

Development of Adaptation and Rehabilitation Potential of A Family That Bring Up A Child With Health Limitations in The Conditions of A Parent Club

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Abstract

Family adaptation to parenting and accompanying a child with disabilities is currently a serious social and psychological problem. This study is aimed at studying the development, adaptation and rehabilitation potential of a family raising a child with disabilities in an inclusive education. This study is also aimed at theoretical substantiation, experimental verification and confirmation of the possibilities to adapt and rehabilitate such families with the help of a parent support program based on the parent club of the Center for Psychological, Medical and Social Assistance. The methodological basis of the study was the systematic and active support to families in inclusive education. The research was carried out by analyzing scientific literature and using psychological techniques. The results of the study deepened the scientific understanding of the principles, mechanisms, methods of measuring the effectiveness and improving the process of accompanying a family raising a child with disabilities in inclusive practice. The article defines the essence and content of the adaptive and rehabilitation potential of a family raising children with disabilities, identifies the structural components; and provides diagnostic tools. The results of the experimental study prove that the actual problem of improving adaptive and rehabilitative potential of a family raising children with disabilities can be successfully solved with the help of a parental support program in a parent club.

Introduction

We associate interest in the problems of the family with an understanding of the importance that it has for the social development. All researchers agree that a family is the main required condition for the socialization of the individual. It is the primary micro community where the personal qualities of the child are formed.

For a child with a defect of a mental or somatic nature, the family as the primary and the most emotionally significant space of life, must fulfill his basic purpose –to become a kind of correctional and developmental environment that provides defect compensation.

The adaptation of the family to the process of bringing up and accompanying a child with health limitations in the living space is a serious social and psychological problem these days. As the analysis of research letters on family problems and the experience of socio-pedagogical activity shows, the life of most families with such children is accompanied by a number of destructive emotional stress, lack of encouragement, and lack of formation of mechanisms for productive adaptation to life. Many of parents and family members need psychosocial support and educational assistance themselves.

In modern studies, they consider family to be a rehabilitation structure containing a developing potential for the child's capabilities (Tkacheva, 2014); they studied the psychological characteristics of parents raising children with disabilities integrated into an inclusive educational environment (Kalinina &Khairudinova, 2013), and examined various aspects of psychological support for parents of children with disabilities (Slyusareva, 2015).The rehabilitation activity of the studied family has been studied in

recent publications (Koritova, 2016); they studied organizational and substantive aspects of psychological and pedagogical support of a family with a child with disabilities (Kosareva & Fominykh, 2017).

Psychological and pedagogical researches carried out by V.A. Vishnevsky, B.A. Voskresensky, R.F. Mairamyan, I.A. Skvortsov, L.M. Shipitsina and others describe the psycho-traumatic effect of a special needs child on family relationships and, in this regard, the occurrence of psychopathological disorders in mothers. So, a psychological study of interpersonal relationships in families raising a child with disabilities, carried out by L.M. Shipitsina in 2005, showed that most families are not able to cope with problems associated with having a disabled child in the family independently.

There are scientific works of such authors as D. Dobson, R. Skinner, D. Klings, N. Finney, K. Flake-Hobson, M. Seligman, R. Darling et al. about parent-child relationships in families raising a special needs child.

In 2011, Potashova I.I. analyzed the current aspects of psychological and pedagogical work with families raising a child with disabilities. V.G. Taktarov and E.G. Babich's research (2011) is on the features of working with families bringing up children with health limitations. This study is determined by the social significance of the results of theoretical and empirical studies of personal and social factors in coping with difficult straits, creating conditions and an effective mechanism of psychosocial support for children with disabilities and their families.

Under the supervision of S.V. Alekhina and M.M. Semag (2012), the author created and tested a model of psychological and pedagogical support of inclusive practice, and worked with families (Chemirilova, 2017). The work of V.V. Tkacheva (2014) contains a lot of longstanding research on the problems of the family raising a child with special needs.

In 2015, R.I. Khayrutdinova made an attempt to study some personal attributes of parents of children with disabilities that underlie the adaptive potential of a person. The data obtained on the developmental delays of the personal psychological characteristics of parents of children with health limitations allow for the conclusion that the adaptive potential of a person in this category is low.

