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Editorial

Papers

Research Notes

Needs Assessment of Parents Raising Children with Disabilities in Preschool Educational Institution

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Abstract

OBJECTIVES: The authors focused on the study to assess the needs of parents of children with disabilities in preschool education institutions in Ukraine. THEORETICAL BASE: The geography of the study covered three regions of Ukraine and seven preschools of different types. The study sample was limited to parents whose children attend preschool and consisted of 107. METHODS: Series of in-depth interviews were conducted with parents of children with disabilities attending preschool. The results were transcribed word for word. To determine the descriptive topics, the pre-coding was performed, and then refined and interpreted using the MaxQDA10 program. OUTCOMES: The results suggest among the basic needs of parents, which they lack in care and upbringing, included: free time (42%); financial capabilities (financial support) (14%); special skills of communication with children and parenting experience (11%); endurance and patience (8%); coherence, understanding between family members (4%); psychological support (3%). SOCIAL WORK IMPLICATIONS: Many indications imply the absence of awareness among parents in the care and upbringing of children with disabilities; misunderstandings with the social environment; lack of knowledge of parents about social institutions where families can receive help and support; lack of meaningful leisure time with children with disabilities, social isolation of the family.

Keywords

parents, children with disabilities, preschool educational institutions, needs assessment, socio-pedagogical support, Ukraine

INTRODUCTION

The ongoing reform of preschool education in Ukraine emphasizes the need to create an inclusive educational environment conducive to children with disabilities and provide effective socio-pedagogical support for their parents in preschool educational institutions.

In Ukraine, the position of social pedagogue has been introduced in preschool education institutions. The main goal of the specialist is to help children socialize and increase the educational potential of parents. This specialist also provides socio-pedagogical support to parents of children in difficult life situations, particularly raising a child with disabilities. However, preschool educational institutions in Ukraine mostly ignore the need for such a specialist in the state and are often not ready to work with the parents of such children.

Understanding the essence of socio-pedagogical support for parents of children with disabilities in preschool education involves, above all, knowledge of the specifics of various types of developmental disorders, assessing the needs of children with disabilities, identifying current needs of parents as

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caregivers, and creating appropriate conditions for providing them with the necessary assistance in preschool education.

Given the peculiarities of the socialization of children with disabilities, they have their own specific needs, which differ from the needs of children without developmental disabilities, requiring more attention and care from adults, in particular from parents. Therefore, the needs of parents are directly related to the needs of children, complicated by their disabilities, and impact the life of the whole family.

According to researchers L. Stasiuk and M. Slyusar, the difficulties that a family with a child with disabilities constantly experiences are significantly different from the daily worries of a family raising a child with typical development. Researchers emphasize that almost all parental functions, with rare exceptions, are not realized or are not fully executed (Stasiuk, Slyusar, 2017). We believe that difficulties in performing parents' functions can affect the development of a child, his/her upbringing and education, and quality of life for the whole family. It also makes it impossible to fully meet the needs of children and parents, hindering the solution of problems directly related to the limited capabilities of the child.

Thus, the first step in organizing socio-pedagogical support for parents of children with disabilities is to determine the child's needs through the parents' needs assessment. Because children are usually unable to express, explain, and justify their needs due to the peculiarities of their age (preschool period) and the specifics of developmental disorders (mental, speech, motor development).

The aim of the study is to assess the needs of parents of children with disabilities in preschool educational institutions in Ukraine. Authors identified the basic needs of parents caring for children with disabilities and determined the interaction of parents of children with disabilities with preschool specialists and the support provided to children and families.

To achieve this goal, the objectives of the study are: to identify the basic needs of parents caring for children with disabilities; to determine the peculiarities of the interaction of parents of children with disabilities with the specialists of the preschool institution, and to specify the assistance they provide to children and families; to develop recommendations for preschool professionals on socio-pedagogical support of parents caring for children with disabilities.

