents confidence and helps them to overcome their fears about the child's future.

Informational support for families with CWD includes the following steps:

- initial individual consultation;
- determining the causes of the problem and working out an adequate solution (reformulation of tasks);
- choosing social partners who can help to resolve the problem;
- developing further strategies;
- psychological support (group meetings and individual consultations);
- workshops, webinars and training sessions for parents (and specialists) on the regulatory basis for education;
- on-site events at education, social, and medical institutions, including the events organised for parent communities;
- assistance in creating groups of parents who act together in order to solve a common problem, occurring either on the governmental level, or at a particular institution;
- organising awareness-raising events at educational institutions;
- collecting, exchanging, and distributing information among parents and the rest of the public.

Taking into account the degree of pressure on parents of CWD, it is necessary to monitor the results of the informational support. It is vital to make sure that parents understand everything they hear during the consultation. It may be advisable to ask them to repeat all the recommendations, as it often happens that people interpret the information incorrectly. It may also be useful to rephrase the information and ask parents to check, if they have written everything down correctly. Another way is to print out the recommendations yourself and give them to parents.

In our research, we analysed the number of requests for advocacy and the types of problems that need advocacy in 2018, using the data provided by the Voronezh regional organisation for the disabled "Iskra nadezhdy". Given below are the results of the analysis.

In 2018, requests for advocacy campaigns came from 23 subjects of the Russian Federation, including Moscow, Voronezh, the Voronezh Region, Volzhsk (the Mari El Republic), Belgorod, Bryansk, Ekaterinburg, Zhygulevsk (the Samara Region), Ivanovo, Irkutsk, Kostroma, Tula, Tambov, Omsk, St.Petersburg, Tyumen, Yakutsk, Rostov-on-Don, Makhachkala, Gornyyak (the Altai Region), Maikop, Yugra (Khanty-Mansi Autonomous Okrug), Krasnodar, and Barnaul.

All in all, in 2018, there were 177 requests. Given below is the list of problems.

- 1) Providing special educational environment for people with disabilities - 67 requests.
- 2) Official procedure of disability confirmation for people with disabilities, re-examination procedure by the medical and social board; appeal of the decision of the medical and social board; development and implementation of a personalised rehabilitation/habilitation programme for a disabled child - 24 requests.
- 3) Comprehensive medical examination by the medical, psychological, and pedagogical board - 14 requests.
- 4) Individual court applications and applications to other governmental and non-governmental institutions - 10 requests.
- 5) Admission of individuals with disabilities, including CWD, and the disabled to educational institutions; procedures of school transfer and enrolment termination - 9 requests.
- 6) Vocational training for people with disabilities - 5 requests.
- 7) Health resort treatment for people with disabilities - 7 requests.
- 8) Provision of housing for families of people with disabilities - 5 requests.
- 9) Free legal assistance - 5 requests.
- 10) Guardianship and custody issues - 3 requests.
- 11) Pensions - 2 requests.
- 12) Preferential provision of medicines for the disabled - 4 requests.
- 13) Medical treatment - 2 requests.
- 14) Preferences and benefits for families of the disabled - 4 requests.
- 15) Provision of land - 3 requests.
- 16) Restriction of legal capacity - 2 requests.
- 17) Other - 1 request.

Advocacy campaigns were aimed at such organisations as education management units, health authorities, and the Pension Fund.

7. Conclusion

Social and pedagogical advocacy of the rights of CWD has a number of special features, starting with the subjects of advocacy (CWD, their parents or guardians, and other concerned individuals) and up to the conditions, forms, and stages of advocacy. Statistical analysis of requests for this kind of advocacy demonstrated that there are over 17 spheres, where CWD face problems and require social and pedagogical advocacy of their rights.

Acknowledgments

The authors express their sincere gratitude to Tatiana Shatalova, a lawyer at the Voronezh regional organisation for the disabled “Iskra nadezhdy”, for her assistance in analysing the actual data.

References

- A guide in advocacy: developing skills to perform social changes (2019). Retrieved from <http://docplayer.ru/26941723Uchebnik-po-advokasi-prakticheskij-gid-po-razvitiyu-navykov-deystviya-dlya-osushchestvleniyaobshchestvennyh-peremen.html>
- Egupova, M. A. (2012). Constitutional and legal ways of enforcement of the right of people with disabilities to education. Krasnodar.
- Federal Law "On Personal Data" № 152-FZ (2006, July 27). Retrieved from http://wko.at/ooe/Branchen/Industrie/Zusendungen/FEDERAL_LAW.pdf
- Levin, A., Logginova, L., Semerik, O., & Trukhan, E. (2004). Organising advocacy campaign. A guidebook. EuroCASO's Eastern European Partnership Office. Retrieved from http://edu.helsinki.org.ua/sites/default/files/userfiles/eurocaso_ru.pdf
- People's advocacy: working for people's power and involvement (2019). Retrieved from <http://mognovse.ru/viv-advokaciya-vlaste-i-uchastie-naroda.html>
- Pishkova, O. V., & Radichev, A. F. (2007). Advocacy - children's rights (a study guide). Moscow: Human Rights. The Convention on the Rights of Persons with Disabilities. Retrieved from http://www.un.org/ru/documents/decl_conv/conventions/disability