The author deduces that building up of adaptive potential is possible in the process of implementing psychological and pedagogical support by forming an adequate idea of the parents about the child's disorders, reducing emotional stress, forming motivation to accept a child's defect, forming an adequate self-esteem, increasing their level of vitality. The goal of the present study is to describe and evaluate a family support program aiming at the development of parents' adaptation and rehabilitation potential.

Theoretical framework

According to most researchers, the basis of inclusive education should be a specially organized process of accompanying the family and personality of the child. The comprehensive support of families is understood as the activity aimed to update the correctional resources of the family ensuring the effectiveness

of its functioning, especially during periods of crisis associated with the upbringing and development of the child. Such organized help of specialists of various profiles is necessary for parents for solving the problems of the rehabilitation process (Tkacheva, 2014, p. 152).

However, a number of problems burden the process of accompanying children with disabilities in the context of inclusion.

As studies have shown, we can distinguish among them the following challenges:

1. Low educational competence of parents due to the limited pedagogical and speech pathology knowledge and ideas;
2. Poorly developed skills for interacting with children, organizing joint practical activities;
3. Lack of opportunities for expanding the social space of families raising children with developmental problems;
4. Inadequate, unrealistic attitude to the limited abilities of a child, disbelief in his success;
5. Difficulties in the implementation of intra-family communication of all family members, contributing to the formation of adequate self-esteem and giving the opportunity to receive emotional support;
6. The problem of insufficient psychological competence of teachers on issues of interaction with families raising children with special needs;
7. The formation of positive adaptation to life.

The successful integration of children with disabilities into the educational environment depends on a number of factors, among which the adaptation and rehabilitation potential of the family is the most important. It is manifested in the ability to have a positive perception of the world despite the illness of a child, the ability to overcome life difficulties, psychological stamina, social activity, etc. By this we mean the whole psychosocial characteristics of the family, the personal characteristics of the parents that can fully contribute to the diversification of the child, his successful socialization, positive adaptation to life in society and rehabilitation.

We can represent the structure of adaptation and rehabilitation potential as a combination of the following components:

1. The rehabilitation activity of parents, which, there for, is expressed in the consistent commitment of parents to close interaction with specialists in order to successfully rehabilitate and socially adapt the child; the correct impression of child's disorders, the ways of his integration into society; active position regarding the creation of conditions for his rehabilitation; having special knowledge and skills in looking after a child;
2. The psychological and pedagogical adeptness of parents, expressed in having full knowledge and perfect skills that allow to put into practice all the necessary developmental measures for a child; the ability to accept the child as he is, to build the right relationship with him; high awareness of parental responsibility;
3. A favorable psychological climate in the family; positive perceptions of family members;

4. The level of compliance with pressures, resilience, allowing to overcome life's difficulties, to plan future with optimism.

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5. Difficulties in the implementation of intra-family communication of all family members, contributing to the formation of adequate self-esteem and giving the opportunity to receive emotional support;
6. The problem of insufficient psychological competence of teachers on issues of interaction with the studied category of families;
7. Difficulties associated with the formation of a positive adaptation to life, overcoming the state of tension and stress.

Methods

We carried out an experimental work on the basis of MBOU "Center for psychological, medical, social, pedagogical support and development of the city of Cheboksary" in the Chuvash Republic where there is a club for parents "Unique Child". The main feature of the club is that both parents of children with disabilities and parents of healthy children participate in the classes.

Guidelines for the work of the parent club:

- Increasing the level of parental competence;
- Methods of productive adaptation to life training, overcoming the state of crisis;
- Integration of parents through discussion of parental problems of upbringing children, their behavior and education.

The Club's program "MiVmeste" ("We are Together") provides complex support for families with children with health limitation and aims at the development of parents' competences and responsibility in caregiving. A total number of 30 families participating in the program have been observed and surveyed. All the families care about children with different types of health limitations including developmental disabilities, visual and hearing impairments, disorders of the musculoskeletal system, congenital heart disease and other physical and mental health issues.

Parents of preschool children participated in the experiment.

The study consisted of the following stages.

