The competence of parents raising a child with special health needs

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Abstract. The topic of the research covers socio-pedagogical problems of formation of significant parental competencies required for effective development of children with disabilities, including intellectual impairment and multiple types of mental deficiency (moderate, severe, profound mental retardation – F 71, 72). This article is the review of the parental competence structure and its distinctive features, it defines the characteristics that lead to deformation of competency comprising rejection of a child with developmental difficulties, hyperprotection, misunderstanding the patterns and uniqueness of personal development of children with special health needs, the narrowness of the applied influencing methods, and analyzes the conditions for guiding parents raising children with disabilities. A few conditions are highlighted among the main terms. They cover the support in understanding the level and state of parental knowledge, pedagogical and psychological competence; and the professional culture of team interaction of all subjects included in the educational process of the educational organization. The importance of persistent accompaniment as the basis for modeling the parental competence is substantiated in the research.

1 Research relevance

Parental competence is defined as a socio-pedagogical phenomenon, containing a combination of integrative qualities of a parent's personality, as well as components and properties (cognitive and informative, value-motivational, emotional and behavioral, communicative and reflexive, technological), addressed to their child and necessary for the successful implementation of the upbringing process [6].

In the analysis of local and foreign sources, it was revealed that the special paradigm of guiding a family in raising a child with disabilities is aimed to normalize the conditions of a child and to form a competency building approach for parents. In some research papers, some particular recommendations for the work under discussion are presented, among which a special attention is paid to advising and consulting parents, as well as to demonstrating different methods and techniques of pedagogical impact on various aspects of child development [7,10].

The examination of the socio-pedagogical aspects of the formation of parental competence, discovered certain features leading to a deformation of competence including

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rejection of a child with developmental disabilities, hyperprotection, misunderstanding the patterns and uniqueness of personal development of children with disabilities, the narrowness of the applied influencing methods, affective disposition, authoritarianism, intimidating, pressuring, etc. [1,3,6].

Also, the authors note that children, whose special needs are not taken into account in the family, and whose interaction with family members is carried out only at the level of satisfaction of physical needs, are inclined to have related disorders in the sphere of social communication and cooperation, increased or decreased emotional reactions, and a low level of social adaptation in educational institutions [9, 76 p.].

This is relevant for children with multiple and severe intellectual deficiencies (F71, F72). It is known that children, that fall into the discussed category, display unpredictable cognitive, communicative, motor skills and emotions, which leads to significant difficulties in choosing pedagogical methods, as well as in providing psychological, pedagogical, social support aimed to coach the parent (legal representative), in order to arrange their future life.

Thus, it results in identifying the problem of finding a proper competence model for the parents in terms of social and pedagogical support in a holistic educational chain (that includes preschool, school and professional fulfillment), based on understanding the attitude to their child, as well as a specific set of pedagogical techniques on the development of the child, and other factors.

Social and pedagogical support of families raising children with special health needs implies the comprehensive assistance, including social, psychological and pedagogical as well as counselling measures implemented in the learning process.

The purpose of the research is to find methods to increase the competence of parents raising children with disabilities, in order to optimize the process of social adaptation and improving the quality of life.

2 Research objectives

1. To describe social problems of raising children with special health needs, including those with severe and multiple developmental disorders.
2. To develop and test a diagnostic methodology in order to study the characteristics of upbringing conditions and parent-child interactions, to determine understanding of child's abilities, as well as expectations of the child's future and the intentions of the parents to support their child in social adaptation.
3. To carry out an experimental analysis of parental competencies in the main aspects and to discover the social and pedagogical conditions that contribute to the optimization of developmental processes, therapy and successful social adaptation of students with special health needs.
4. To define persistence as a methodological system modeling approach to coach parents raising children with disabilities, including severe and multiple developmental disorders.

The hypothesis of the research is based on the assumption that consulting a parent, as the main person involved in the upbringing of a child with disabilities, including children with severe multiple developmental deficiencies, should be persistent throughout the training; take into account the level of parental competence, including knowledge, pedagogical and psychological aspects; and have a professional culture of teamwork in the educational organization.

Research methodologies include **theoretical methods** comprising analysis, synthesis of the data outlined in sociological, psychological and methodical literature. The following techniques were applied as research methods: profound interviewing, survey with application of both basic and specialized questionnaires, survey addressed to parents aimed

to reveal social expectations and inquiries; observation of the methods (provision of incentives, encouragement, reproach) affecting development and behavior of a child in a family and in public places; **methods of data processing** – mathematical analysis, statistical data processing, content analysis with the use of IT tools.

