

The Issue on Classification of Needs of Families Raising Children with Special Needs (Systematic Approach)

**До питання класифікації потреб сімей,
які виховують дітей із особливостями розвитку
(системний підхід)**

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ABSTRACT

Families raising children with special needs differ from other families in the large number and variability of needs. Scientific studies highlight the issue of the specific needs of the family, but for the most part their generalized totality is described.

*Therefore, the **purpose of the article** is to explore and highlight the needs in such families and describe them in the context of the individual, marital, parental and sibling subsystems of the family system.*

*To achieve the goal the following **methods** were used: theoretical – analysis, systematization, classification and generalization; empirical – observation, conversation, interview and method of expert assessments.*

***Research results.** A total of 18 family needs were identified and distributed in accordance with family subsystems – individual, marital, parental and sibling. In the context of the individual subsystem the following needs are identified: the need for emotional response to negative emotions, the need for personal space, the need for support, the need for care in relation to one's own self. For the marital subsystem common needs for both partners are defined (in love, support, guardianship, closeness of the partner, material and sexual needs). In the parental subsystem specific needs are characterized: for truthful information, adaptation and acceptance of the role of "parents of a special child", in finding the meaning of interaction in the "parents-special child" system; in society's acceptance of a special child, the need to confirm the changes/dynamics of the child's development. The needs of brothers and/or sisters in the sibling subsystem are formulated: in attention and love from parents, informing about the somato-psychological characteristics of a special child, distribution of responsibilities according to the age of siblings.*

Conclusions. *Identifying the needs of the family and determining the degree of their severity is of practical importance for the implementation of effective socio-psychological support. Frustration of unconscious needs leads to increased tension and deterioration of the family microclimate. At the same time awareness of the needs of family members will be the impetus for finding the necessary resources and finding the best ways to meet them.*

Key words: *family needs, children with special needs, subsystem, family system, family raising a child with special needs, siblings, parental subsystem*

Introduction

The study of a family with a special child was started by specialists from the middle of the twentieth century. The stimulus for this was the emergence of the idea of a family as a system. From the point of view of the systemic family approach, it is not constructive to focus solely on a child with special needs, since the dynamics of the functioning of the family remains unexplored. "The problem faced by one of the family members affects the system as a whole (which in turn determines its personal situation)" (Seligman & Darling, 2009). It is obvious that a child with specific needs affects the livelihood of the family and it is under constant influence of intra-family interaction, that is, there is a certain interdependence of processes. On the one hand, such children need more effort, time and attention from the other members of family through a set of special needs that cannot be met on their own. As a result, the needs of parents, siblings and other family members become secondary. On the other hand, the existing changes in the life of the family eventually affect the quality of care for a child with special needs. All this leads to an imbalance and negative feelings; causes changes in the level of physical health of family members; mental status (cognitive, emotional, social spheres), general family functioning (Lara & Pinos, 2017). In these families there is a decrease in the level of family functioning (Pisula & Porębowicz-Dörsmann, 2017), a lower level of family cohesion and adaptability, low level of expression and expressiveness of feelings (Heiman & Berger, 2008).

In order to ensure the maximum effective coexistence of family members and children with special needs, attention should be paid to the actual needs of the family as a system. Thus, the **aim of the article** is to investigate and identify the needs of such families and describe them in the context of individual, marital, child-parent and sibling subsystems of the family system. Obviously, a family that understands their own needs, has the ability to satisfy them and cares about their own resources, can give the child with the peculiarities of development the necessary level of support for successful socialization and integration.

Research methods

The study used a set of theoretical methods, such as analysis, systematization, classification and generalization. The group of empirical methods includes: observation, conversation, interview and expert evaluation method.

Results and discussion

To determine the most pressing needs of families raising children with special needs, the method of expert assessment was used – a survey of a group of experts. The experts in this study were 20 leading specialists: 12 psychologists and 8 social workers who have significant experience in socio-psychological support of this category of families. Their practical work experience averaged 16.5 years. The expert assessment was carried out in Mykolaiv (Ukraine).