THEORETICAL BASE

Many foreign studies have investigated the organizational characteristics of an inclusive environment in preschool institutions. In particular, the socio-pedagogical support for parents of children with disabilities in Hungary was analysed by Costin (1969) and McMonagle (2012). The researchers emphasize that local autonomy and assessment of parents' needs are the key features of preschool education in Hungary. Local institutions and schools have the opportunity to adapt to their conditions one of the 15 approved programs from the national database, such as "Waldorf", "Freinet", "Montessori", "Step by step", or to prepare and get the approval of a local educational program. As part of the comprehensive programs of Hungarian preschools aimed at addressing the general needs of children and their parents, an integrated package of services is provided, including health care, nutrition, and psychosocial stimulation; special events for children and families; the participation of parents and community in the curriculum reform is ensured. According to the needs of children, professionals of the health service, psychologists, teachers of special education, speech therapists regularly visit preschool institutions. The focus of Hungary, which strives to provide families with quality and affordable support, is on services for children and parents (McMonagle, 2012).

The studies of the psychological well-being of parents caring for children with disabilities give a basic understanding of how to meet the communication, medical, educational, and other needs of families. Based on different studies exploring the quality of life and mental health of caregivers of children with disabilities (Yamada et al., 2012; Guillamon et al., 2013; Marchal, Maurice-Stam, Hatzmann, van Trotsenburg, Grootenhuis, 2013) it has been proved that raising a child with disabilities is associated with lowered quality of life. Parents of children with disabilities encounter stresses unlike families with typically developing children, so the physical and mental health impacts on the parents of a child with a chronic disability should be appreciated (Chambers, Chambers, 2015).

There are universal factors that contribute to family quality of life and specific such as context and culture. The coping strategies of parents are also important (Sergienko, Kholmogorova, 2019). The mental health of parents caring for a child with an intellectual disability is influenced by child and family factors (Baker, Devine, Ng-Cordell et al., 2021). To provide effective, culturally relevant support that enhances the quality of life for families of children with disabilities it is important to recognize the influence of context-specific factors (Jansen-Van Vuuren et al., 2021). Researchers Bogdanović and Spasić Šnele made the meta-analysis of life assessment of parents of children with developmental disabilities and indicated the need for developing better and more focused interventions aimed at providing support and assistance to this group (Bogdanović, Spasić Šnele, 2018).

Research team Vasiljević-Prodanović, Krneta and Markov report a need for planning guidelines and implementing practical procedures that would contribute to better cooperation between preschool institutions and, parents of children with developmental disabilities (Vasiljević-Prodanović, Krneta, Markov, 2021). It is also important to emphasize that educational staff should be more engaged in the development of parental competence (Vukusic, 2018).

According to the study of psychological well-being of parents with children with intellectual disabilities conducted by Kislyakov and Shmeleva, educational personnel plays an important role in providing support, so interconditionality of psychological well-being of children and their parents can and must be supported and adjusted by the educational institution (Kislyakov, Shmeleva, 2017).

Research by Hanson and Lynch focuses on socio-pedagogical support for parents of children with disabilities in the United States. Researchers identify that the main feature of such support, besides providing them with general support (to provide psychological support, to listen about worries and problems), is the promotion of parenting and meeting the needs of parents raising children with disabilities (advice on child problems, help in caring). Such support in the United States is called child support (Hanson, Lynch, 2013). Scientist Fenlon emphasizes the peculiarity of parents' involvement and providing support in the process of admission of a child with disabilities to a preschool educational institution, taking into account the needs of the whole family (Fenlon, 2005).

Researchers A. Turnbull, V. Turbiville and H. Turnbull provide recommendations reflecting parent-centred practices, including, above all, the recognition and consideration of the needs of the child and his or her parents in practice; the organization and provision of accessible services taking into account the identified needs of the child and parents (Turnbull, Turbiville, Turnbull, 2000).

The research team Surel, Douglas, Finley and Priver (2011) has studied various practices of socio-pedagogical support in Denmark, Scotland, and Germany. They emphasize that the main aim of such support is to ensure the child's well-being, and to support the whole family, instead of focusing only on the child. Therefore, the social pedagogue provides practical support aimed at solving everyday life problems with parents, as well as the formation of parents' skills to support these new positive changes without outside help and support (Surel, Douglas, Finley, Priver, 2011).

The researchers Ha, Greenberg and Seltzer have studied the role of social support for African-American parents of children with special needs. Based on their study the practical recommendations for social workers working with parents of this category are provided, including programs for these families that should facilitate their emotional stress and provide financial assistance. The authors identify two main ways of socio-pedagogical support for parents: social workers provide parents with information about the child's disability and the types of support that parents require, and work with the emotional burden of family members (Ha, Greenberg, Seltzer, 2011).