3 Research outline

The research was conducted in 2014-2019, the process consisted of three stages.

At the *preparatory stage*, the main focus of the study was on discovering and developing the methodological basis of the research, as well as the selection of research subjects, and the support of the research in the context of organization and methodology.

At the *second stage (the ascertaining part)* of the research, the knowledge, pedagogical and psychological competence diagnostics of those parents whose children with either moderate, severe or deep mental deficiency attend educational institutions was carried out.

At the *third (summarizing) stage of the research*, the results obtained were summarized and analyzed.

The group of the research subjects – respondents (there are 150 respondents total), included parents or legal representatives (one from each family), carrying out primary care for the child. The study of the impact on parental influence was carried out in families whose children studied and received psychological and pedagogical support in educational organizations in Moscow (5 institutions) and Oryol (3 institutions).

Among the research subjects, who are the students of educational organizations, three subgroups were distinguished (taking into consideration the level of education). They are the preschool group - 50 pupils, with the age between 2 and 7 years (G1); the school group – 50 students, between 8 and 15 (G2), and the pre-professional group – 50 students, between the age of 16 and 18 years (G3).

The structure of disorders in the subjects was represented by the deficiencies listed below: infantile cerebral paralysis and its forms; noticeable mental retardation, complete mental deficiency; severe speech disorders, sensory-motor allolalia, rhinolalia, dysarthria; noticeable sensory impairment – sensorineural hearing loss and deafness, partial optic nerve atrophy, blindness; autism spectrum disorders, atypical autism; various genetic diseases – Martin-Bell syndrome, Refsum disease, Marfan syndrome, Cornelia de Lange syndrome, tuberous sclerosis, etc; related neurological (epilepsy, neuroticism) endocrinologic (cystic fibrosis, etc.), somatic diseases.

4 The main content of the research

The introduction section of the research covers the explanation of the relevance of the study, the description of the scientific development of the issue at hand; the identification of the problem, purpose, object, subject, hypothesis of the study, methods applied, and the plan of the research. In addition, the section under discussion includes the outline of theoretical and practical significance; as well as the information on the testing of the work and the implementation of the obtained results.

At the preparatory methodical stage, the effective conditions that contribute to the successful formation of the following competencies were determined. They are:

- *the knowledge competence*, which reflects parents' awareness in matters of education and development, socialization, and adaptation of a child with special health needs;
- *the pedagogical competence*, that is the establishment of a meaningful cooperation between a family and an educational organization;

- *the psychological competence*, which indicates parents' positive attitude and acceptance of the child's individuality, and predictable results of education and socialization.

Among the main conditions that enable the formation of parental competence, the following aspects have been highlighted: the consistency of the guiding process, the integrity of the interdisciplinary approach applied by the specialists; the flexibility of the interaction between the specialists in informing the parent and developing an educational plan for the child.

The experimental data (questionnaires, observations), obtained at the ascertaining part of the study, allowed to distinguish a few levels of parental competence, taking into account the socio-pedagogical terms of the positive development and upbringing of children.

To determine the levels under discussion the following criteria were considered: 1 – a parent's acceptance (objective, biased) of the child's deficiencies; 2 – awareness of incentive methods, behavior encouragement or reproach techniques (leniency, ignoring, reasonableness) and their implementation; 3 – consistency of the influencing method implementation (either permanent or short-term); 4 - taking into account the opinion of the experts in socio-pedagogical support (cooperation, ignoring).

The analysis of parents' understanding of behavior encouragement and reproach techniques and their implementation was carried out in the process of cooperative practical activities with children. Each criterion reflected in the protocol was evaluated in points.

In the ascertaining part of the research, the data on the levels of competence was obtained. The summarized quantitative description is presented in the diagram (Figure 1)

Fig. 1. The competence of parents raising children with special health needs.

It should be pointed out that the summarized characteristics of competency components vary significantly in different groups depending on a child's age (displayed as a percentage of the overall response). This factor supports the idea of continuous guidance of parents and family during the educational process.

Fig. 2. The competence of parents raising children with disabilities considered in different age groups.

One of the examples of the dynamics discovered is described below.

