

Technology of the Psychological and Pedagogical Support of Families with Preschool Children with Cerebral Palsy

Nina Dubrovina¹ and Nina Serova²

Abstract

The purpose of the research was to determine effectiveness of habilitation of preschool children with cerebral palsy in the process of pedagogical support of their families. The authors present the study of psychology-pedagogical problems of families with preschool children with cerebral palsy and the universal program of pedagogical support of families. As the movement disorder, cerebral palsy is visible to the other people. Also children with cerebral palsy have to use a lot of additional technical tools for moving. These are caused many psychological and social problems of the families with children with movement disabilities. The technology of support includes not only parents or child lessons, but their connection in the pedagogical process, and optimization their psychological status on this base. The advantage of the technology is the opportunity for families to use methods of habilitation by themselves. It is important for families from the regions. There are 22 children and their families in the research. The technology includes six stages: diagnostic, forming, activity, consulting, information and summarizing. As a diagnostic complex, authors used a questionnaire by Varga and Stolin and Monitoring of motor skills formation. In the conclusion, the authors determine effectiveness of social adaptation of children with cerebral palsy and their families.

Keywords: Habilitation, Cerebral palsy, Pedagogical support, Social adaptation.

In the development of scientific bases of the training of athletes of varying qualifications great importance is given to the creation of models. Their significance is indicated in the works of leading experts in theoretic and practice of physical training due to the need of the training process management and selection of promising athletes. The “model of the fittest athlete”, its structure and place in the general system of training were considered. Traditionally psychologists select the most pronounced personality traits of successful athletes using the test and thus get the “athlete’s personality profile”. However, there is a disagreement among scholars in the choice of indicators of readiness and the tests for their study. The concept of the “model of athlete’s preparedness” as the construction of a generalized image of a successful athlete in a particular sport creates some discussion. The idea of an “athlete’s model” relating to such a complex activity as a sport one is sometimes questioned, since it is impossible to consider in «model» all the characteristics of activities and highlight a recognized as standard-model «profile of personal».

One of the most common causes of disability among kids is cerebral palsy, occurring as a consequence of organic brain injury (Badalyan, 1987; Mastukova, 1992). A characteristic feature of cerebral palsy is the damage to the movement brain function from birth. Which disturbs a child’s development and creation of movement functions. Despite this, cerebral palsy means disorders in the development of higher analytic functions, speech, and mental

retardation. As a result, conditions for disability are created which significantly complicates education and socialization processes for children with cerebral palsy. Consequently, it affects the psychological condition of parents.

The problem of organizing pedagogical assistance for children with cerebral palsy in different educational environments has been studied and discussed in the scientific researches of Vlasova (1973), Evseev (1996), Shipitscyna (2002), Shapkova (2000) and others. One of conditions for successful adaptation of children, as discussed in those researches, is a deliberate consideration of physical and mental health. The organization of work with disabled children’s families has been reported in scientific researches of Tkachyova(1999), Zabramnaya (2005), Levchenko (2001), Mastukova (1997) and others.

According to Tkachyova (2008), personality disorders of parents appear as disruption of behavioral adjustment and inadequate forms of interaction with the world, including the child. This, in turn, explains a traumatized child’s personality, the lack of special correctional facilities for the child’s development in the family, and a violation of social adaptation processes. This creates an urgent need to provide special support for the families of children with developmental disabilities.

Movement disorders affect parents of children with cerebral palsy most significantly. First of all, movement disorders are visible to the other people and are accompanied by noticeable deformities: asymmetrical face and body fea-

1 Нина Дубровина. Ural Federal University. E-mail: poletaevanina@gmail.com

2 Нина Серова. Ural Federal University. E-mail: ninasero@mail.ru

tures, speech and pose disorders, a voice modulation, salivation, usage of handicapped devices. Excessive attention of people around is a tremendous stress factor for parents of children with cerebral palsy.

Second, lack of independence, immobility or other movement difficulties imply the need of constant physical care for the children. It requires special effort from parents. At the same time, the purchase of new handicapped devices and habilitation of children leads to higher material expenses. Even if the child walks himself or uses a walker, or a cane, his movements are slow and clumsy which creates a deep emotional challenge for the parents.

