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Modern Technologies of Working with Families of Children with Disabilities

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Abstract

The authors research the problems of families having children with mental retardation and autism spectrum disorder (ADS), from the point of view of their socialization. The following key spheres of the socialization process are identified: activities, communication, self-awareness. In the authors' opinion, work with this category of families should be conducted with consideration of these spheres.

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1. Introduction

The recent years have seen a positive phenomenon of social life in Russian society as the emphasis in evaluating the condition of a child with disabilities shifted from a predominantly medical and etiological aspect to functional and social ones which take into account both the social and psychological effect of the disorder and the effect of the social environment on developing the personality of a child with disabilities. In this context we consider it important to look at the peculiarities of families having a child with disabilities from the point of view of the socialization process because the basic characteristics of this process are a key to developing the technologies needed to work with the given category of families.

The well-being of its family has a strong impact on the development of a child with disabilities. The degree research by Kulagina, E.V. [1] reviews different aspects of the social and economic adaptation of parents having a child with disabilities, including the integrate evaluation of their adaptation capacities (their system of values, social status, family and marital status, family members and their age, presence of dependents). Among such indicators of a family's well-being the author of the present research considers the level and quality of life.

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The material, social and psychological difficulties facing a family that has a child with disabilities, cause absolutely new problems of educational nature. Unconfident parents stop taking care of children with disabilities, assuming that this is the liability of the state system. This rearrangement of family functions, often connected among other things, with parents' irresponsible attitude towards their children, tends to cause secondary development defects in them.

Meanwhile, modern research by some Russian scientists suggests that when provided at the right time social, psychological and pedagogical help and support for the family optimize a child's personal development, relieve the parents themselves from psychological and social problems, and promote the activation of family resources [2, 3, 4, 5, 6, 7, 8, 9, 10,11]. For example, in her scientific paper E.U. Firsova [8] says that if mothers, who bring up mentally-retarded children, are provided with psychological, social and pedagogical help, they are more positive in their attitude to their children and are better adapted socially.

2. Methods of research

The following methods were used during the research: analysis, comparison and generalization, didactic modelling, questionnaire.

3. Sample description.

The general term "a family having a child with disabilities" comprises families with different educational potential and performing different functions in the sphere of family education of children aged 0-18 years with deviations in physical and/or psychic development.

Considering the fact that according to the statistical data of the Russian Ministry of Labour, children with mental retardation and autism spectrum disorder constitute the majority of children with disabilities, and also that the family education of these categories of children is the most difficult, special attention is given here to families with children of these categories[12].

The research embraced 44 parents of children of 4-9 years with mental retardation and ASD from Moscow and Ryazan.

4. Presentation of the results

To identify effective technologies of working with families having a child with mental retardation and ASD, we studied the specific features of these family categories, their demands for psychological help and expectations about a psychologist's main professionally relevant qualities.

The study of psychological and educational literature shows that the functionality of a family with a mentally-retarded child is characterized by weaker interfamily connections and lower adaptability [13]. In general, such families are overburdened with intense emotional stress most unlikely to create the right living conditions for the child's development. Meanwhile, as modern research shows, this category of families is not marked with an ability to identify the problem, seek solutions, apply trial and adequate measures, as opposed to the so called "normal" families. While a focus on the sick child's problems sometimes results in the outer stabilization of the family unity, it may, however, lead family members to chronically disregard their own needs. In their existing situation a lot of parents are unable to handle the overwhelming burden of problems on their own. Some of them, mostly mothers, have to lower their professional status and transfer to less qualified jobs enabling them to stay with the sick child while others have to abandon any social activity altogether.

The analysis of the families bringing up a child with ASD enables to give the following characteristic. Almost all the parents show signs of depression, anxiety and a tendency to accuse others of the situation. If viewed from the position of correcting autistic children's affective development, what Russia needs to do in order to enhance the efficacy of its work, is to create, in addition to special psychological and educational activities, a special regime of his life at home which stimulates the child's emotional development. It requires certain efforts on the part of all the family members. However, as E. R. Bayenskaya points out, parents of children with ASD, especially in the early stages of psychological and educational assistance, often fail to understand the reasons why the specialist (most frequently a psychologist) recommends them to initiate change within themselves first,

these recommendations sometimes even causing their aggression or a total refusal from psychological help [14]. This stems from the parents' lack of self-confidence, determined by the basically hindered feedback from the child, and the absence of common affective experience which parents and children usually get at the early stages of emotional interaction.