Stage 1 – Diagnostic. At this stage, we studied the adaptation and rehabilitation potential of the studied family by which we mean the whole psychosocial characteristics of the family, the personal characteristics of the parents who can fully contribute to diversity of the child, his successful socialization, positive adaptation to life in society and rehabilitation.

The adaptation and rehabilitation potential of the family manifests itself in the following components:

1. The rehabilitation activity of parents which, in turn, is expressed in the parents' commitment to close interaction with specialists in order to successfully rehabilitate and socially adapt the child; the correct idea of child's disorders, the ways of his integration into society; active position regarding the creation of conditions for his rehabilitation; possession of special knowledge and skills in caring for a child;
2. The psychological and pedagogical competence of parents, expressed in the possession of full knowledge and perfect skills, allowing to put into practice all the necessary developmental measures for the child; the ability to accept the child as he is, to build the right relationship with him; high awareness of parental responsibility;
3. A favorable psychological climate in the family; positive perceptions of family members;
4. The level of compliance with the pressures, resilience, allowing to overcome life's difficulties, to plan future with optimism.

To identify the level of rehabilitative activity of parents, a questionnaire was compiled, which included the following questions:

1. Do you take care of keeping your child's daily routine?
2. Does the child undergo regular medical examinations?
3. Do you have sufficient knowledge of your child's developmental characteristics?
4. Do you regularly seek advice and assistance from specialists related to your child's development?
5. Do you cooperate with a rehabilitation therapist?
6. Do you follow your child's progress in the process of mastering adaptive education programs?
7. Do you seek pedagogical assistance?
8. Have you mastered the necessary developmental and correctional techniques?
9. Are you actively looking for sources of material and moral assistance necessary for the treatment, education and upbringing of your child?
10. Have you heard about the program of social and pedagogical support of your child and adaptive programs developed in the educational organization?
11. Are you a member of a parent's community (club) uniting parents raising children with disabilities?
12. Are you aware of social guarantees for a child and the possibilities of providing social assistance?

The respondents, having chosen the answers “yes”, received 3 points, “no” – 1 point, “I do not know” (“I am not at a loss”) –1 point. Maximum everyone could score 36 points, minimum 12 points. We classified the respondents who received the total number of points in the range from 25– 50% of the maximum possible to the low level; to the average level –from 50–75%; to high –above 75% of the maximum possible.

A high level of parents commitment to cooperate with specialists of the rehabilitation process, understanding of defects in the development of the child; familiarization with education adaptive programs and social and pedagogical support of the child, frequent contacts with teachers, psychologist and a social teacher, mastery of some developmental and corrective methods for studying with the child, an intensive search for sources of financial help and moral assistance needed for treatment, education and upbringing of the child. All these are the hallmarks of parents’ rehabilitation activity.

We can find more than half of the studied characteristics in parents with moderate rehabilitation activity, for a low level activity parents – one third of the studied characteristics.

Among the reasons for insufficient rehabilitation activity parents named the following: incomplete knowledge of the developmental features of their child, inability to master the necessary developmental and correctional techniques, difficulties in mastering adaptive education programs, insufficient financial help and moral assistance necessary for treatment, education and upbringing of the child, lack of tutors’ educational organizations accompanying the child.

Vitality is an important characteristic of adaptation and rehabilitation potential of a family. D.A. Leontiev defines it as an individual’s ability to withstand the stressful situation of choice maintaining internal confidence, balance and not reducing the success of an activity (Leontiev& Rasskazova, 2006).

To measure this quality, we used the “Viability Test” by D. A. Leontiev and E. I. Rasskazova (2006), which allows to assess a person’s ability and willingness to actively and flexibly act in a situation of choice or difficulties. During the examination, we asked parents 45 test questions from the questionnaire. We scored an answer to each question.

The vitality test includes three interdependent scales: involvement, control and risk taking. Each vitality indicator has three levels of expressiveness: high, medium and low. The overall viability is the sum of the indicators for each of the three subscales (involvement, control, risk taking).

We carried out a study on the psychological climate in the family using the Family “Biofield” test that consists of 35 statements, which parents had to agree or disagree with.