In the context of our research topic, the experience of social institutions in Australia is of scientific interest. There have early intervention services – Early Childhood Intervention Services (ECIS) that support children with disabilities and their families from birth to school. The services are focused to meet the individual needs of the child, supporting him/her in the natural environment, and supporting parents in their daily life and activities. These services are designed to provide parents with the necessary knowledge and skills and support to meet the family needs. The services are funded through the Department and are provided with specialized services for children and early childhood settings (Drabble, 2013).

Researchers Solomon, Pistrang and Barker report forms of support for parents of children with disabilities through the activities of parent groups. They emphasize that members of parent groups are usually satisfied with the support they receive from other team members. Such support is useful in three areas, in particular: socio-political, which includes the development of a sense of control and management in the outside world; interpersonal, which includes belonging to a certain community; internally individual, which includes self-change (Solomon, Pistrang, Barker, 2001).

METHODOLOGY

The geography of the study covered three regions of Ukraine, and seven preschool institutions became experimental sites: Kyiv preschool institutions number 280, 611, 662, and 590; Center for Child Development "I+Family"; municipal institution "Preschool educational institution (nursery-kindergarten) of the combined type № 4" Teremok" of Kirovohrad city council"; Poltava preschool educational institution (nursery-kindergarten) of compensatory type № 78 "Piznayko" of Poltava city council, Poltava region.

A series of in-depth interviews were conducted with parents of children with disabilities to gather information. The study sample was limited to parents whose children attend preschool and consisted of 107 people (71 women and 36 men), among them 59 individuals from complete nuclear families, 31 members of multigenerational families, and 17 single-parent families (Table 1).

Table 1: Information about respondents

Characteristics of family composition	**Distribution of respondents** *(n=107)*
Preschool educational institutions:	
№ 280	20 people
№ 611	15 people
№ 662	10 people
№ 590	15 people
"Center for Child Development "I + family"	15 people
Municipal institution "Preschool educational institution (nursery-kindergarten) of the combined type № 4 'Teremok' of Kirovohrad city council"	15 people
Poltava preschool educational institution (nursery-kindergarten) of compensatory type № 78 'Piznayko' of Poltava city council, Poltava region.	17 people
Gender composition:	71 woman
	36 man
Family composition:	
Complete nuclear family	59 people
Multi-generational family	31 people
Single-parent family	17 people

At the same time, it should be noted that it was originally planned to conduct a series of focus groups. However, during the piloting of the guide for the focus group, it became clear that the parents-participants kept their problems secret, were afraid to voice their position, or were inherently conformist, as they adjusted to the opinion of the most authoritative parent. It should be also mentioned that parents were on the grounds of the preschool institution, which didn't contribute to openness. To exclude these factors, in-depth interviews were chosen as a method of gathering information. The peculiarities of in-depth interviews are their duration, detailing, taking into account non-verbal signals such as intonation, gestures, postures, and increased attention to the respondent. The above-mentioned allow us to study the issue deeper, to reveal details, to discover new facts, and not just evaluate the already known.

We were also aware of the shortcomings of the chosen method, such as the complexity of the organization, high requirements for the qualifications of the interviewer, his/her potential bias, non-standardization, possible impact on the respondent, and suggestion.

We have created appropriate conditions to neutralize and overcome these shortcomings. In particular, to cover a large number of respondents, five volunteer interviewers were trained from among students of the specialty "Social Work" who did not work in preschool education, which ensured their impartiality; an interview plan and a mechanism for transcribing the data were developed. To minimize the effect of suggestion, a list of indicative questions was sent to the respondents in advance, so that they could formulate a clear position of their own before the conversation.

Given the peculiarities of socialization and types of disabilities of children, the psycho-emotional state, and the current situation of their parents, the questions of in-depth interviews began with establishing a trusting relationship with parents, finding out the composition of the family, and identifying family members who help care for a child, asking about family leisure and available free time for parents. The next stage was a gradual transition to identify problem situations and issues that reveal the current needs of parents, complicated by the child's disability, and determining the lifestyle of parents in general. The target group of the study parents was the parents of children attending preschool institutions, so to clarify their needs, the in-depth interview plan included questions about the specifics of the interaction of respondents with preschool workers and about the support they provide to children and families. Thus, such a sequence of questions, a trusting atmosphere between the participants, and the peculiarities of this type of interview contributed to the needs assessment of parents of children with disabilities in preschool education.

