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# Tutoring in a family raising an infant with special health needs

## Tutoría en una familia criando a bebé con necesidades especiales de salud

Victoria Sergeevna VASILYEVA 1; Liliya Aleksandrovna DRUZHININA 2; Lyubov Mikhaylovna LAPSHINA 3; Larisa Borisovna OSIPOVA 4; Elena Vasilyevna REZNIKOVA 5

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ABSTRACT:

The article deals with topical issues on developing the tutoring institute within the system of complex assistance to families raising an infant with special health needs. The data of scientific research confirming the hypothesis about the role of tutors in the correction and rehabilitation process and the impact of their activities on the expansion of social space, the individualization of correctional work, and the development of rehabilitation competence of parents raising infants with special heals needs are presented. The professional activity of a tutor is considered from the standpoint of an important condition in preventing the emergence of secondary disabilities in the development of children, expanding the possibility of implementing an individual educational program in working with the family, overcoming the social isolation of this category of families, increasing the competence of parents in child's socialization, preventing surrenders of children with disabilities.

**Keywords:** tutor, assisting a family of an infant with special health needs, disabled children, rehabilitative competence of parents.

#### **RESUMEN:**

El artículo trata temas de actualidad sobre el desarrollo de tutoría institucional dentro del sistema de asistencia a las familias que crían a un bebé con necesidades especiales de salud. Los datos de investigación científica que confirman la hipótesis sobre el rol de los tutores en el proceso de corrección y rehabilitación y el impacto de sus actividades en la expansión del espacio social, la individualización del trabajo correccional y el desarrollo de la competencia de rehabilitación de padres que crían infantes de atención especial. Se presentan las necesidades de sanación. La actividad profesional de un tutor se considera desde el punto de vista de una condición importante para prevenir la aparición de discapacidades secundarias en el desarrollo de estos niños, ampliando la posibilidad de implementar un programa educativo individual para trabajar con la familia, superando el aislamiento social de esta categoría de familias, aumentando la competencia de los padres en la socialización del niño, previniendo entregas de niños con discapacidades.

**Palabras clave**: tutor, ayudar a una familia de un bebé con necesidades especiales de salud, niños

discapacitados, competencia de rehabilitación de los padres.

#### **1. Introduction**

Currently, the scientific community and practitioners are actively discussing innovative processes in the system of early care for children with special health needs and are developing issues to expand the field of services for parents raising this category of children.

E.A. Ekzhanova, Yu.A. Razenkova, and E.A. Strebelova note in their studies that if the system of early detection and comprehensive assistance to families raising disabled infants and infants with special health needs (SHN) is optimized, it will be possible in 35-50% of cases to reach the age norm, in 50-75% of cases to prevent the progression of severe developmental disorders, and in 85-95% of cases this system will contribute to preventing surrenders of children (Ekzhanova, & Strebeleva, 2008; Razenkova, 2011; Nazarova, 2008).

An analysis of modern scientific research and the experience of scientific and practical activities prove the relevance of the topic under consideration, which is conditioned by the following issues:

- the needs of infants with health disabilities for effective integrated support of their development and an inadequate efficiency in using technologies to correct developmental disorders of children, taking into account their individual characteristics of psychophysical development;
- significant potential opportunities of a family raising an infant with SHN and low level of rehabilitation competence of parents necessary for their inclusion into the modern correctional and rehabilitation space and social environment;
- an increase in the incidence of tutors in the early care system for the comprehensive development of infants with SHN and in the assistance to their families and the lack of evidence-based, organizational, managerial and methodological bases for the development of a system of comprehensive assistance to families that raise infants with SHN in social protection and preschool educational institutions.

The relevance of the study is also confirmed by statistical data provided by the Ministry of Health of the Russian Federation. It is noted that in recent years, there has been a positive trend towards a decrease in the number of children whose developmental disorders were diagnosed at birth and in the first months of life (born sick or went sick: in 2013 - 623.2 thousand newborns, in 2014 - 630.8 thousand newborns, and in 2015 - 607.4 thousand newborns). At the same time, the percentage of children with congenital anomalies in the last five years remains practically unchanged at 2.9% (with an increase in 2013 up to 3%). It is important to note that there is a negative tendency to increase the number of children first recognized as disabled from 72,801 persons in 2014 to 73,106 in 2016, which naturally affects the stable increase in the number of disabled children in the Russian Federation as a whole.