We carried out data processing according to the “key” and it allowed to distinguish 4 types of psychological climate in the range from “stable positive” to “stable negative”. We investigated the nature of the parent-child relationship using conversations with parents and the Parental Relationship Questionnaire.

The second stage of the experiment involved: a) the conclusion of a treaty with parents; b) the implementation of the program of full support for parents raising children with disabilities organized in the conditions of the parent club.

The support program included:

- Training sessions aimed to understand and acknowledge their hidden powers and reserves, rethinking problems in order to reduce stress, depression, etc.;
- Individual and group psycho-correctional work using elements of fairy tale therapy, game therapy, choreography therapy, sand therapy, art therapy, etc.;
- Counseling – practical assistance to the family which involves finding solutions to problem situations of a psychological, educational, pedagogical, medical and social nature;
- Teaching parents special methods and ways of working with a child to carry out an individual rehabilitation program (developing skills of general and fine motor skills, self-care, sensory learning of the world, speech and social skills, etc.);
- Organization of meetings with specialists based on requests.

Third and final Stage included an analysis of the results of experimental work, determining the level of effectiveness of the work done. We carried out a second examination depleting techniques that are used in ascertaining experiment.

Results

In the course of questioning parents, we obtained the following results. The average age of parents – 30–40 years – 75% of respondents. Only 37.5% are married, i.e. families, at most, are incomplete, where all the hardships and problems of the family burden mother. Only 25% of respondents noted their financial situation as sufficient.

50% of respondents rated their living conditions as satisfactorily adapted to the needs of the child. 75% of respondents esteemed medical services satisfactorily and 62.5% – social services.

According to the results of the survey, 41.7% of the parents surveyed have a high level of rehabilitation activity, a moderate level –46.7%, and a low level have 11.6% of respondents.

According to the study, a high level of resilience was observed in 35% of respondents; the average level is in 45% of half of the respondents, the low level is in almost 20% of the parents surveyed.

20% of parents surveyed rated the climate in their family as stable positive. 40% of respondents rated the psychological climate in the family as unstable, variable, which is characterized by the alternation of a favorable picture in relations and periods of quarrels and conflicts, tension in relations, lack of understanding in worldly matters. 23.3% of parents identified the psychological climate in their family as

uncertain, complex, ambiguous, which is characterized by protracted downturns but generally positive trends prevail.

A stable negative psychological climate is observed in families where phenomena such as constant quarrels, chronic stress, anxiety, emotional discomfort, and exclusion predominate. 16.7% of parents noted the presence of such climate.

The results of a psychological examination showed that only 33.3% of families have harmonious parent-child relationships. 26.7% of families are characterized by authoritarianism and high demands; 20% – disengagement, negative feelings towards the child; 23.3% – the presence of psychological distance; 40% of families observe the attitude to the child as a small loser, ignoring the interests, hobbies, thoughts and feelings of the child.

We consider the following criteria for the effectiveness of the implementation of full support program for parents of children with health limitations:

- Improvement of the measured indicators of the adaptation and rehabilitation potential of the family: the level of rehabilitation activity, the psychological climate, the level of vitality, the type of parent-child relationships.
- Parents' requests satisfaction;
- Assistance in resolving problems of relationships in the family, parent-child relationships' difficulties;
- Increasing the level of psychological and pedagogical competence of parents raising children with disabilities;
- Improving the psycho-emotional state of parents, a positive passion, self-confidence.
- Harmonization of parent-child relationships.

A secondary examination of the parents showed an improvement in the measured indicators of the adaptation and rehabilitation potential of the family. So, according to the results of the survey, at the control stage of the experiment, the number of parents with a high level of rehabilitation activity increased to 50%, with a moderate level it decreased slightly (up to 45%) due to the fact that the number of parents with a low level of rehabilitation activity decreased to 5%.

41.7% of respondents now demonstrated high level of resilience; 48.3% of respondents have moderate level, 10% of parents surveyed have low level.