The research procedure included 3 stages: 1) experts' selection of the list of needs of families having children with special needs, which are most often manifested in working with different family subsystems: individual, marital, parent-child, sibling; 2) ranking by experts of the identified family needs by the factor of significance for families raising a child with special needs; 3) determining the consistency of expert opinions – the calculation of the concordance coefficient (M. Kendall). The formula for calculating the concordance coefficient is as follows:

$$W = \frac{12S}{m^2(n^3 - n)} \quad (m - \text{number of experts in the group, } n - \text{num-})$$

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ber of factors (needs), S – sum of squares of deviations from the arithmetic mean). The concordance coefficient is defined in the range from 0 to 1: if the opinions of experts are completely opposite – it is equal to 0, if they agree, the value of the coefficient should be more than the tabular for the level of significance $p \leq 0.05$. According to the results of the Kendall coefficient, its value ($W = 0.982$) exceeds the tabular value ($W = 0.1035$) for the significance level of 0.05, which indicates a high level of agreement of experts on the current needs of families of children with special needs.

The survey of experts identified 18 the most pressing needs of families of children with special needs, which are correlated with individual, marital, parent-child, sibling family subsystems. Needs within the relevant family subsystem are a kind of group of needs, the specifics of which are affected by its functioning. The classification of the needs of families having children with psychophysical features from the standpoint of a systems approach is presented in Figure 1.

Particular needs of families within the individual subsystem. An individual subsystem is a subsystem represented by one member of the family. In the nuclear family, there are so many individual subsystems as there are members of the family system. The needs of family members in the context of an individual subsystem depend on age, gender and personal characteristics.

The need for emotional response to negative emotions. It is known that the birth/appearance of a child with special needs in a family causes stress and the experience of negative emotions. Thus, I. Kandel & J. Merrick note that parents experience a complex of emotions and feelings that are similar to the experiences of a close friend's death (shock, grief, anger, guilt, etc.) (Kandel & Merrick, 2007). Most parents experience frustration, dissatisfaction, anger, shock, and guilt (Heiman, 2002). It is worth noting that brothers and sisters are also experiencing negative emotions. The experiences of healthy children may not have such an intensity and depth as to the presence of a special member of

the family, but they are sensitive to the experiences of parents. Accordingly, it is extremely important for each family member to have the opportunity to experience/react to any emotion that arises in accordance with the actual family situation.

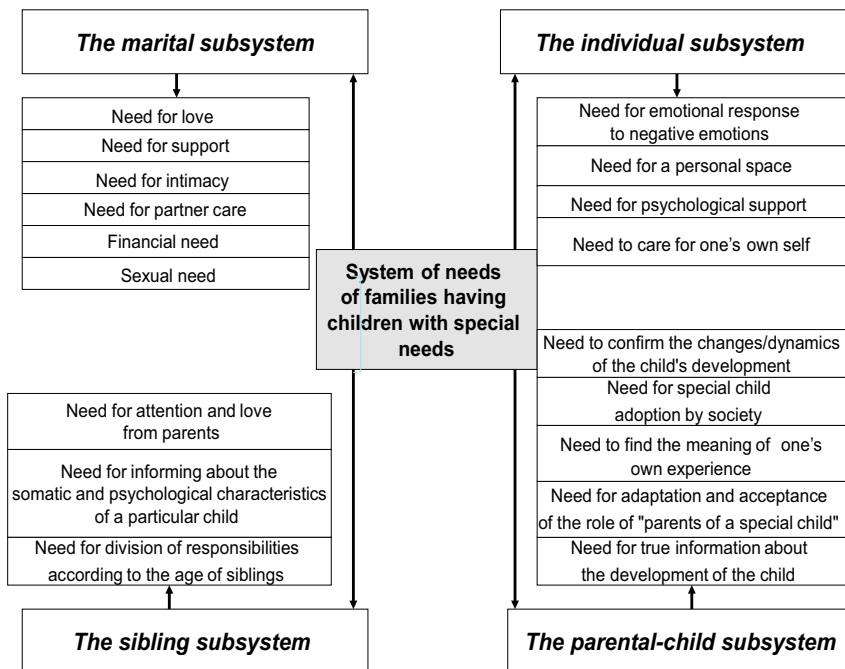


Fig. 1. Classification of needs of children with special needs

The need for a personal space. Personal space is an indicator of physical and topographical parameters of human life; evidence of its subjectivity. Members of families who bring up children with special needs usually experience a decrease in their personal space. This is due to the fact that such children are constantly in need of assistance, extremely demanding or because of existing violations cannot distinguish between the personal space of another person (Asada et al., 2016). Reducing the person's space leads to certain experiences: from discomfort to a