The results of the in-depth interviews were transcribed word for word. To determine the descriptive topics, the pre-coding was performed, and then refined and interpreted using the MaxQDA10 program.

RESULTS AND DISCUSSION

By analysing the answers to the in-depth interviews, we identified the basic needs of parents caring for children with disabilities and determined the interaction of parents of children with disabilities with preschool specialists and the support provided to children and families.

The answers to the first set of questions gave us a description of the family composition and the distribution of roles in caring for children with disabilities.

Most children are raised in complete families (54 people) and multigenerational families (29 people) with grandparents and other relatives. Single-parent families represent a small proportion (15 respondents), typically the mother is the caregiver. In the context of this parameter, the smallest representation has complete large families (4 persons), consisting of a father, mother, and 3–4 children. One more type of family is the single-parent extended family, comprised of a mother and her close relatives.

The majority of families (77%) demonstrate the active participation of all adult members in the care and education of children with disabilities. During the interview, the woman raising a child without any help of relatives stated: *"I have no one to count on", "I'm tired of the heavy burden on me, and my responsibility is very high", "I often need more than just physical support, and at least the opportunity to be consulted about certain aspects of parenting".*

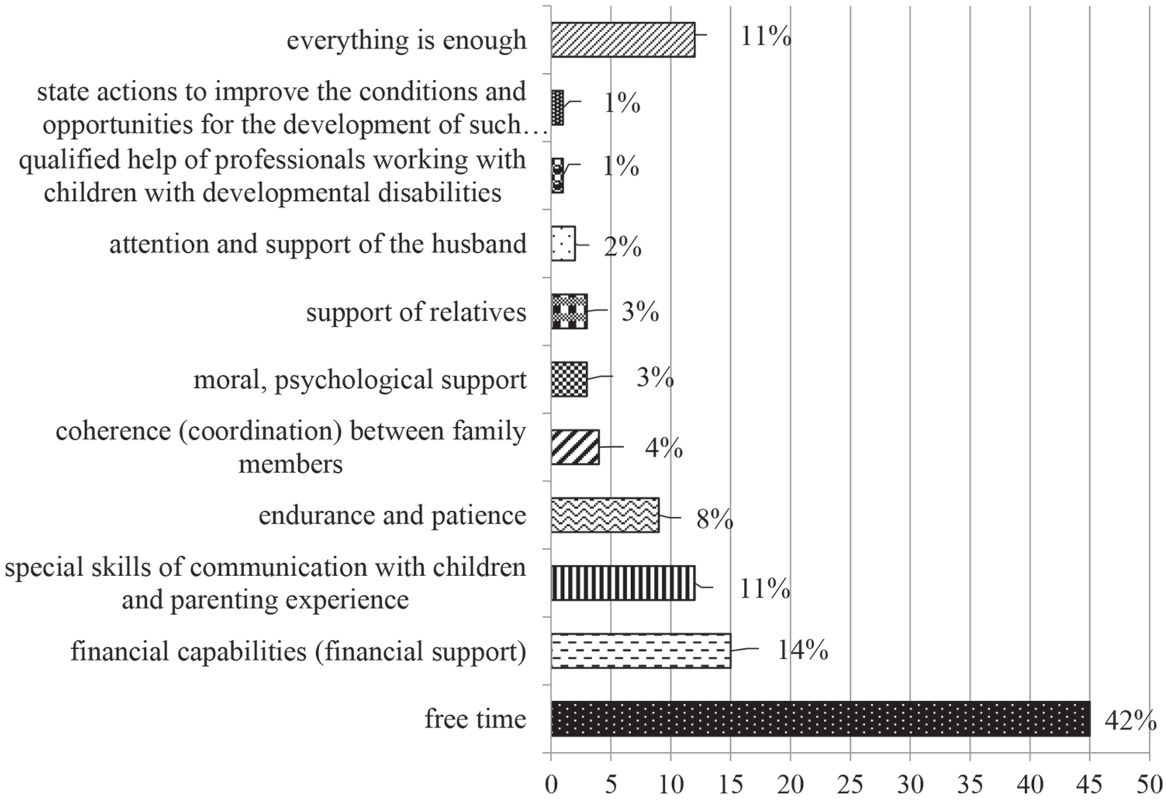
The analysis of the parents' answers to the question "What roles do you play in the family, what functions are you responsible for?" made it possible to determine that the main roles of parents caring for the child are education and upbringing, care (feeding) and meaningful leisure, also that there is a proportion of mothers who don't have help.