At the control stage of the experiment, respondents assessed the climate in their families slightly in a different way. So, 30% of the parents surveyed rated the climate in their family as stable positive; 45% - as an unstable, variable, which is characterized by the alternation of a favorable picture in relations and periods of quarrels and conflicts, tension in relations. 15% of the parents surveyed identified the psychological climate in their family as uncertain, complex, ambiguous, which is characterized by long

negative phenomena, but generally positive trends prevail. 10% of parents noted stable negative psychological climate.

Analysis of quantitative data obtained using the Parental Relationship Questionnaire showed that in 30% of the examined families we can observe positive changes on the scales: acceptance-rejection, symbiosis, control, attitude to child failures.

During the entire research period, we faced the following problems:

- Before testing: it turned out to be quite difficult to attract parents to participate in the experiment;
- During testing: not all participants willingly performed the proposed tests, expressing doubts about their appropriateness;
- After testing: despite the fact that, in general, we received positive results from the implementation of the program, not all parents' requests were satisfied.
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- Before testing: it turned out to be quite difficult to attract parents to participate in the experiment;
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Throughout the entire time of classes, we observed the following picture: distrust and wariness disappeared, the atmosphere in the group changed, and from meeting to meeting, parents became more natural, open, began to express their feelings more freely, we began to notice smiles on their faces. This indicated that the situation in the communication group became more relaxed, psychologically comfortable, which allowed us to solve the tasks successfully.

A questionnaire aimed to study the effectiveness of the work carried out showed that:

1. All the parents, according to them, gained positive experience by visiting the group of parental communication;
2. 81.7% noted that they received assistance in resolving difficulties of parent-child relations, indicating that their relationship with children has changed for the better, as they have begun to understand their child successfully and have a different attitude towards him;
3. 46.7% of program participants said they observe successfully positive changes in family relationships;
4. 66.7% of respondents noted an improvement in their psycho-emotional state, the emergence of a positive attitude;
5. 41.7% of participants noted that they gained confidence in their abilities, gained skills and ability to cope with a stressful situation;
6. 50% of the parents surveyed began to positively perceive the future of their family and their child.

Since all respondents indicated that they were satisfied with their participation in the group, we asked parents to write a review about the impressions received during the group's work and describe the emotions that they experienced throughout all the classes.

Lilia and Vadim:

We want to express the opinion of many parents that we have spent this time together with benefit. The classes were interesting, useful and affordable. We got a tremendous psychological relief! We shared our problems and experiences with each other. For a while, we seemed to be children: we played, painted, laughed. We were very happy, we were understood and helped! A lot of positive moments! And we are grateful to all the specialists who were with us!

Irina and Oleg:

We want to express our gratitude to the specialists of the Development Center for their support and understanding! There was a feeling that we visited a fairy tale, where there is no anger, violence, and misunderstanding. There were friends next to us who could come to the rescue at any time. We understood not only our inward, but also the world of other people. And it is very valuable! We have found the right path for children and ourselves. Thank you so much!

Elena and Andrei:

Participating in these classes, we learned to build relationships with children, constructively resolve conflicts, and be creative in solving problems. We changed our attitude towards our children. Learned to listen and hear our children. We even learned a lot about ourselves. If we do not understand ourselves, then how can we understand our children? Center specialists have always come to our aid. Thank you for the great and necessary work!

Discussion

Family care giving for children with disabilities is believed to be of great value for society and caregivers themselves (Wang & Singer, 2016, pp. 1–2). For society, it can significantly reduce the public funds necessary to maintain the professional care services and facilities while at the same time providing care in a more natural, personalized and emotionally supporting environment. For parents, care giving is able to produce psychological and existential benefits such as sense of meaning, moral satisfaction or empowerment.

At the same time, the role of the family in the long-term assistance to children with health limitations is often taken for granted, and their special needs and problems are often underestimated. AsKing, Williams and Hahn Goldberg (2017) point out, institutional support for children with disabilities is typically focused on children themselves, whereas programs for their parents and other family members are underdeveloped, chaotic, and seldom take into account their actual needs. Numerous studies show that parents and other caregivers often suffer from chronic stress, numerous health issues, activity limitations,

financial pressure, job changes; difficulties with family functions, and other negative outcomes (Rogers & Hogan, 2003; Isaet al., 2016; Reschet al., 2010; Ahmadiet al., 2011). Addressing these problems is the major challenge of institutional efforts for family support. There is evidence that social support and access to resources are among key factors increasing parents' ability to maintain their caregiving abilities and the family wellbeing (McConnellet al., 2014; Reschet al., 2012).