The research outlined that the pedagogical component of parental competence in the age group of 2-7 years old (Gr.1) allowed to distinguish some negative patterns in the interaction with a child which are the disregard of child's abilities (31%), indifference towards child-rearing (57%); predominance of destructive types of parent-child interaction (31%).

The data that reflect the component at issue vary significantly in other age groups.

Fig. 3. The pedagogical component of parental competence in different age groups.

During the assessment of the pedagogical component of parental competence, the questionnaire revealed that a very low (43%) and low (37%) levels of educational activity of parents prevail in all groups. According to the diagnostic results, 72% of responding parents of two groups believe that the major purpose is to conduct the correct

treatment and to surround a child with special care and attention. At the same time, parents showed a high level of anxiety for the future of their children.

It should be noted that the significant increase in the level of pedagogical literacy of parents occurs in the pre-professional group. The number of parents reading pedagogical literature and attending the events in order to fill the gaps in their pedagogical knowledge increased from 44% to 69%. It ought to be remarked that the respondents in this group apply more pedagogical methods of incentives, encouragement and reproach. The motivation is carried out in a consistent approach, implemented together with a team of specialists of an educational institution.

According to the questionnaire, the number of appeals of parents who are engaged in a fruitful cooperation with a team of specialists of an educational organization has changed significantly. This fact demonstrates the provision of substantial assistance to the family, the development of the parental pedagogical experience and the increased confidence in parents showed by the counselling professionals.

Fig. 4. The quantitative dynamics of appeals for counseling made by parents raising children with special health needs.

Where: 1 - a group of inquired parents of children who are from 2 to 7 years (Gr.1);

2 - a group of inquired parents of children who are from 8 to 15 years (Gr.2);

3 - a group of inquired parents of children who are from 16 to 18 years (Gr.3).

The survey results determine that 72% of the inquired parents are satisfied with the psychological and pedagogical support provided by the team of specialists (a speech therapist, a specialist on mental defects and physical handicaps and a psychologist), and consider the assistance in making the parents' attitude to the abilities of their children more objective as well as in upbringing to be substantial. Moreover, these parents consider the activity of the institution to play a significant role in the adaptation and socialization of their children. The parents accept the responsibility for the future of their child (according to the methodology of Tkacheva V.V. "Psikhologicheskii tip roditelia"). 80% of the adults believe in the prospects for further development of their child resulting from the adaptation.

The responses of parents of group 3 who regard the prospects of their children's adaptation as vague is worth paying attention to. As a result of the analysis of the responses received during the questionnaire survey, the low indicators of motivation concerning the prospects and the necessity of obtaining a profession for their children are revealed. Most of the responses displayed parents' focus on the adolescent's pastime (73% of the answers) - "I want my child to not be bored, to have fun, and have someone to spend time with", 15% - "I want my child to continue being tutored, it's hard for me to engage with him/her at home" and only 9% of the answers expressed "I want my child to find occupation", "to enjoy his job and to pursue this goal", 3% of the inquired parents mentioned the children's ability to make a living on their own ("I want my child to be able to provide

himself/herself⁹). Thus, the obtained data demonstrated the existing level of parents' doubts about the future of their children, the denial of the necessity and efficiency of vocational training and especially the further employment of their children.

The comparative data received during the survey of parents and students with special needs are presented below. The survey clarified the view on the necessity and benefits of work and obtaining a profession.

Fig. 5. The comparison between the answers of parents and students with special health needs (group 3).

The data points out the parents' position that it is possible to develop a profession, to obtain an insignificant work activity, while the students themselves demonstrated the need for their own employment. This fact allowed the support group to concentrate the counseling on the formation of an objective position of parents in relation to their child's life arrangement.

5 Results

At the third (concluding) stage the results were summarized and the conclusions were drawn concerning the necessity of taking into account the level of parental competence in the context of different components; the continuity of psychological and pedagogical support of parents raising children with special health needs; the establishment of consistency of the interdisciplinary approach among specialists. It was noted that the level of parental competence in each of the components change in the holistic educational chain (that includes preschool, school and pre-vocational education). The greatest change occurs in knowledge and pedagogical components, the psychological component changes slightly. Positive changes are instigated by the complex impact of a team of specialists who carry out a pedagogical influence not only on a child, but also on the child's parent; as well as by taking into account the level of the parental competencies, the persistence and the consistency of the complex impact.

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