Badalyan reveals the concept of “habilitation” as a system of medical and pedagogical interventions, which aim to prevent and treat pathological conditions of infant age children, who haven’t adapted to a social environment yet, and which lead to a permanent loss of learning and working abilities.

The urgency of pedagogical work with such parents is caused by the fact that disabled child’s family is a rehabilitation structure, which has a potential to create favorable conditions for healthy development and education of the child. A comprehensive study of parents’ personal features and designing specific forms of psychological-pedagogical assistance to families can help them to overcome difficulties in the process of social adaptation as well as to find a “social niche” for themselves and their children.

Children with severe forms of cerebral palsy often don’t have an ability to attend preschools because of mere lack of specialized groups for them. It deprives them of the right to receive full remedial help. Short stay in hospitals (2-3 times in a year) can’t solve this problem. Parents of children with cerebral palsy don’t have the necessary information on habilitation process benefits and don’t know the remedial methods and technologies. In addition to pedagogical literacy, there is a problem of psychological alienation of families of cerebral palsy children. Parents find it difficult to accept their child, and this, in its turn, negatively affects the habilitation process of preschool age children.

The purpose of the study is to determine effectiveness of habilitation of preschool age children with cerebral palsy in the process of pedagogical support of their families.

Based on the analysis of relevance, purpose, subject and matter of study, we put forward the following hypothesis: we assumed, that if we organize the process of pedagogical support for the families, the habilitation of preschool age children with cerebral palsy will be more effective, parents will be more active participants of this process, they will be able to conduct it themselves, monitor changes and to adequately assess the results of habilitation procedures.

In accordance with the purpose and hypothesis of the study we identified the following objectives: (1) To analyze the scientific and methodological literature on the characteristics of the psychological and physical development of children with cerebral palsy including multiple disorders, the content matter of the remedial work with them in dif-

ferent conditions, and psychological and pedagogical problems of families of preschool age children with cerebral palsy; (2) To study psychological and pedagogical problems of families with preschool age children with cerebral palsy and multiple disorders; (3) To develop and introduce the universal technology of pedagogical support for families for the purpose of habilitation of preschool age children with different forms of cerebral palsy; and (4) To determine the effectiveness of social adaptation of children with cerebral palsy.

Method

Participants and procedure

The study was conducted in the specialized school №17 and the family association “Nadezhda” in Ekaterinburg, Russia. 22 children ages three to seven with different forms of cerebral palsy and 22 parents of disabled children participated in the research. Children and parents were divided into two groups: 12 children and their parents in the first group (those who attended specialized kindergarten five days a week), and ten children and their parents in the second group (those who were members of the family association “Nadezhda” one day a week). Children from both groups had the following forms of cerebral palsy: spastic diplegia, spastic quadriplegia, and ataxic. The study was conducted in three stages from 2008 to 2012.

For the study we used a questionnaire by Varga and Stolina, 1988. We used these authors’ technique of monitoring formation of motor skills in order to assess the development of movement functions in the children.

Analysis of present techniques for monitoring children with cerebral palsy has shown the need to create a technique, which will be available for use by not only specialists, but parents as well. By available we mean simplification of reading results interpretation system, and reducing the number of tools for conducting it, which would enable parents to perform it without a specialist. This characteristic obviously presents a crucial meaning for families, who take care of their child on their own when they are unable to attend regular classes with the specialist. Monitoring of motor skills formation was conducted based on the following groups of parameters: the presence of tonic reflexes, motor skills in lower extremities, crawling, motor skills of upper extremities, sitting, walking, and spatial movements.

The study of parental attitude to preschool age children with cerebral palsy proved the need for a pedagogical support when creating adequate conditions for the child’s development. The interpretation of questionnaire results helped us to design a technology of pedagogical support for families that must have a single structure, i.e. a list of procedures. Same procedures should have different content matter depending on the individual characteristics of families and children with cerebral palsy. The correct motor skills study mode for the child with cerebral palsy shouldn’t start

and end in a sport gym. It is necessary, that all members of the family followed it. Families and specialists should work as a team, a single mechanism. This is the essence of the process of pedagogical support for such families.

Technology

The main purpose of this technology is a social adaptation of the child with cerebral palsy, which can't be done without active and adequate participation of the child's family.

