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**SOCIAL SUPPORT FOR CHILDREN
WITH SEVERE MULTIPLE DEVELOPMENTAL DISORDERS
AND THEIR FAMILIES AT A DAY-CARE CENTER**

Abstract. The article presents the experience of looking after children with severe multiple developmental disorders (SMDD) at a day care-center. It considers different aspects of organization of daily activities and lessons in the structure of such center as a socialization mechanism for children with SMDD. The main aim of support of children with SMDD consists in their socialization which is looked upon in the article as a process and as a result of acquisition and active reproduction of social experience by the individual. The article describes the inclusion of children with SMDD in the educational space of the day-care center, and the creation of an optimal situation for the development of this category of children when they enter society. The article presents various forms of work with the children with SMDD, describes a special developing role of the process of caring provided at a day care-center, which ensures maximum involvement of the child in the process of learning, games, eating, performing daily living activities, etc.

It is noted that the work of the specialists of this center is aimed at the socio-pedagogical support for children, as well as at stimulating various abilities of each child and ensuring interaction between children within the created system of measures. It is also pointed out that a significant proportion of the parents caring for a child with SMDD need support; most of the parents are in a difficult financial situation, which creates a negative background for the upbringing of children and can lead to a depression. Such families need complex assistance from the state and public structures.

Keywords: children with disabilities; disabilities; severe multiple developmental disorders; socialization of children; socio-pedagogical support; day-care centers.

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One of the main tasks of the state policy not only in the field of education but also in the sphere of demographic and socio-economic development of the Russian Federation consists in ensuring the realization of the right to education by children with disabilities. The relevant conditions for the realization of the right to education by children with disabilities are guaranteed by international documents in the field of education and are enshrined in the Constitution of the Russian Federation. The creation of comprehensive conditions for receiving education by all children of the above mentioned category taking into account their psycho-physical specificity should be regarded as the main task in the field of realization of the right to education by children with disabilities.

In 2012, Russia ratified the Convention on the Rights of Persons with Disabilities. This document obliges our state to take real measures to remove the barriers

restricting the rights of persons with disabilities, guarantee their freedom, equality, respect and dignity. The right to education is one of the unconditional rights of any person, both child and adult. This right does not depend on their psychophysical state.

Nowadays, many specialists discuss the search for the ways to support the realization of this right by children with severe multiple developmental disorders (SMDD) [2; 12; 15]. It is these children that are the least protected both in the legal and social aspects. Until recently, the children with SMDD have been considered uneducatable, as a result of which practically no work on creation of conditions for their education has been carried out. Many social and educational services are beyond their reach even now, as they have been worked out without due consideration of their special educational needs.

There can be no denying that significant change is taking place in

the sphere of special education which is substantiated by the following factors:

- expansion of the contingent of the children with various developmental disorders, including SMDD;
- design of the Federal State Educational Standard for the education of children with intellectual disabilities.

Thus, classes for children with SMDD begin to be formed in education institutions in which adapted general education programs for pupils with mild and severe forms of intellectual disability are realized. Nevertheless, not all children of the given category with special educational needs have a chance to get education in school. A certain number of such children either stay at home or are placed at stationary institutions of a “closed” type.

Isolation of these children from the life of the local community and lack of communication with typically developing peers remain to be quite important factors as well. To crown it all, the family caring for a child with developmental disorders is itself not infrequently isolated from the society: the friendly ties get ruined and the parents lose work and have no opportunity to take rest from the daily routine. The parents of “special” children live in the situation of chronic stress and in a number of cases experience the feeling of guilt and inferiority of their family; they are left without

support of the surrounding people and often have the feeling of uncertainty about the future; very often they remain in the state of constant fatigue and depression. As a rule, they are doomed to professional and social deprivation. The situation is aggravated by widespread disintegration of such families, which often brings the family to the brink of poverty. And if assistance to special children is being developed, the family rehabilitation service in our country is still at the very beginning of its establishment [2; 6; 7; 10; 12].

The factors enumerated above make the problems connected with socialization of children with disorders of psychological development even worse. In this connection, the issue of creating a system of educational, psychological and rehabilitation support for the families caring for children with SMDD becomes especially urgent.

Certain measures have been taken by public organization and parents’ unions, some education institutions and independent practicing specialists in order to change this situation. The charitable public organization “*Perspektivy*” is one of the successful Russian initiatives which helps collect the experience of teaching and social inclusion of children with SMDD. Since 2000, the organization “*Perspektivy*” provides social support for the families with children and adults with severe disability in Saint Petersburg with

the aim of preventing social orphanage of children with severe congenital disability and helping young people avoid living at special boarding schools. The ratification of the Convention on the Rights of Persons with Disabilities created the legal foundations for this activity.

The organization supports the families caring for children with severe disability. Helping overcome the isolation, in which the child and his relatives who have to look after the child day and night find themselves, the organization "*Perspektivy*" tries to help the family live a full life and create the future for the child.

To support the families, the organization is realizing the program "Family Support" the structure of which includes various projects, such as the "Day-care Center for Children with Severe Multiple Developmental Disorders" (since 2011) and the project "School for Everyone" (since 2013).