sense of danger. Accordingly, each member of the family should be aware of the importance of his/her own space and find ways to build it within the family.

The need for psychological support. It is known that members of a nuclear family are experiencing chronic stress associated with the implementation of intensive care of a particular child and overcoming emotional reactions to a child (Bonab et al., 2017). Studies show that 70% of mothers and 40% of parents of children with complex forms of disability experience a high degree of distress (Jones & Passey, 2004) The experience of stress and certain symptoms of depression is also characteristic of siblings (Breslau & Prabucki, 1988). Therefore, psychological support at different levels is extremely important for every member of the family system. At the same time, it should be emphasized that in programs of support, for the most part, universal strategies are used, however, it is desirable to rely on the individual vision of family members for an effective type for them, a way of psychological support. In other words, it is up to family members to ask: How would you like to be supported?

The need to care for one's own self and meet individual needs. It is known that family members mostly take care of a child with special needs: caring for, implementing educational functions, solving urgent problems etc. Satisfying the needs of the child is a priority in such families. Consequently, awareness and satisfaction of the personal needs of family members remains beyond the scope of attention. At the same time, it is known that ignoring their own actual needs leads to the emergence of stress and, consequently, the emergence of psychological, somatic and social problems. In this way, the situation may get worse, because it is similar to a "closed circle": dissatisfaction with the needs of the individual subsystem produces tensions, accordingly, the person gradually loses his own resources and, consequently, cannot support and care for the child with peculiarities of development. The basis for the classification of the basic individual needs may be the proposed pyramid of needs

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(Maslow, 1970), needs of children (Borg-Laufs, 2013). However, it should be noted that the key aspect in this issue is the awareness that each individual has individual needs that, in their totality, are unique. That is why in modern psychological science there is no universal classification of human needs. Thus, it is extremely important for each member of the family with a special child to focus on understanding their own diverse needs and take care of their satisfaction.

Needs of marital subsystem. The marital subsystem consists of a spouse – husband and wife. Within a family relationship system, marital relationships are fundamental and pivotal.

A number of studies have found that the development of a child causes a significant stress, a low level of marital satisfaction, causes the risk of divorce between partners (Urbano & Hodapp, 2007; Hartley et al., 2017). It has been established that marital partners raising children with different developmental disorders are 5.97% more likely to be divorced than families with healthy children (Risdal & Singer, 2004).

Sufficiently tense relationships can arise for a number of reasons. In such families, the relationship between partners is deformed: on the one hand, formal well-being is maintained, and on the other hand, the spouses are emotionally removed from each other, changing their vision of oneself and their perceptions about the partner. Birth of a child with developmental disabilities leads to an increased level of care for it and, accordingly, reduces the amount of time partners spend with each other (Hartley et al., 2017). Problems with the child's externalization, its behavior and peculiarities of development lead to conflicts between partners and the appearance of frequent, intense and unresolved conflicts in the marital subsystem (Hartley et al., 2017). In addition, the presence of a child with peculiarities of development can serve as a kind of catalyst that actualizes latent problems of partners.

However, modern research psychologists show that harmonious relationships in marital subsystem reduce feelings of

stress and depressive symptoms in families with a special child, regardless of the quality of social support, the characteristics of the child and social and economic status of the family (Kersh et al., 2006). Obviously, in such families partners invest their time and energy on building a dyadic relations and meet the needs of each other, which helps them cope and survive the crisis family situations.