Studying the degree and depth of the scientific elaboration of problems in tutoring a family that raises an infant with SHN made it possible to systematize existing studies, which are the main structural components of the problem under consideration.

## 2. Materials and methods

The studies by E.F. Arkhipova, O.G. Prikhodko, Yu.A. Razenkova, E.A. Strebelova et al., as well as the studies by foreign authors, discuss the need for early diagnosis of psychophysical developmental disorders in children (Arkhipova 2012; Ekzhanova, & Strebeleva, 2008; Prikhodko, & Yugova, 2015; Razenkova, 2011; Hellbrügge, Lajosi, Menara, Schamberger & Rautenstrauch 1985). The logical continuation is an analysis of studies by I.Yu. Levchenko, A. Moskovkina, M. Seligman, V.V. Tkacheva et al., which reveal the role of the family in the psychophysical development of infants with SHN (Levchenko, & Tkachev, 2008; Moskovkina, 2015; Dobryakov, & Zashcharinskaya, 2007; Seligman, & Darling, 2013; Tkacheva, Arkhipova, & Butko 2014). At the same time, L.A. Druzhinina, E.A. Ekzhanova, L.B. Osipova, O.G.

Prikhodko, E.V. Reznikova, E.A. Strebeleva, leading domestic and foreign experts prove the need for special methodological support for early assistance to families raising children with SHN and disabled children, taking into account the current trends of special (corrective) and inclusive education (Andryushchenko 2016; Ekzhanova, 2016; Ekzhanova & Strebeleva 2008; Kudrin & Serkina, 2013; Prikhodko & Yugova, 2015; Nazarova 2008; Kruse 2012; Naig 2010; Johnson-Martin, Attermeier & Jens 1986).

Considering innovative processes in the system of national education in general, it can be concluded that the requirements to the level of professional training of specialists working with children with SHN are significantly increased. The studies by L P. Anisimova, V. S. Vasilyeva, Yu. A. Razenkova present the data on the need to improve the professional competence of specialists working with children with SHN (Anisimova 2002; Anisimova 2002; Razenkova 2011).

A modern trend in improving the quality of providing not only educational services in general, but also correctional and rehabilitation services in particular, can be considered the introduction of the institute of tutoring, which is regarded as an innovative technology in the education system as a whole. At the same time, E. Gordon, T.M. Kovaleva, E.B. Kolosova, N.V. Pilipchevskaya et al. note that the tutor's profession is new for Russian education. At the same time, as practice shows, tutor services are quite in demand in the modern educational environment, which is at the stage of reform. At the same time, tutors can ensure the creation and implementation of an individual educational program (Gordon, & Gordon, 2008; Kovaleva, Kobyshcha, Popova (Smolik), Terov, & Cheredilina, 2012; Kolosova 2008; Pylypchevskaya 2009).

Given that the fundamental condition for the quality of providing correctional and rehabilitation care for infants with SHN is their continuous support, the development of the institute of tutoring is becoming topical in order to expand the field of social interaction and build up rehabilitation competence in parents and ensure the integrity and complexity of this process.

Taking into account the modern spectrum of scientific research, it is important to note that the issues of early care for children with SHN are relevant and deeply and comprehensively considered by specialists from many scientific fields (pedagogy, psychology, neurology, and sociology). At the same time, the introduction of the institute of tutoring into the system of comprehensive assistance to a family raising an infant with SHN, for objective reasons, remains insufficiently studied (Vasilyeva, Kuznetsova, Politskaya, & Abulkhanova 2017) and is not the subject of scientific research.

The basic conceptual provisions of the theory of early care make it possible to consider it as a complex of psychological, pedagogical and medico-social measures aimed at ensuring and improving the development of newborns and infants with SHN or the risk of their emergence, for the maximum possible socialization of children, including information, methodological, psychological, pedagogical and advisory assistance to their parents (legal representatives). At the same time, it is important to note that early care includes diagnosis of child development; diagnostics of resources and family needs; prevention or correction of abnormalities in the development of a child; support and assistance to family.