Foreign experience shows that the process of social integration of special children, and specifically children with severe disorders of psychological development is impossible without social integration of the families with such children. To this end, the parents should first of all have certain knowledge in the sphere of law, psychology and pedagogy; and in order to obtain this knowledge, it is necessary to have means, specialists, place and time.

But the current system of support for special children in our country does not always adequately include the parents in the process of assistance, thus depriving them of the needed information provision.

According to T. M. Ratynskaya, interviews show that the parents of children with severe psychological disorders are, as a rule, incompetent in the issues of organization of the child's adequate living environment, and do not know how to facilitate the development of the skills of daily living activities and cannot orient in the multitude of the suggested rehabilitation technologies [12]. The parents also lack good knowledge of their rights to adequate medical assistance and social support. The fact of giving birth to a baby "which is not the same as in other families" is extremely stressful for the parents. This stress has a considerable damaging effect on the parents' psyche. Without having enough accessible information, the parents usually turn to the medical institutions only and try to "cure" their child. Sometimes the parents simply do not know how to express their love for such a child and find it difficult to define their role under the new complicated conditions, and cannot create the conditions for the child's normal development, learning and self-realization [11; 12; 13]. Such a child usually spends his preschool period of life at various medical institutions, and the

adults try to keep *him* away from interaction with the typical environment. But still the majority of the parents believe that their child should receive education, if only for the sake of getting a school leaving certificate. In relation to what educational route (or no route at all) has been chosen by the parents for their child, they may be conventionally subdivided into three groups: those who send their child to special school or boarding school; those who agree to home education; those who keep their child at home without providing him with any kind of education.

The children who had not attended rehabilitation centers before school and who had had little experience of close contacts with peers and adults turn out to be psychologically unprepared for schooling. Socialization appears to be extremely complex to the child with severe intellectual and psychological disorders. The problems of socialization usually consist in inability to organize one's participation in the life of society independently; what is more, the special child's behavior goes beyond the typical standard pattern, seems strange to the surrounding people and is naturally rejected by them. The school structure presents certain requirements to the child's behavior, habits and skills, which he cannot satisfy.

The following main problems are singled out in preschoolers with SMDD [7; 11; 13]:

- non-formation of communicative skills and interest in interaction with other children;
- inability to express their wishes, opinions and decisions;
- ignorance of the rules of behavior in the group, the structure of the group and the daily routine;
- non-formation of the skill to live without help and support of the parents during the day;
- inability to turn for help to other adults and to accept assistance from them.

There is common belief that the society should be ready to accept children with disabilities. The process of integration does not mean only this; it also presupposes the possibility of the child to enter the society by himself without violating its rules and to establish relationships with other members of the community. They say now that schools and kindergartens are ready to take such children and adapt their requirements and rules to match each concrete child. But this is not enough: the child should be also ready to integrate in the given society – not only to follow the rules of the children's group but also to become an active participant of events going on in it without violating the usual course of things for the surrounding children. This becomes possible only when the child

has experience of establishing relationships with the surrounding peers and adults [2; 10].

It is due to this that socialization and integration of such children needs design and organization of a carefully considered system of special measures and serious effort of the specialists. The work of the Day-care Center for Children with Severe Multiple Developmental Disorders consists in leading the child step-by-step along the chain of developing environments towards getting such experience. The work of the Center is based on the principles of humanism: each person under care is unique, and the main task is to reveal his potential and to create the conditions for his self-determination and self-realization.

The main aims of the Center's activity are:

- 1) to support the families caring for children with SMDD; to ensure normal conditions of life for such families and to give the parents spare time for work and rest;

- 2) to improve the position of such children via creating adequate conditions for communication and receiving different impressions and experience of self-realization.

The Center carries out preparation for schooling of children with intellectual disabilities, complicated motor, sensory and behavioral disorders, as well as children with severe intellectual disorders. Lessons with these children are organized in

two groups: *Adaptation* and *Graduate*.

The Adaptation group, as a rule, is made up of children who have not attended rehabilitation institutions. They remain in this group from 1 to 3 years and after that pass on into the Graduate group.

Such specialists as pedagogue-defectologist, instructor in adaptive physical training (APT), assistant instructor in APT, psychologist, tutors, assistant tutors and volunteers work in the Center. An individual support plan (ISP) is worked out for each child by the specialists. It contains the information about the child concerning level of self-service, communication, emotional-volitional sphere and social development, cognitive sphere, mobility and fine motor skills. Two or three main tasks are identified in the ISP in accordance with which the specialists work during a year. All persons under care attend the Center according to the individual timetable. It depends, as a rule, on the child's capabilities and the parents' wishes.

The organization of the Center's activity includes events of daily routine (breakfast, lunch, sanitary-hygiene procedures, etc.), group and individual training. Performance of routine procedures is significant not only for the child's acquisition of elementary daily living skills but in terms of rehabilitation process as well. Thus, for example, at breakfast

the children do not only learn to take food but also practice communicative skills (for example, wish each other good appetite). In the course of group sessions (“morning” and “evening” cycle) the children learn to express their emotions; their positive emotional mood is formed for the whole day, and they also sum up the results of the day’s activity. In addition, the Center’s timetable presupposes conduct of group and individual sessions according to the plan made up for each child for half-year in accordance with the aim and tasks determined in the ISP.