The study identified a number of needs that are important to marital partners, namely the need for love, support, affinity, partner care, as well as material and sexual needs. These needs are common to both men and women. We can assume that these needs are similar to most of the marital subsystems of different categories of families. The essential difference is that for parental families with peculiarities of development, the parent subsystem is more significant and significant in their ideological system, in contrast to the marital one. The systematic frustration of the needs of men and women leads to the accumulation of tension and gradually causes the destruction of the relationships in this subsystem.

A group of needs in the parental-child subsystem

Parental subsystem (mother-child, father-child) is a subsystem that unites family members who perform parental functions: they care about the upbringing, development and socialization of children. In families with special children, the parent subsystem is extremely overloaded. For the most part, this is due to many factors: constant search for parents for optimal ways of developing a child, lack of hope for relief, long-term dependence of the child from adults, isolation from society, etc.

The need for true information about the development of the child. The birth of a child with special needs requires a family of additional resources for appropriate care and upbringing. Accordingly, parents need to be informed about different aspects of the life of a particular child. Parents' main problems are focused on how to ensure that the child is effectively adapted and integrated into society. That is why the information needs concern

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regarding the peculiarities of education, the search for additional resources and understanding of the rights of children who have a developmental disorder. Parents need accurate information about the child's condition and further steps as they must realize a new vision of themselves and their further family life (Hedderly et al., 2003). Research shows that most parents need information about the ways and means of disclosing the potential of a child with specific needs (Gowen et al., 1993). However, this need in different categories of parents is uneven: mothers are more interested in information about the education of special children than their parents; most mothers and parents are interested in the peculiarities of social, emotional and cognitive development of children (Gowen et al., 1993).

Some studies emphasize that the information needs of families don't relate only to the specifics of the child's life. Thus, parents need information on paternal self-efficacy and ways to receive support. Those parents who experienced a higher degree of control over services showed a low need for information (Huus et al., 2017).

The need for adaptation and acceptance of the role of "parents of a special child". The birth of a child with special needs drastically changes the usual way of life of the family. To the usual stressors associated with the upbringing of any child the following is added: uncertainty about health and further prediction of the child's development; systematic visits to the doctor and additional medical procedures; specific care for a child. Accordingly, such parents have a need to adapt to the situation that arose, and realize their parental role in some other way.

Adaptation to the role of "Parents of a Special Child" involves the process of experiencing the destruction of dreams by parents and building new, more realistic expectations for the future of the child and further performance of parental functions. In addition, parents must be ready for a long, sometimes life-long exercise of their guardian functions regarding the child. The children in this category express the need for the presence of another person, since they are significantly restricted in their

own independence and cannot satisfy most of the basic needs (Kuchmanyh & Opanasenko, 2018).

Adaptation also implies the implementation of parental roles in a number of other family and social roles of men and women. It is a question that the role of "special children's parents" should occupy only one of a number of social roles, rather than supersede most of the roles that occurred before the birth of a child with special needs.

Simultaneously with the notion of "adaptation" the concept of "adoption" is used. The validity of the use of this term is due to the fact that adaptation is a continuous process, and "acceptance of a role" determines the level of readiness of parents to the conscious, not distorted illusions of interaction in a certain period of time in accordance with the individual properties of the child. In addition, the constructive acceptance of parental role involves the inclusion of it in the system of male/female interpersonal roles. Thus, the adoption of the role of "parents of a special child" involves finding a peculiar balance between acknowledging the limitations of the child and the excessive desire to compensate them; providing love for a child without excessive care or rejection (Kandel & Merrick, 2007).

Consequently, the need to adapt and adopt the role of "parents of a special child" is manifested in the realization of the real situation, readiness to interact with the child, modifications of expectations and prospects for future planning in accordance with the diagnosis and condition of the child, finding an optimal balance between parent's role and other male/female roles, building a joint child development strategy with supporting specialists.