To the question "Do you get enough help from family members?" the majority of respondents (48%) indicated that they have enough help from other family members; some (16%) responded "Not always", and almost the same proportion (18%) answered, "No, not enough". One of the families uses the nanny service, and 15 people (14%) are mothers raising children on their own, so they do not have help.

Therefore, these data should be considered in the further development of recommendations for socio-pedagogical support of parents of children with disabilities for specialists of preschool education, considering the need to develop skills to build harmonious family relationships, good interaction between parents and children, distribution of parental functions, building a system of values, and others.

The second set of questions related to the basic needs of parents of children with disabilities in the context of care and education, recreation, and leisure. Among the basic needs of parents, which they lack in care and upbringing, the respondents included: free time (42%); financial capabilities (financial support) (14%); special skills of communication with children and parenting experience (11%); endurance and patience (8%); coherence, understanding between family members (4%); psychological support (3%). At the same time, 11% answered that they were satisfied with the situation, they have enough of everything. It is probably the case when parents are from complete families in which there is a clear delegation of parental functions and roles. As a result, most of the needs of each family member are met, and the difficulties associated with caring for a child with disabilities are overcome together (Figure 1).

Figure 1: Answers of respondents (%) to the question "What do you (and the adults listed by you) lack in caring for a child with disabilities?"

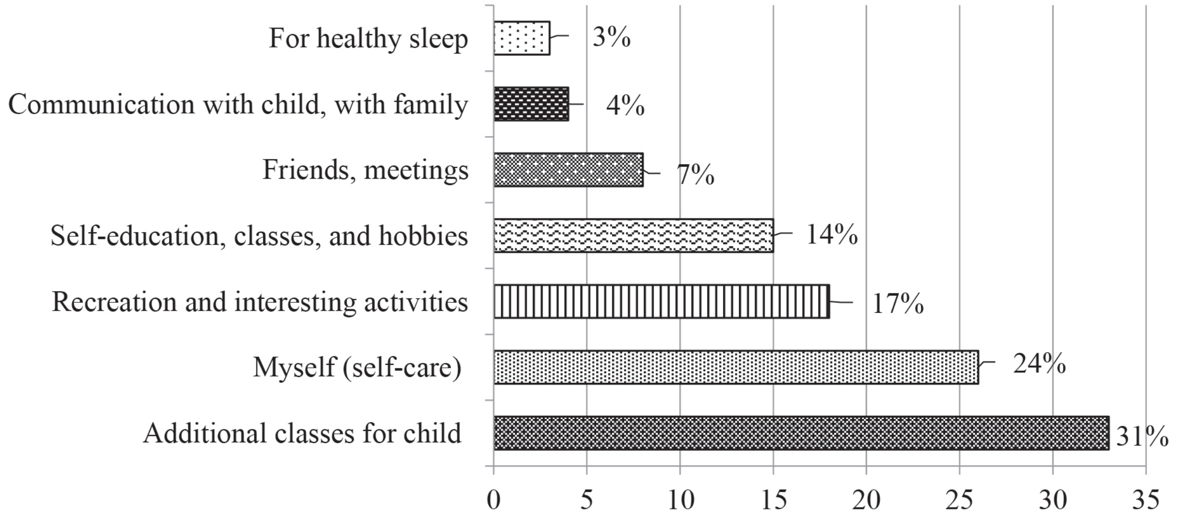


It was also important for us to find out how the daily routine and weekends look like for parents of children with disabilities, their usual activities. Most parents work during the week (65%), and children are in preschool; in the evening adults are mainly engaged in household chores (85%). A small number of parents (37%) can provide children with private psychological and pedagogical services. Only 23% of respondents said they play with a child at home, read fairy tales, paying close attention to a child; and 9% of respondents attend clubs and swimming pools with their children. Thus, parents do not have enough time to spend meaningful leisure time with children with disabilities and lack knowledge in this context.