However, how institutional support for families of children with health limitations and developmental disabilities should be provided, remains unclear. Singer and Wang claim for the need of evidence-based practices as a foundation of any institutionalized efforts in supporting such families (Wang & Singer, 2016). Although this claim seems reasonable and important, one has to take into account the actual limitations of developing evidence-based policies and practices, especially in dealing with such complex social problems as wellbeing of families with children with disabilities. Due to enormous diversity of social, political, cultural and economic contexts, types of children's disabilities and family settings, as well as inapplicability of experimental method in the strict sense, there will inevitably be a lot of practices based on different theoretical assumptions or non-scientific social innovations.

The present study describes an emerging practice of a parents club implemented in the context of one Russian region, and relies on theoretical framework and reevaluation of existing practices developed by V. Tkacheva (2014). An important theoretical idea underlying the present study is the concept of the family's adaptation and rehabilitation potential, which consists of both competences, activities, and psychosocial components. The idea behind the practice based on this concept is that development of the adaptation and rehabilitation potential requires a multi-method approach targeting all the components underlying parents' care giving abilities throughout the children's life course. This is the key difference of the program as compared with typical practices in Russian specialized institutions, such as legal support, training or family consulting, and with another program implemented in the center and focused on online consultations of families providing care to children with health limitations.

According to Singer and Wang, family supporting interventions can be divided into four broad categories, with various scope and scale: techniques; programs consisting of multiple techniques; interventions consisting of several programs; systems change (Wang & Singer, 2016, p. 5). In turn, King, Williams and Hahn Goldberg proposed in 2017 a framework based on a scoping review of the literature, which identified six types of family-oriented services provided by pediatric rehabilitation centers: information resources; education services; training services; support groups; psychosocial services; care services coordination. They also concluded that providing informational resources, support groups and psychosocial services are underrepresented in research and require a special attention of both researchers and practitioners.

The family support program "We are Together" described in this article, can be classified as a multi-technique program in terms of Singer and Wang (2016), as it includes several different types of activities. Regarding the typology proposed by King et al. (2017), it includes techniques and methods of all the types excluding care service coordination. This means that the rehabilitation practice of the parents club

addresses most important functions, which can be provided by an individual care provider, thus developing the core components of the family's adaptation and rehabilitation potential.

One limitation of such multi-method programs is that it is difficult to evaluate the contribution of any specific method or technique to the overall outcome and to establish specific cause-effect relationships. The study showed that the program is especially useful in improving the parents' rehabilitation competences and psychological wellbeing. An important future direction of research is to better understand, which components of the multi-method program contribute to specific components of the family's adaptation and rehabilitation potential and to what extent the overall positive outcome is due to the integral effect of implementing different techniques. As present, the results of the study shows that this complexity and multi- technique approach proved to be highly effective and workable in addressing families' needs related to caring about children with various types of health limitations and developmental disabilities. Although the program is implemented in the context of Russia's institutional settings, in which social services targeting families with children with disabilities are scarce, fragmentary and inaccessible for many parents, it can also be used as an argument in favor of complex, multi-method approaches to family support services.

Conclusion

Thus, the analysis of the results of the control phase of the experiment showed that in the families examined there was an improvement in the family and child-parent relations, as well as in the psychological state of the parents, the level of psychological and pedagogical competence of the parents increased. These changes indicate that the implemented program for accompanying parents of children with disabilities in the conditions of the parent club was successful, because it helped to increase the adaptation and rehabilitation potential of the family and should be further developed.