The need to find the meaning of one's own experience. Many studies emphasize that the presence of a child with special needs changes the configuration of family relationships, habitual lifestyle, requires extraordinary emotional and financial resources (Baker-Ericzen et al., 2005). However, a number of studies suggests that in the process of successfully adapting parents to

the situation and their role, positive points are also highlighted. Parents can transform their own negative experiences in a positive way by finding the positive aspects that have occurred because of the appearance of a child with a developmental disability in the family. Studies have documented that childhood disability has contributed to raising awareness of goals; personal growth; improvement of mutual relations and social relations; raising spirituality; enhancing tolerance and sensitivity; more positive view of the future (Neely-Barnes & Dia, 2008). Accordingly, parents who care for a child with special needs, have one of the basic needs – the desire to find meaning for their own experiences; to transform the existing negative experience into a positive one; find the benefits that take place in the situation of raising a particular child.

The need for special child adoption by society. In the general context, “adoption” is a complex process based on such a perception of reality that is not distorted by stereotypes, negative guides, fears, illusions, expectations, etc. Adoption of a child with special needs by others is an active process of awareness and adequate treatment of personality constraints (that is, something that a person cannot change); the recognition of multivariance and “other” forms of existence. At the heart of this perception there are no estimates. Adoption by parents of a child with special needs requires a lot of time and resources, however, this process is natural. At the same time, the attitude of the society and adoption of a child with developmental problems is a problem that is very relevant today.

The external factors that impair the process of successful integration and adoption by the child’s society with peculiarities of development are stigmatization. Parents of children are often separated from society by accusing them of disabling the child. It was found that 21.7% of parents were accused of having their own children’s social disabilities: 46.2% of those accused were relatives, 38.5% were neighbors, and 15.3% were married partners (Duran & Ergün, 2018).

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The need to confirm the changes/dynamics of the child's development. A child with special needs has an individual trajectory of development. Quite often in such a child there are not so bright and visible markers of its formation. Accordingly, parents make great efforts to support the child in its maturation. In addition to physical care, parents' activities are aimed at socializing children and improving their psycho-emotional state. Parents' actions are aimed at bringing happiness to the child, maintaining a sense of dignity and maximizing and unleashing its potential.

At the same time, parents desperately need others (specialists, relatives, acquaintances) to provide support and be part of a team involved in the child's development (Ilias et al., 2018). It is important for parents that close people with them are aware of and note the changes that are happening to the child. On the one hand, it helps parents find a positive meaning for their own experience. Thus, 73% of parents raising children with autism spectrum disorders reported that even the small achievements of their child helped them maintain a sense of hope and overcome difficulties (Ilias et al., 2018). On the other hand, children's success (in some situations they may be insignificant) emphasizes the success of parenting and upbringing and contributes to the formation of parents' sense of competence and effectiveness (Katkis et al., 2017).

Needs in sibling subsystem

The sibling subsystem consists of siblings of the nuclear family. The main function of the subsystem is to promote the development of children's interaction skills with peers. It is in relationships with peers that a child develops leadership qualities; learns to negotiate and, at the same time, defend one's position; compete; make friends, etc.

For children who have developmental disabilities and experience significant difficulties in the process of socialization, the subsystem of siblings is important, because this is where

the first and most intense experience of building relationships with peers. Siblings provide communication, help and emotional support, which is crucial for the socialization and integration of children with special needs. At the same time, siblings of children with special needs often do not have the opportunity to understand and articulate to parents their own needs, which may be somewhat frustrating. Three specific needs of siblings of a child with special needs have been identified.

The need for attention and love from parents. Having a child with special needs can cause emotional (negative experiences) and structural (coalition of a sick child and one of the parents) transformations in the parental subsystem. Accordingly, changes in the parental subsystem affect all other subsystems, including sibling. In addition, parents can spend a lot of time on a child with special needs and much less on meeting the needs of healthy children (Ilias et al., 2018). Usually children are extremely sensitive to such a differentiated attitude of their parents and react painfully to it. Children experience depression, anxiety, and low self-esteem if they are dissatisfied with their parents' attitudes toward themselves (compared to their parents' attitudes toward other children). At the same time, if children can realize the meaning that parents pay more attention to the other child and see justice in it, it does not cause their resistance (Kowal et al., 2002).

It is important to understand that healthy siblings often cannot identify and verbalize their current needs. Due to the systematic frustration of their own needs, they begin to show certain deviations in behavior in order to attract the attention of parents. Accordingly, parents should adapt to the individual needs of healthy children, respond in a timely manner and find the best ways to meet them.