On the issue of optimizing early care for children with SHN, there are several points of view that can be reduced to two main ones: expanding the range of integrated early care services for children with SHN and the need to include parents into the process of accompanying a child, while helping families that raise this category of children.

Based on the data of modern science, regarding the questions of rendering assistance to families that raise infants with SHN as well as the results obtained during the synthesis and analysis of existing experience, a questionnaire has been prepared and a survey of parents (legal representatives) raising infants with SHN has been conducted with a view to determining the parents' request for the provision of services for comprehensive early care of children with SHN and for determining the possibilities for including parents into this process.

The questionnaire includes 30 questions systematized in 6 blocks (5 questions per block), allowing a comprehensive study of parents raising infants with SHN to determine their level of rehabilitation competence and determining the structure of the request for comprehensive support in order to provide a corrective-rehabilitation assistance, taking into account the individual characteristics of each family and a particular child.

The questions are divided into 6 main blocks, which allow drawing a conclusion about the following issue:

- the level of formation in parents of the knowledge that ensures the complexity of rehabilitation activities, taking into account the individual psychophysical characteristics of a child;
- the level of formation in parents of the skills of providing practical medical assistance to children;
- the level of formation in parents of the skills of providing practical social assistance to children;
- the level of formation in parents of the skills of providing practical psychological assistance to children;
- the level of formation in parents of the abilities and habits to regulate their own psychological and emotional state;
- the structure of the parents' request for comprehensive family support and the possibilities of providing correctional and rehabilitation assistance to children.

Analyzing the answers provided by the respondents makes it possible to make conclusions about the level of rehabilitation competence of parents, the possibility of including their comprehensive system of child rehabilitation and the specifics of the tutor's work.

## 3. Results

The rehabilitation competence of parents that raise infants with SHN is understood as the totality of objectively necessary knowledge, skills and abilities, personally significant qualities of an individual solving the tasks of teaching, raising and developing a child with disabilities, taking into account the features of his/her psychophysical development in conditions of the social and rehabilitation space.

For a number of years, scientific research has been conducted on the basis of preschool educational organizations and social rehabilitation centers in Chelyabinsk, and it has used questioning as one of its methods. 685 respondents have taken part in the survey within 3 years. The data obtained in the course of the study indicate that there is a stable tendency to maintain a sufficiently large number of parents, for whom a reduced level of rehabilitation competence is characteristic (Table 1).

Assessment of results	2014	2015	2016	Total
Number of respondents	215	225	245	685
	100%	100%	100%	100%
Low level of rehabilitation competence	55	54	62	171
	(25.6%)	(24.1%)	(25.3%)	(25%)
Reduced rehabilitation competence level	44	48	51	143
	(20.4%)	(21.3%)	(20.8%)	(21.2%)
The relatively satisfactory level of rehabilitation competence	84	91	95	270

Table 1Indicators of the level of rehabilitation competenceof parents raising infants with SHN

	(39.1%)	(40.4%)	(38.8%)	(39.2%)
Satisfactory level of rehabilitation competence	24	25	28	77
	(11.2%)	(11.1%)	(11.4%)	(11.3%)
High level of rehabilitation competence	8	7	9	24
	(3.7%)	(3.1%)	(3.7%)	(3.5%)