While working with the family of the child with cerebral palsy the following tasks should be completed: (1) to determine the compliance of an environment in which the child is growing and educated at home with the requirements for the child's level of development; (2) to identify in-family factors, which either enable or disable healthy development of disabled children in the family; (3) to determine causes, destabilizing the atmosphere and interpersonal relationships within a family; (4) to determine inadequate models of the education and destructive forms of a communicate in the family; (5) to determine ways of the stabilizing family "climate"; (6) to identify ways of the socialization for both children with cerebral palsy, and their families; (7) to adapt the home environment to the needs of the child with cerebral palsy; and (8) to develop motor skills of the child with cerebral palsy

In addition to general tasks of this technology, we developed objectives for each stage. The technology of support consisted of 6 stages, which were aimed at work with both children and their parents. The each stage has procedures designed to complete specific objectives. Let us look at the each stage in more detail.

1. The diagnostic stage. It includes the diagnosis of the child's motor skills development and the parent-child interaction.
 - 1.1. The monitoring of motor skills formation for children with cerebral palsy. It is first conducted by the physical therapist with parents present. Then parents, who are familiar with the procedure of monitoring, are able to do it themselves. Objectives for this procedure:
 - to teach how to conduct monitoring of motor skills formation processes;
 - to form awareness about the stages of motor skills development of children with cerebral palsy;
 - to detect a "zone of actual development" and "zone of proximal development".
 - 1.2. The study of parental attitude based on a questionnaire by A.J. Varga and V.V. Stolina. The survey is about the child's environment, family and living conditions. Objectives for this procedures:
 - to study parental attitude;
 - to get to know the child's family.

2. The forming stage. The main purpose of this stage is to create an individualized program of motor skills development of the child with cerebral palsy. The individualized program is a list of exercises, which are necessary for a transition to the next level of motor skills development. In addition, it includes recommendations on organization of the child's motor mode schedule at home. Objectives for this procedure:
 - to make a list of exercises for the child's motor skills development;
 - to raise awareness of parents about the motor mode schedule and environment of the child, which are necessary for this particular level of development.
3. The activity stage includes conducting lessons of adaptive physical education with children with cerebral palsy.
 - 3.1. A physical therapist conducts lessons of the adaptive physical education in the presence of parents. The specialist teaches parents about forms of work with the child, and necessary exercises, which are a part of the individualized program.
 - 3.2. Parents conduct lessons of the adaptive physical education in the presence of the physical therapist. Parents perform exercises with the child by themselves. The specialist helps in difficult situations during the lesson. Objectives for this procedure:
 - to form parents' independence in conducting lessons of the adaptive physical education;
 - to reduce fear in parents and increase confidence in their abilities;
 - to increase emotional feedback from lessons for the whole family.
4. The consulting stage involves conducting separate consultations for parents about problems of the habilitation of children with cerebral palsy. The most frequently asked questions are as follows: how to form self-service skills, what are the tools of habilitation process, how to create "accessible environment" at home and in daily life. Objectives for this procedure:
 - to counsel parents and answer their most urgent questions;
 - to inform parents of new means of habilitation process of children with cerebral palsy.
5. The information stage is an informative support of parents, which includes:
 - 5.1. to design an info stand for parents in the kindergarten and the family association;
 - 5.2. to distribute printed recommendations about the organization of motor mode schedule of children with cerebral palsy;

- 5.3. to distribute video lessons of the adaptive physical education aimed at development of different functions and skills.
Objectives for this procedure:
- to provide informative support for parents;
 - to organize independent work of parents with their children.
6. The summarizing stage consists of procedures, which are designed to consolidate all the skills, and to increase positive emotional response of the whole family.
- 6.3. To set up lessons and playdates with dogs and horses. Objectives for this procedure:
- to acquaint parents with the benefits of animal therapy;
 - to improve an emotional interaction between children and parents;
 - to develop and improve of motor skills;
 - to develop a sense of responsibility in the child.
- 6.2. To plan collaborative sport events with parents and children. Objectives for this procedure:

- to improve emotional contact between parents and children;
- to promote social adaptation of parents and children;
- to improve the mastered skills in the form of a game or a competition.