On weekends, parents run the household (82%), less than a third visit play centres and playgrounds (45%). A small proportion of parents (18%) have the opportunity to visit cultural institutions and parks. At the same time, 5% of parents said that the main reason to stay at home on weekends is lack of money. In this context, here is the answer of one of the mothers: *"Weekdays are like everyone else's, but on weekends there are not enough places to take such a child"*. Thus, the situation of isolation of families is revealed not only in education but also in leisure.

Parents do not have enough time for activities with children and recreation (31%), self-care (24%); recreation and interesting activities (17%); self-education and hobbies (14%). The main reasons for this are employment (35%) and "all attention is focused on family life" (28%): *"I don't have enough time for myself: manicures, exhibitions ... I try to dissolve in children and don't notice what I am missing" and "I don't have enough time to sleep… I would like to sleep"* (Figure 2). Thus, parents are overloaded with work and household chores, which increases the level of dissatisfaction with their needs. Therefore, timely qualified support is necessary to them.

Figure 2: Answers of respondents (%) to the question "What (Who) do you lack time for?"



The next set of questions was to determine the specifics of the interaction of parents caring for children with disabilities with the preschool staff and the support they provide to children and families. The following answers were received while determining the types of support provided by specialists of preschool educational institutions to children with disabilities and their families: they receive partly psychological support (31%) in the form of consultations and advice; moral support (27%) – specialists are positive, meet the child with understanding and support the parents; general information support, more than a message (22%) – specialists provide information on the regime of the preschool educational institution, the structure of educational classes, others. Some parents (4%) openly stated that they did not receive any help: *"The period of adaptation was difficult for us. It was difficult for me as a mother ...I panicked... I didn't have enough instructions from the specialists on how to behave as a mother of a special child. I wish that the actions of mom and teacher were coordinated, and there was a better result ..."*

It was also found that the general information on the peculiarities of the development of children with disabilities, their upbringing, further education, respondents is provided by an educator (41%; 54 people), a speech therapist, or a special education teacher (22%; 29 people), and by a practical psychologist (13%; 17 people).

The answers of the respondents on the content of the work of a practical psychologist with parents in a preschool institution were important. In particular: *"I saw a psychologist once at a parent meeting. I don't know if the psychologist works with my children, she hasn't met with me. Do my children have mental health problems? I don't know ... "," I haven't consulted a psychologist because I have a negative experience with a psychologist in a polyclinic ...", "Several times a psychologist tested my child and helped to do the homework because I don't know Ukrainian well...", "Educators in the group coped with everything, we did not visit a psychologist...", "I don't think there is a need to go to a psychologist...", "I didn't visit a psychologist, because I don't see the point in taking a child there. She will withdraw, she won't speak to a specialist..."*. The above-mentioned answers indicate the lack of informational support for parents of children with disabilities in this preschool educational institution and the inability of specialists of the institution to establish partnerships with parents.

Only 17% of parents (18 people) partly know the content of the work of a practical psychologist in the institution, such as: *"Psychologist should work with both the child and parents, give advice on how best to approach a child..."*. In practice, the functions and professional duties of a practical psychologist are much broader according to the classifier of professions (Ministry of Social Policy of Ukraine, 2021).

When asked about the problems associated with raising a disabled child and the help they need, most parents (44%) answered that they are satisfied, and some parents (28%) answered they "do not know". We have suggested that parents do not have information on the types of care that should be provided by preschool professionals. Thus, there is a problem with informational support for parents. Parents also noted that the following issues remain unresolved: further education of their children (6%), a small number of special speech therapy and psychological classes (7%), absence in the institutions of an assistant (assistant) educator or attendant (4%), the problem of lack of interaction between parents and professionals (4%).

Here are some answers that were informative for us: "*… should be more educational work with parents, so that they understand and accept the child's problem, and not just pass it on to specialists, expecting miracles…*". Thus, this situation once again indicates the provision of inadequate informational support and lack of teamwork interaction.