The need for informing about the somatic and psychological characteristics of a special child. Information about the peculiarities of the development of a special child is usually discussed with parents, adult relatives and acquaintances. In most cases, children are left out of the discussion of issues related to

their sister / brother with special needs. In addition, parents may not pay attention to the current needs of healthy children for information on the health of siblings with developmental disabilities.

Instead, a lack of awareness of healthy children raises a number of questions: Who is to blame for the sibling disorder? Is it possible to get this disease? Is it worth telling acquaintances and friends about it? How best to talk about it? What does it mean to have limited sibling opportunities for each family member's future and their own future? How to deal with negative emotions that arise (anger, pain, guilt, fear)? How to behave with a brother/sister and other people in the immediate environment? (Seligman & Darling, 2009). These and other questions, which the child does not find answers to themselves and cannot get from parents, cause extreme stress and the emergence of negative emotions.

Therefore, at different stages of ontogenesis, siblings of people with disabilities need comprehensive information. And this information should be adequate to the question and age of the child, clear, concise, true.

The need for division of responsibilities according to the age of siblings. It is known that in families raising a child with special needs, the relationship between siblings is more adult, because siblings, regardless of age, care more and are responsible for children with certain developmental disabilities. The need to be constantly present, pay attention, care and help parents causes a set of negative emotional experiences (anger, irritation, guilt, etc.). Moreover, these experiences can have several vectors of direction: brother/sister; parents who are unable to provide adequate care on their own; himself. In addition, the intensity of the experience depends on the size of the family and the number of sibling subsystems. Thus, research has shown that in families with several healthy children, each of them feels less pressure and, accordingly, is not so obliged to "compensate" parents for the developmental disorders of their siblings (Seligman & Darling, 2009).

It should be emphasized that the so-called “role conflict” (when siblings become “parents” of a child with special needs) is not typical for all families. Mostly, it occurs if the parents ignore the individual needs of a healthy child and at the same time delegate their own parental responsibilities to her/his part. Instead, in cohesive and friendly families, where care for a particular child is recognized as a shared responsibility and takes into account the age characteristics of healthy children, siblings are actively involved and help parents.

Besides identifying groups of urgent needs for families raising a child with special needs, we determined the severity of these needs (see Figure 2).

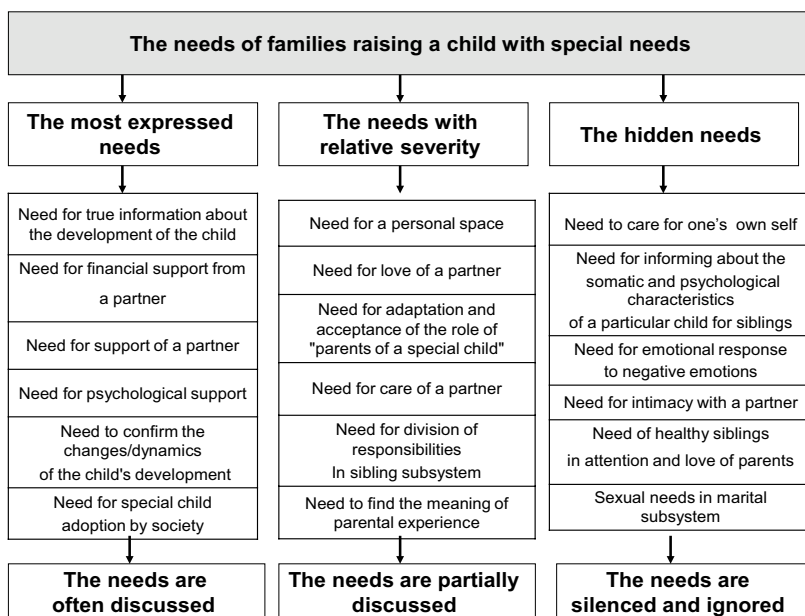


Fig.2. The degree of expressiveness of needs of families raising a child with special needs

The application of the expert assessment method (ranking stage) allowed to identify 3 groups of needs according to their

importance for families of children with special needs: the most pronounced needs (often discussed), needs with relative severity (partially discussed) and hidden needs (silenced and ignored). Outlining the essence of the above needs to some extent determines the areas of work of specialists in the implementation of quality socio-psychological support for families of children with special needs. Thus, the specialist must understand that beyond the more "expressive" needs for the family there are a number of other, no less important. The needs that are often discussed in the family circle or with specialists are mostly related to the parent subsystem. They are recognized by family members and determine their movement towards these needs.