Results

As a result of the study, scores in the monitoring have increased. Overall, the results in the both groups increased by 12.85 and 14 scores (see table 1). This proves that both groups of children have had a positive dynamic of the motor skills development, which has an effect on the readiness of the skills. The largest increment of motor skills development's results was detected in the second group. It could be explained by the fact that the results from the first group were slightly exceeded compared to the initial data from the second group, however the diagnosis and ages of children from both groups were the same.

Table 1

Results of the motor skills development for the both groups of children (scores)

Groups of parameters of the readiness of motor skills	The presence of tonic reflexes		Motor skills in lower extremities		Crawling		Motor skills in upper extremities		Sitting		Walking		Spatial movement		General changes of parameters at the beginning and end of the study
	beginning	end	beginning	end	beginning	end	beginning	end	beginning	end	beginning	end	beginning	end	
The first	3.4	3.6	2.9	5.25	5.3	7.2	4.6	6.5	3.75	5	1.9	5.1	1.2	3.25	+12.85
The second	3.3	4	2.2	4.6	3.6	6.3	3.7	6.2	2.9	4.5	0.5	2.8	0.4	2.2	+14

The monitoring procedure is designed in such a way, that results of children match the level of children's independence, which is the main goal of the habilitation process as a whole. Thus, the higher the result, the higher level of independence and self-service skills observed. The higher independence, the better social adaptation identified.

It should be noted that the adaptation of the child with cerebral palsy to the environment cannot go without the family. The family is a direct participant of the adaptation process.

Accordingly, the rising level of the social adaptation of children increases the adaptation to the new changing environment of their parents.

To confirm this, in our study, the presence of the motor skills development of children changed the parental attitude in the positive way. Results of the study of parental attitude are presented in the second table.

In the first scale "acceptance - rejection" parents of the both groups improved their results – they had reduced negative emotions towards their child. Parents of the first group improved the average score by 4.6 and parents of the second group – by 3.2 scores. According to our observations, it is due to the fact that parents began to spend a lot of quality time with the child. According to parents, before the beginning of the study they were constantly with their children, took care of them, but never performed exercises.

es by themselves leaving that for specialists. Participation in the program implied that the parent is to act not only

as a person, who organizes daily life of the child, but as a co-participant of the development process.

Table 2

Results of parental attitude at the beginning and end of the study (scores)

Groups of parents	Indicators of parental attitude									
	Acceptance - rejection		Cooperation		Symbiosis		Authoritarian hypersocialization		Attitude to failures	
	Beginning	End	Beginning	End	Beginning	End	Beginning	End	Beginning	End
The first	11.1	15.7	6.3	6.5	3.7	4.3	3.7	3.7	1.7	1.5
The second	13.3	16.5	6.5	6.8	4.8	4.8	4.6	4.1	1.4	1.4

In addition to the above discussed reasons for the changed parental attitude towards their children, was increased positive feedback after everyday classes, which was visible to parents. This affected emotional attitude towards the child and increased the parent's self-esteem. In the end of the study, parents of the first group have stopped trying to establish an excessive psychological distance between them and the child. Parents of the second group have started to show more empathy in the parenting of the child. Both groups' results are in the medium, which demonstrates the adequacy the chosen parenting style: neither hard not gentle.

Conclusions

In conclusion we have made the following findings: First, the process of pedagogical support for families with preschool age children with cerebral palsy, by using tools of the habilitation, has to include: (a) monitoring of motor skills formation; development and implementation of habilitation procedures, which are designed to form social adaptation; (c) study of parental attitude to children; (d) prognosis of developmental process of the child; and (e) control of the effectiveness of the habilitation program. Second, negative emotions of parents towards their preschool age children with cerebral palsy were detected in 100% cases, it is hard for them to accept their disabled child. This, in turn, leads

to the inadequate attitude towards the child and creates adverse conditions for his or her development. Third, the content of individualized program for the child's motor skills development has to reflect the abilities of the child and characteristic features of the family. The correct motor mode schedule has to be set up and followed in child's daily life. It is very important to create "accessible environment" for the child with cerebral palsy, in which the child's development will be more successful. Using the author's technique of monitoring motor skills formation is an effective tool for the assessment of the child's motor skills development and forecast of the "zone of proximal development". And fourth, the organization of pedagogical support for families has allowed to significantly improve the motor skills development in all children, who have participated in the study; to develop a more positive attitude of parents to themselves and their children, and to increase the social adaptation of children with cerebral palsy.