Using of this program on the basis of a parent club allows to achieve positive results in the family therapy which are conditioned by its advantages:

- The ability to implement various programs to support families; to use various different areas of psychocorrectional work, productive methods of art and fairy-tale therapy, film and cartoon therapy, sand and game therapy, body-oriented and music therapy, psychodrama, etc.
- Planning of work depending on the problems of a particular group of participants;
- Uniting the participants into a group of supporters, creating and strengthening relations between families, harmonizing marital relations;
- The possibility of forming a parent's valuable attitude to a child with disabilities in the development;
- Motivating the family members to search and establish contacts with various communities and organizations;
- Prevention of prolonged stress, which can have a strong deforming effect on the psyche of parents, provoke somatic or mental diseases;

- The possibility of providing psychological assistance at all stages of a child's life, since as the child grows and develops, new stressful situations and problems arise in the family, for which parents are often completely unprepared;
- Providing psychological assistance to families allows through the organization of psychocorrective measures with the child and parents to ensure the neutralization of personal problems of parents, arising as a result of their emotional experiences, related to the child's disabilities, and to optimize his development and integration into society.

At the same time, we can note the disadvantages of this program:

- Some negative consequences of participation in the work of the club: self-closure of the participants, they are closed in communication outside the group; fixation on their own problems;
- The formation of a hostile attitude towards those, who do not experience similar problems (for example, with a high level of aggression among group members, the presence of a negatively disposed leader).
- It is possible to involve in the work of the club only those parents, whose children visit the Centre.

One can single out the following directions for further research:

1. Identification and substantiation of the most effective components of a complex support program, which contribute to the development of the adaptive and rehabilitation potential of the family;
2. The influence of the rehabilitation potential of the family on the social integration of children with disabilities;
3. Development of a model of complex support for families raising children with disabilities, in an environment of a parent club, based on a differentiated approach, taking into account the severity of the child's illness, gender characteristics of the process, the level of psychological and pedagogical culture of the parents.

Declarations

Ethics approval and consent to participate

I declare that I solely drafted the work, critically revised it for important intellectual content, approved the version to be published, and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Consent for publication

The author(s) read and approved the final manuscript

All authors have given their consent to the publication of the article

Availability of data and material

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

Authors declare that they have no conflict of interests

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Authors' contributions

I. A. Chemerilova - concept, methodology, research design, interpretation

O. V. Kirillova - primary article processing, article style, heretical overview

I.V. Gavrilova-the research design

N. Akyeva-the draft article, the interpretation

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References

1. Ahmadi, Kh., Khodadadi, Gh., Anisi, J., & Abdolmohammadi, E. (2011). Problems of families with disabled children. *Iranian Journal of Military Medicine*,13, 49–52.
2. Alekhina, S. V, Semag, M. M. (Eds.). (2012). *Sozdanie i oprobatsiya modeli psikhologo-pedagogicheskogo soprovozshdenia inkluzivnoi praktiki: metodicheskoe posobie* [Creation and testing of a model of psychological and pedagogical support of inclusive practice: a methodological manual]. Moscow State University of Psychology and Education.
3. Chemerilova, I. A. (2017). Psikhologo-pedagogicheskie zatrudnenia roditelei, vospitivauschih detei s ogrannichennimi vozmozshnostiami zdorovia, v usloviyakh inkluzivnoi praktiki [Psychological and pedagogical difficulties of parents raising children with disabilities in an inclusive practice]. In *Pedagogical education in a changing world – Proceedings of the 3rd International Forum on Teacher Education* (pp. 286 – 291). Otechestvo.
4. Isa, S. N. I., Ishak, I., Ab Rahman, A., Mohd Saat, N. Z., Che Din, N., Lubis, S. H., & Mohd Ismail, M. F. (2016). Health and quality of life among the caregivers of children with disabilities: A review of literature. *Asian Journal of Psychiatry*, 23, 71–77. <https://doi.org/10.1016/j.ajp.2016.07.007>