A low level of rehabilitation competence of parents is present in 171 (25%) respondents and is characterized by a lack of any knowledge regarding possible rehabilitation activities, the predominance of their superficiality, inadequacy, lack of any skills of providing practical help to children of medical, psychological, social and household character. 143 (21.2%) respondents demonstrate unsystematic knowledge, possession of separate skills of helping child and their episodic, irregular use in practice, fetishizing the value of certain types of rehabilitation and denying others, which corresponds to a reduced level of rehabilitation competence. The most numerous group consists of parents whose level of rehabilitation competence can be characterized as relatively satisfactory - 270 (39.2%) persons. They are characterized by insufficient knowledge and skills in the rehabilitation of children, the cyclical nature of adequate involvement in the provision of rehabilitation activities, and insufficient understanding of the need for comprehensive medical, psychological and social rehabilitation. A satisfactory level has been identified in 77 (11.3%) respondents. This group is characterized by sufficiently complete knowledge and skills that are realized in practice, adequacy and interest in carrying out rehabilitation activities in combination with socioeconomic difficulties (for example, low material wealth, chronic shortage of time, etc.). The smallest group consists of parents who have a high level of rehabilitation competence -24 (3.5%). This group is characterized by extensive knowledge and skills, their practical implementation, the social and economic well-being of the family in terms of the possibility of providing a child with a whole range of rehabilitation services.

Simultaneously, based on the survey, the parents' request for comprehensive support not only for children, but also for the family as a whole is studied and analyzed. The analysis of the data obtained identifies a steady trend in increasing the number of requests concerning the relevance of the role of parents in expanding social contacts, obtaining the necessary knowledge in the issues of child upbringing and development, the need for comprehensive psychological assistance to parents themselves who are constantly in a state of stress caused by objective difficulties in raising an infant with SHN. There are several groups of characteristic requests:

- assistance to a family raising a child with SHN;
- assistance to a family raising a child with a complex defect structure;
- assistance to parents in the process of building interaction with infants with SHN, due to the lack of not only practical skills, but also theoretical knowledge in these matters.

The parents' interest in obtaining assistance from all the specialists taking part in supporting a child is high, while the parents note a high role of a coordinator (tutor) capable of providing qualified answers to current and existing questions, and in case of difficulties, giving recommendations and referring them to narrowly specialized specialists who disclose issues of individual characteristics of children.

## 4. Discussion

As a result of the study, the material has been obtained, the analysis of which has led to the conclusion that modern research that develops innovative technologies in the system of special (corrective) and inclusive education is increasingly justifying the possibility and necessity of

introducing the institution of tutoring in this field.

According to I.V. Karpenkova and E.V. Kuzmina, tutorship is a practice oriented towards the construction and implementation of a personal educational strategy that takes into account the person's individual potential, the educational and social infrastructure, and the tasks of the main activity. This definition supports the idea that tutoring in the pedagogical process is based on the principles of complexity and individualization. Considering the specifics of introducing tutoring into the system of special (corrective) and inclusive education, it is important to note that it implies a system of organizing special conditions for each child with SHN and his/her family, based on his/her zone of "actual" and "nearest" development.

As noted above, statistical data show that recently, due to objective and subjective reasons, the number of children with SHN has increased significantly in terms of manifestations and severity. Therefore, the specialists have an acute need for the allocation of new assistance technologies and the provision of comprehensive assistance to parents experiencing certain difficulties in the process of interacting with this category of children.

Not always, because of objective socio-economic conditions, the family can receive professional assistance necessary for permanent comprehensive care, even in conditions of a social rehabilitation center and preschool educational organization. Parents often face difficulties due to the lack of specialists, the inability to leave a child in need of constant monitoring by an adult to receive individual counseling and psychological help to them as parents.

In solving all the issues mentioned, tutors play an important role in fulfilling the tasks of comprehensive assistance to families raising an infant with SHN. At the same time, it goes not only about professionally trained specialists, but also about volunteer students who, under the guidance of specialists from social rehabilitation centers and pre-school educational organizations, can take part in assisting a family that raises an infant with SHN.

It is necessary to clarify that the tutor's assistance is considered based on the studies presented by the specialists of the Interregional Tutoring Association (Moscow), who propose the following wording. A tutor's assistance is "the tutor's movement along with the changing personality of the tutored person, next to the tutor, developing and realizing his personal individual educational program, implementing timely navigation of possible ways, if necessary, providing assistance and support" (Kovaleva, Kobyshcha, Popova (Smolik), Terov, & Cheredilina, 2012). At the same time, the role of the tutor is performed by highly qualified specialists who have the appropriate education and volunteer students taking part in this process and providing appropriate assistance in the process of carrying out all correctional and rehabilitation measures. A tutored person is a family raising an infant with SHN (a child himself and his parents).