The questionnaire research conducted among the parents of children with mental retardation and ASD allowed it to specify the main aspects of organizing social and psychological assistance to this family category. As the analysis of responses shows, the parents of the above categories of children with disabilities have the highest demand for correcting retardation in their child's development (Table 1). This enables to make an assumption that most parents consider themselves not competent enough to bring up and educate their child, and rely on specialists' assistance. The overwhelming majority of parents have a need for urgent help in understanding their child. Parents feel unable to establish a fully independent contact with their child. Most parents need informational support. Almost all the parents admit to requiring assistance in identifying the disorder in the development of their child and making a forecast of his further development.

It is worth paying attention to the fact that a lot of parents assume that they do not need help in settling the relationships with their family members, considering it the family's internal affairs, or doubting that a specialist can assist in this matter. A considerable part of the parents also believe that they do not need or do not have an urgent demand in widening the circle of communication of their family. This testifies to a certain isolation of the child with disabilities from society and a lack of desire to establish and widen their contacts with the outer world.

Table 1. Comparing the demand for psychological assistance among parents of disabled children

Type of assistance	1. Yes, I need it	2. I would like it	3. I don't need it	χ^2
Detecting and forecasting	54.5	40.9	4.5	17.6 ($p < 0.001$)
Information and correction	63.6	31.8	4.5	23.1 ($p < 0.001$)
Help in understanding the child	75	18.2	6.8	35.2 ($p < 0.001$)
Correction of development retardation	95.5	4.5	0	36.4 ($p < 0.001$)
Help in dealing with the situation	31.8	43.2	25	2.2 ($p = 0.328$)
Settling the relationship within the family	18.2	18.2	59.1	29.5 ($p < 0.001$)
Widening the circle of family's interactions	13.6	45.5	40.9	7.8 ($p = 0.02$)

Analysis of the questionnaires detecting a psychologist's priority qualities of relevance to the parents has shown that parents consider it the most important thing to possess correctional and developing methods, firmness in one's professional position, tolerance and good will. These professional and personal qualities correlate with their most expressed demands for a specialist's professional assistance. The least relevant qualities, in the parents' opinion, are those of congruence and an ability to control the situation. This is because parents tend to refrain from the specialist' interference and withhold their reliance on him should the family problem go out of control.

Table 2. Ranking the qualities that parents consider relevant

Professional qualities	Place in ranking	Professional qualities	Place in ranking
Possession of correction and development methods	2.5	Positive attitude	8
Firmness in professional position	5.5	Ability to think prognostically	9
Good will	6.5	Sociability	9
Objectivity	8	Clear speech	9.5
Tolerance to other people	8	Ability to control oneself	9.5
Self-confidence	8	Wholeness (congruence)	10
Considerate attitude towards other people	8	Ability to keep the situation under control	11
Ability to listen carefully	8		

5. Discussion

Thus, the conducted theoretical and empiric analysis of the research into families having a child with mental retardation and ASD shows that the above families are characterized by certain features that depend, to a different degree, on the structure and depth of a child's defect:

Family interactions are damaged and distorted;

The family's social status is lowered, and the emerging problems not only affect the family interactions, but also lead to the changes in their closest environment;

A special psychological conflict emerges in the family of a child with disabilities as a result of an encounter with public opinion, which does not always evaluate adequately the parents' efforts in educating and treating such a child.

6. Conclusion

Considering the problems identified we can formulate the following key spheres of socialization process for families having a child with disabilities, which, in our opinion, a psychologist should rely on when giving assistance to this category of families.

1. Activity - because during the whole process of socialization a family, as well as an individual, have to deal with an ever increasing "catalogue" of activities, i.e. they have to learn one new activity after another.
2. A sphere of interaction, which has to do with an increased number of family's contacts, the specificity of these contacts at each age period of the development of a child with disabilities.
3. Self-awareness, where the specifics of the needs and motives sphere are brought into the foreground.

We maintain that this particular interpretation of the notion "socialization" enables a family which brings up a child with disabilities to become both an object and a subject during its interaction with a specialist.

Thus, working with families with disabled children becomes an activity rich in content and technologically determined ensuring, in the first place, that they overcome the socialization difficulties associated with raising a child with disabilities and enhance the quality of their life.

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