5. Kalinina, N. V., & Khairudinova, R. I. (2013). Psikhologicheskiye osobennosti roditeley, vospityvayushchikh detey s ogranichennymi vozmozhnostyami zdorov'ya, integriruyemykh v inkluzivnyuyu obrazovatel'nyuyu sredu [Psychological features of parents raising children with disabilities that are integrated into an inclusive educational environment]. *European Social Science Journal*, 2(12), 156–160.
6. Khayrutdinova, R. I. (2015). Lichostnie osobennosti i adaptivnie resursi roditelei, vospitavushchih rebenka s ogranichennymi vozmozhnostyami zdorovia v usloviyakh realizatsii inkluzivnogo obrazovaniya [Personal characteristics and adaptive resources of parents raising children with disabilities in the context of the implementation of inclusive education]. *Modern problems of science and education*, 6.
7. King, G., Williams, L., & Hahn Goldberg, S. (2017). Family-oriented services in pediatric rehabilitation: a scoping review and framework to promote parent and family wellness. *Child: Care, Health and Development*, 43(3), 334–347. <https://doi.org/10.1111/cch.12435>
8. Koritova, E. A. (2016). Rol reabilitatsionnoi aktivnosti semyi v vospitanii rebenka s ogranichennymi vozmozhnostyami zdorovia [The role of family rehabilitation activity in raising a child with disabilities]. In *Problems and prospects for the development of education – Proceedings of the VIII international scientific conference* (pp. 88–91). Novatsia.
9. Kosareva, A. A., & Fominykh, E. S. (2017). Organizatsionno-soderzhatelnie aspekty psikhologo-pedagogicheskogo soprovozshdeniya semyi rebenka s ogranichennymi vozmozhnostyami zdorovia [Organizational and substantive aspects of the psychological and pedagogical support of a family of a child with disabilities]. *Koncept*, 35, 79–84.
10. Leontiev, D. A., & Rasskazova, E. I. (2006). *Test zshiznestoikosti [Vitality test]*. Smysl.
11. McConnell, D., Savage, A., & Breikreuz, R. (2014). Resilience in families raising children with disabilities and behavior problems. *Research in Developmental Disabilities*, 35(4), 833–848. <https://doi.org/10.1016/j.ridd.2014.01.015>
12. Potashova, I. I. (2011). Sovremennye aspekty psikhologo-pedagogicheskoy raboty s semiyami, vospitavushchimi rebenka s ogranichennymi vozmozhnostyami zdorovia [Modern aspects of psychological and pedagogical work with families raising a child with disabilities]. *Psikhologicheskaya nauka i obrazovanie*, 3.
13. Resch, J. A., Benz, M. R., & Elliott, T. R. (2012). Evaluating a Dynamic Process Model of Wellbeing for Parents of Children with Disabilities: A Multi-Method Analysis. *Rehabilitation Psychology*, 57, 61–72. <http://dx.doi.org/10.1037/a0027155>
14. Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology*, 55(2), 139–150. <https://doi.org/10.1037/a0019473>
15. Rogers, M. L., & Hogan, D. P. (2003). Family Life with Children with Disabilities: The Key Role of Rehabilitation. *Journal of Marriage and Family*, 65(4), 818–833. <https://doi.org/10.1111/j.1741-3737.2003.00818.x>

16. Shipitsyna, L. M. (2005). *“Neobuchaemii” rebenok v semie i obschestve. Sotsializatsia detei s narusheniyami intellekta* [An “uneducable” child in the family and society. Socialization of children with intellectual disabilities]. Rech’.
17. Slyusareva, E. S. (2015). Psikhologicheskoe soprovozhdenie roditel’ei v usloviyakh inkluzivnogo obrazovaniya detei s ogrannichennimi vozmozhnostiyami zdorovia [Psychological support of parents in the context of inclusive education of children with disabilities]. *Fundamental research*, 2 – 1, 179–183.
18. Taktarov, V. G., Babich, E. G. (2011). Tolerantnoe otnoshenie obschestva k semiam, vospitivayushchim detei s ogrannichennimi vozmozhnostiyami zdorovia: ot preodoleniya izolirovannosti k resheniyu voprosov inkluzivnogo obrazovaniya [Tolerant attitude of the society towards families raising children with disabilities: from overcoming isolation to solving issues of inclusive education]. *Scientific notes of the Russian State Social University*, 7(95), 5–9.
19. Tkacheva, V. V. (2014). *Semia rebenka s ogrannichennimi vozmozhnostiyami zdorovia: diagnostika i konsultirovanie* [Family of a child with disabilities: diagnosis and counseling]. National Book Center.
20. Wang, M., & Singer, G. H. S. (2016). *Supporting families of children with developmental disabilities: evidence-based and emerging practices*. Oxford University Press.