Psychological and pedagogical assistance to a family raising an infant with SHN within the toy library (lecotheque) is one of the tutor's work forms. As E.P. Kudryavtseva notes, it is especially effective in the period of the child's stay in the social rehabilitation center and in the period of his/her adaptation in the pre-school educational organization (Kudryavtseva 2013).

Toy library is a service of psychological and pedagogical assistance, in the conditions of which children are provided with psycho-prophylactic, psycho-corrective help through gaming activity.

The goal of organizing the activity of a toy library is to provide medical and psychologicalpedagogical assistance to infants with SHN, disabled children (not attending a pre-school organization) and their families to develop skills of social adaptive behavior, form the prerequisites for learning activities, support the development of the personality of children and provide psychological and pedagogical assistance to parents.

The main tasks are as follows:

- ensuring access to early correctional care for children with SHN, children with disabilities;
- implementing consultative and methodological assistance to families raising children with SHN, disabled children of early and preschool age;

 organizing by tutor of individual correctional and developmental assistance to infants with SHN, children with disabilities.

Participants of educational relations as part of a toy library are different pedagogical specialists (tutors, teacher-defectologists, speech therapists, special psychologists, music teachers, instructors of exercise therapy), parents. The coordinator of the work is a tutor who has a special (defectological) education.

The main priorities are:

- studying comprehensively infants with SHN, disabled children and their families (with the written consent of parents (legal representatives));
- compiling and implementing an individual correction-development program according to the peculiarities of psychophysical development and individual abilities of children;
- conducting corrective-developing activities with infants with SHN, children with disabilities;
- conducting psycho-preventive and psycho-corrective work with families raising infants with SHN and disabled children;
- assisting parents in the selection of appropriate means of communication with their children;
- teaching parents methods of gaming interaction with infants with SHN and children with disabilities in the context of the subject-spatial environment of a toy library;
- coordinating activities of participants in correctional, rehabilitation and educational relations within the framework of psychological and pedagogical assistance to infants with SHN, disabled children and their families.

To implement the tasks and directions of the toy library's work, it is necessary to create an object-spatial environment that includes diagnostic tools, teaching aids, didactic manuals, games and materials.

Let us list some organizational requirements to the arrangement of corrective-developing work with children in a toy library:

- a child is enrolled to a toy library based on the conclusions of the psychological, medical and pedagogical commission;
- specialists of preschool educational organizations (social rehabilitation centers) conduct an interview, during which the basic information about the child's family is systematized and a decision is made to enroll the child to the toy library;
- a preschool educational organization/social rehabilitation center (represented by the head/manager) and parents (legal representatives) sign a contract in the established manner;
- activity within the toy library assumes carrying out of correctional-developing actions with children without provision of meals, sleep and open air walks;
- classes in toy libraries are held in individual and group forms;
- the duration of individual, group sessions should correspond to the "Sanitary and epidemiological requirements for the device, content and organization of the operating mode in preschool organizations" (SanPiN 2.4.1.2660-10; SanPiN 2.4.1.3049-13);
- classes are held in the presence of parents;
- an infant can stay in a toy library for no more than two hours.

Let us reveal the content of the tutor's activities in the above-mentioned areas.

As part of a comprehensive study of an infant with SHN or a disabled child, the tutor collects and analyzes the data of the clinical and physiological state of the child, the conclusion of the psychological, medical, and pedagogical commission. In addition, the tutor organizes targeted monitoring of a child in the process of joint and independent activities. Together with the psychologist, the tutor studies the child-parent relations in the family, the parents' attitude toward the child's illness, their willingness to provide correctional and developmental assistance to the child, and the style of family upbringing. Based on the data obtained, the tutor makes up an individual correction-development program, determining the main directions, the necessary content, forms, methods and means of working with the child for the near future. Tutor determines the conditions for the implementation of an individual correction-development program: the organization of the workplace, the rules of employment with regard to age, health and personal features of the child, the creation of ergonomic conditions. For each child, a network of studies is drawn up, the time of his/her stay in the kindergarten (from 1 to 2 hours a day) is determined. The tutor independently conducts individual correction-developing classes with infants with SHN, children with disabilities.