In conclusion, the study has shown that the presence of physical therapist in the each lesson is not necessary, if there is the meaningful organization of pedagogical support for families. Parents are able to independently organize habilitation process, to conduct monitoring procedures, and to adequately interpret the results of habilitation by themselves, if there is a specialist ready to assist or counsel them.

Технология психолого-педагогической поддержки семей с детьми дошкольного возраста с детским церебральным параличом

Резюме

Целью исследования было определить эффективность абилитации дошкольников с церебральным параличом в процессе педагогической поддержки их семей. Представлен анализ психолого-педагогических проблем семей с дошкольниками с ДЦП и технология психолого-педагогического сопровождения семей. В отличие от других нарушений, последствия ДЦП видны окружающим, помимо этого для передвижения в пространстве необходимо использовать различные технические средства. Это является причиной различных психологических и со-

циальных проблем не только для детей с ДЦП, но и их семей. Технология психолого-педагогического сопровождения включает в себя не только отдельные занятия для родителей или детей, но и совместные мероприятия, направленные на оптимизацию их психологического статуса. Преимуществом технологии является возможность для семей самостоятельно использовать методы абилитации. Это важно для семей из регионов. В исследовании участвуют 22 ребенка и их семьи. Технология включает в себя шесть этапов: диагностика, формирование, деятельность, консалтинг, информация и обобщение. В качестве диагностического комплекса авторы использовали опросник Варги и Столина и мониторинг формирования моторных навыков. В заключении авторы определяют эффективность социальной адаптации детей с церебральным параличом и их семьями.

Ключевые слова: абилитация; детский церебральный паралич; педагогическое сопровождение; социальная адаптация.

Tecnología del apoyo psicológico y pedagógico de familias con niños en edad preescolar con parálisis cerebral.

Resumen

El propósito de la investigación fue determinar la efectividad de la habilitación de niños en edad preescolar con parálisis cerebral en el proceso de apoyo pedagógico de sus familias. Los autores presentan el estudio de los problemas psicológicos-pedagógicos de las familias con niños en edad preescolar con parálisis cerebral y el programa universal de apoyo pedagógico de las familias. Como el trastorno del movimiento, la parálisis cerebral es visible para las otras personas. Además, los niños con parálisis cerebral tienen que usar muchas herramientas técnicas adicionales para moverse. Estos son causados por muchos problemas psicológicos y sociales de las familias con niños con discapacidades de movimiento. La tecnología de apoyo incluye no solo lecciones para padres o niños, sino también su conexión en el proceso pedagógico y la optimización de su estado psicológico en esta base. La ventaja de la tecnología es la oportunidad para que las familias usen métodos de habilitación por sí mismas. Es importante para las familias de las regiones. Hay 22 niños y sus familias en la investigación. La tecnología incluye seis etapas: diagnóstico, formación, actividad, consultoría, información y resumen. Como complejo diagnóstico, los autores utilizaron un cuestionario de Varga y Stolin y Monitoreo de la formación de habilidades motoras. En conclusión, los autores determinan la efectividad de la adaptación social de los niños con parálisis cerebral y sus familias.

Palabras clave: habilitación; parálisis cerebral; apoyo pedagógico; adaptación social.

References

- Badalyan, L. O. (1987). *Neuropathology*. Moscow: Medicine.
- Kozyavkin, V. I., Shestopalova L. F. and Podkorytov, V. S. (1999). *Cerebral palsies. Medical and psychological problems*. Lviv: The Ukraine technologies.
- Mastukova, E. M. (1992). *The disabled child. The early diagnosis and correction*. Moscow: Prosveschenie.
- Shapkova, L. V. (2004). *Private techniques of adaptive physical education*. Moscow: Medicine.
- Smirnova, I. A. (2003). *Special education of preschool age children with cerebral palsy*. Saint-Petersburg: DETSTVO-PRESS.
- Tkachyova, V. V. (2008). *The family of the disabled child: Diagnosis and counseling*. Moscow: Publishing house "Knigolub."