Those needs, which are only partially discussed, are mostly related to other subsystems and do not attract the attention of adult family members. Accordingly, they may be partly aware and satisfied. The group of needs that experts have categorized as "Silenced and ignored ones" is that is not expressive and well-informed by members of the family. On the one hand the needs are important to the psychological health of each member of the family. On the other hand, they are ignored, and silenced. Therefore, social and psychological support should be aimed at helping family members find the best ways to meet those needs that are realized; support for family members and assistance in understanding the needs of the group, which are partially discussed or generally kept silent.

Conclusion

The study, using the expert assessment method, identified 18 special needs of the family bringing up a child with special needs. These requirements allow to focus on the specificity of the needs of each family member, depending on the subsystem in which it is included. The outlined group of needs was correlated with the functioning of the individual, marital, parent-child and sibling subsystems within the family system. In addition, by experts' ranking the identified family needs as a factor of relevance for families, they were categorized into three categories:

those that are often discussed, partially or generally ignored and ignored. This approach, in our opinion, will help to implement more effective socio-psychological support by focusing on different needs groups and developing the best ways to meet them.

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Кучманіч Ірина, Опанасенко Людмила. До питання класифікації потреб сімей, які виховують дітей із особливостями розвитку (системний підхід)

Сім'ї, які виховують дітей із особливими потребами, відрізняються від решти сімей більшою кількістю та варіативністю потреб. У наукових

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дослідженнях висвітлюються питання специфічних потреб сім'ї, однак здебільшого описано їх узагальнену сукупність.

Отже, **мета** статті – дослідити та виокремити потреби у таких сім'ях та описати їх у контексті індивідуальної, подружньої, дитячо-батьківської і сиблінгової підсистем сімейної системи.

Для реалізації мети використовувались такі методи: теоретичні – аналіз, систематизація, класифікація та узагальнення; емпіричні – спостереження, бесіда, інтерв'ю та метод експертних оцінок.

Результати дослідження. Загалом було виокремлено 18 потреб сім'ї і розподілено їх відповідно до сімейних підсистем – індивідуальної, подружньої, батьківської та сиблінгової. У контексті індивідуальної підсистеми виокремлено такі потреби: потреба в емоційному відреагуванні негативних емоцій, потреба в наявності особистого простору, потреба в підтримці, потреба в піклуванні щодо власного Я. Для подружньої підсистеми визначено спільні потреби для обох партнерів (в любові, підтримці, піклуванні, близькості з боку партнера, матеріальні та сексуальні потреби). У батьківській підсистемі схарактеризовано специфічні потреби: у правдивій інформації, адаптації та прийнятті ролі «батьки особливої дитини», у знаходженні сенсу взаємодії в системі «батьки-особлива дитина», у прийнятті суспільством особливої дитини, потреба в підтвердженні змін/динаміки розвитку дитини. Сформульовано потреби братів та/або сестер у сиблінговій підсистемі: в увазі та любові з боку батьків, інформуванні щодо сомато-психологічних особливостей такої дитини, розподілі обов'язків відповідно до віку сиблінгів.

Висновки. Виокремлення потреб сім'ї та визначення ступеня їх виразності має практичне значення для здійснення ефективного соціально-психологічного супроводу. Фрустрація неусвідомлених потреб спричинює посилення напруження та погіршення сімейного мікроклімату. Натомість усвідомлення потреб членами сім'ї стане поштовхом для знаходження необхідних ресурсів та оптимальних шляхів їх задоволення.

Ключові слова: потреби сім'ї, діти з особливими потребами, підсистема, сімейна система, сім'я, що виховує дитину з особливостями розвитку, сиблінги, батьківська підсистема.

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