The key needs of parents caring for children with disabilities can be defined as: improving the financial situation of a family (17%), establishing psychological interaction with a child (17%), obtaining timely and detailed information on various aspects of care and upbringing of children with disabilities (18%). Here are some of the parents' answers: *"... We need more information about our rights and opportunities, as well as material assistance because it takes a lot of money to raise such children!", "Material assistance ... we have a limited choice of work ... how to finance services for a child…We don't know our rights, don't know about social security, nobody knows where to go, so you are left alone with your problem."*

Besides, there are other urgent needs for parents of children with disabilities: the need to accept their children by others, a positive attitude towards them from healthy children and their parents (12%), consolidation between social institutions (16%). During the interview, parents of children with disabilities stressed that *"... our children should be treated as equal members of society. Such children should be in the group with healthy children "," ... very little information is provided to society, many people put labels on such families* ". At the same time, it should be noted that 9% of respondents stated that they have no problems. In particular, here is the answer of one of the mothers of a child with disabilities: *"... I have a question: what about development? My child is normal, she has no developmental disabilities, we have no problems."* This may indicate that the parents do not accept the life situation, do not recognize the child's problems and special needs. And since the developmental disorders of a child and disabilities give rise to the corresponding needs of a child and his/her parents, this fact should be taken into account by specialists in the organization of work with parents, in particular in providing them with socio-pedagogical support.

CONCLUSION AND RECOMMENDATIONS

Summarizing the results of in-depth interviews, the main needs of parents in the care and upbringing of children with disabilities have been identified by parents as: lack of information on various aspects of care and education of children; financial difficulties; misunderstandings with parents of healthy children and with the social environment in general; lack of knowledge of parents about various social institutions (rehabilitation centres, educational institutions), where families of children with disabilities can receive help and support; lack of time for meaningful leisure with children with disabilities, and lack of knowledge in this context, social isolation of the family in both education and leisure.

Based on the generalization of the results obtained on the needs assessment of parents caring for children with disabilities in preschool education, we can identify the following basic needs:

- Informational and educational needs (various aspects of care for children with disabilities, further education, knowledge of rights and responsibilities, the peculiarities of integration into society)
- Social and legal needs (mediation in receiving various types of social assistance, raising awareness about social protection of children with disabilities and their parents)
- Psychological and pedagogical needs (improving the level of pedagogical culture, the formation of skills to establish a positive psychological microclimate in the family, the

formation of a tolerant attitude towards children with disabilities in parents of healthy children)

Determining the peculiarities of interaction of parents caring for children with disabilities with preschool professionals and the assistance they provide to children and families, it appeared that parents typically receive counselling from a practical psychologist in the form of individual meetings; they don't understand the content of work and functions of a social pedagogue; there is no coordinated teamwork of specialists.

Thus, determining the basic needs of parents caring for children with disabilities and the peculiarities of their interaction with specialists of preschool education, we can outline the following recommendations for preschool professionals on socio-pedagogical support of parents caring for children with disabilities:

- Proper professional training of specialists of the preschool institution for the implementation of socio-pedagogical support for children with disabilities
- Organization and implementation of timely qualified pedagogical, psychological and social support for parents of children with disabilities
- Strengthening informational and educational work on issues relevant to parents
- Developing skills for building harmonious family relationships, proper interaction between parents and children, distribution of parental functions, building a value system
- Work with parents who do not currently accept the child's problems and disabilities. Such parents are practically unable to provide their children with full-fledged care and upbringing, cultural and social development, do not help in social adaptation and rehabilitation. These parents need professional involvement to meet current needs.

The authors of the article consider the following ways to improve the socio-pedagogical support of parents of children with disabilities in a preschool institution as effective:

- Drawing up an individual program of work of a social educator with parents of a child with disabilities, aimed at revealing and maintaining the positive personal qualities of parents necessary for successful cooperation with the child; and increasing their level of adaptation to living conditions
- Assistance in the normalization of family relations, and relationships with others, by teaching parents how to interact with a child with disabilities, methods of education, and training
- Help parents to adapt to living conditions complicated by the child's disabilities
- Analysis of individual functionality of a family with a child with disabilities, identification of the specifics of its socio-cultural development (individual work)
- Organization of work of self-help and mutual aid groups in the conditions of preschool educational institutions for communication, exchange of experience between parents, and meaningful leisure (club meetings)
- Use of the problem-oriented model (concentration of specialists' efforts on the problem that the family is aware of and on which it is ready to work)
- Education and training of parents, their acquisition of practical skills in education, training, and rehabilitation of children with disabilities (lectures and seminars)

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