An important function of the tutor is to accompany the child during classes, conducted by other specialists. The tutor helps the child to carry out activities in class, stays together with the child, if necessary, ensures his inclusion into the group of peers. In this case, the tutor acts not only as a mentor and assistant to the child, but also as a coordinator of the actions of all specialists, as well as a family assistant.

During the child's stay in the toy library, the tutor keeps a diary of observations, where he records his successes and failures, reveals his interests in various activities, studies the behavioral side of the pupil, pays attention to his psycho-emotional state, which serves as the basis for adjusting the content of the individual program. It should be recalled that parents are obligatory participants in the implementation of all areas of work with the child.

As a rule, working with parents of an infant with SHN is a complicated and very responsible task, since family members are often incompetent in matters of education and training and assess their child ambiguously. Tutor introduces parents to the content of the program and motivates them to participate in the implementation of corrective-development activities with the child. The individual work of the tutor with the parents consists in counseling, discussing the behavioral characteristics of the child, organizing the interaction of the child and the mother during the classes in a toy library.

The tutor assists parents in the selection of appropriate means of communication with the child, teaches parents the methods of working with children, the use of gaming and didactic material in conducting classes with children. The tutor recommends which games, exercises and activities, in the first place, are necessary for the child, i.e. determines the child's request.

Thus, the tutor carries out the individualization of the psychological and pedagogical assistance to an infant with SHN within the toy library environment providing the following issues: the creation of conditions for detailed observation and analysis of problems and success in the development of the child due to appropriate corrective support and stimulation of child's activity; adequacy of the content of corrective work to the individual capabilities of the child; the introduction of an infant with SHN into activities; the formation of corrective-compensatory skills and abilities, ways and skills of socially adaptive behavior in the child, and ensuring the possibility of staying in a preschool organization.

## **5.** Conclusion

Summing up, it is important to note that the modern researches in the field of providing comprehensive assistance to infants with SHN and helping their parents solve a wide range of issues pose new challenges for specialists in the development of new technologies, forms and methods of work in this area. An undoubted resource in this area is the development of the main theoretical, philosophical and psychological-pedagogical foundations of the possibility of introducing the institute of tutoring into this process.

The following possibilities of introducing the institute of tutoring are determined:

- basic values and goals of the integrated correction-rehabilitation process shared by all its participants;
- the presence of an optimal correctional-rehabilitation and subject-developing environment provided with resources for building individual rehabilitation programs and creating conditions for providing comprehensive assistance;
- sufficient standard (at the level of local regulatory acts), methodical and documentation support for the activities of student volunteers who carry out tutoring assistance to families raising infants, and professionals participating in this process;
- timely and sufficient permanent training by increasing the professional competence of specialists

engaged in tutoring of families that raise infants with SHN and professionals participating in this process.

The development of the institute of tutoring is a timely new opportunity to address the urgent tasks of expanding the field of comprehensive rehabilitation of infants with SHN and providing comprehensive assistance in shaping the rehabilitation competence of their parents that can meet the necessary needs of all participants in the correctional and rehabilitation process, expanding the opportunities for interaction and obtaining comprehensive assistance.

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1. Federal State-Financed Educational Institution of Higher Education South-Ural State Humanitarian Pedagogical University, 454080, Russia, Chelyabinsk, Lenin Avenue, 69; E-mail: fortune18@mail.ru

2. Federal State-Financed Educational Institution of Higher Education South-Ural State Humanitarian Pedagogical University, 454080, Russia, Chelyabinsk, Lenin Avenue, 69

3. Federal State-Financed Educational Institution of Higher Education South-Ural State Humanitarian Pedagogical University, 454080, Russia, Chelyabinsk, Lenin Avenue, 69

4. Federal State-Financed Educational Institution of Higher Education South-Ural State Humanitarian Pedagogical University, 454080, Russia, Chelyabinsk, Lenin Avenue, 69

5. Federal State-Financed Educational Institution of Higher Education South-Ural State Humanitarian Pedagogical University, 454080, Russia, Chelyabinsk, Lenin Avenue, 69

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