Preparation of the children with SMDD for schooling is one of the aims of the Center. But what is meant here is not preparation in the usual sense when the child acquires primary knowledge, habits and skills from various subject areas, such as math, reading, etc. It means work over the formation of the skills needed for the child’s socialization at school. The Center specialists proceed from the conception of the environmental approach which postulates that man develops in society and through society. In this connection, several basic lines of activity have been singled out in the work of the Center:

1. Teaching to accept and follow the rules of behavior in the Center, inclusion in the conduct of routine procedures and specially organizes lessons.

2. Formation of communicative skills, interest to group interaction in the process of joint activity, teaching to express wishes, opinions and decisions.

3. Formation of socially significant skills, habits and concepts, their application in accessible activity:

- orientation in social relations: adult – child, teacher – pupil, child – child;
- formation of concepts about oneself and surrounding people;
- formation of interest to the surrounding world and ability to orient oneself in it.

For example, if at the primary stage of group activity the children, as a rule, do not take notice of each other and ignore interaction, after regular participation in group activity they begin to pay attention to each other expressing various emotions into the bargain.

4. Formation of the skills to live without the parents’ help and support for the whole day and the skills to turn to adults for help and accept assistance from other people.

The first thing the children learn at the Center is to trust other people as they have no parents to turn to. These adults help the child get involved in social relations via accessible activity (to look at those who are moving or making noise; to take objects or toys; to perform actions together, etc.), teach to perform

routine procedures and follow the Center's rules and establish relationships with other children.

5. Formation of the skill to cope with stress and discomfort via socially acceptable means and to control one's emotional state.

Creation of the multi-sensory environment is one of the inseparable conditions for the formation of communicative and social daily living skills in the children. To this end, it is first of all necessary to single out the capabilities and strong points of each child and proceed from them. Thus we can give him the orientations, or "targets" which would help him orient in space. For example, working with children with loss of hearing it is necessary to fill the space with pictures, pictograms and objects-symbols to activate visual perception. In another case of the blind patient, whose strong point was tactile perception we hung out a bright rectangular next to his towel for orientation every time he washed his hands. For yet another child with good vision we placed the letter A (the first letter of his name) which he clearly saw and could find his towel independently.

We equipped a place for children with severe form of CP where the child can be laid in a therapeutic position to feel the boundaries of his body better.

Developing care plays an important role in the process of prepa-

ration of children with SMDD for school. Developing care is a kind of looking after children ensuring their maximum involvement in the process of learning, playing, taking food, etc. It is necessary that the child feel comfortable in the process of any activity for which purpose we should always take into account the child's state at each particular moment of time. We must keep in mind that the primary task is to create the foundation on the basis of which the child can change, will feel better and will be ready to demonstrate independent activity. But the boundaries of the child's capabilities should be expanded, that is why it is important to stimulate the child's potential and try to achieve his maximum independence even if it is not satisfactory enough. Thus, for example, while teaching to take rest or playing position, we should always take into account the child's physical properties; it is necessary to choose the position matching the child best of all and change it when he gets tired (responding to all signals of the patient). It is the position that determines the effectiveness of training – a comfortable position facilitates the maximum activity of the child.

Cooperation with parents is the indispensable condition of preparation for school and the main pillar of organization as it is only in close cooperation that we can achieve the desired results. The parents are full

participants of the life of the Center taking active part in the coordination of the ISP aims. The Center holds regular meetings of the parents and open doors activities in the course of which the parents can see their child during lessons and have a chance to observe the changes that have taken place in the child. Apart from that, the parents are invited to take part in individual sessions with specialists. Not least important in the work with the parents are common holidays which can be to a certain extent viewed upon as intermediary results of the work of the Center with each particular child. For example, each year the children celebrate the Autumn Holiday and the Holiday of the Autumn Night, birthdays, the New Year, etc.

In order to expand social contacts and the concepts about the surrounding world, the Center's patients together with the pedagogues, specialists and parents go on trips to cafes (for example, "the MacDonald's"), the zoo, oceanarium, children's city of professions "Kidburg", etc. The visit of the pupils of the Center and being present at the lessons of the surrounding world, reading and drawing at one of Saint Petersburg gymnasiums was one of the significant events.

In recent years, as a result of the work of the specialists from the organization "*Perspektivy*", 24 children have been enrolled in the classes in which the adapted

general education program for pupils with moderate and severe intellectual disability is realized. We believe that even singular positive examples of successful development of children with SMDD in the educational environment facilitate overcoming the stereotypes and expanding the opportunities of integration of children of the given category in society.

Thus, the whole activity of the Center creates the foundation for successful socialization and integration of the child in the educational environment, for the positive dynamics of the child's health, and for psycho-pedagogical competence of the parents. To solve these problems, the Saint Petersburg charitable public organization "*Perspektivy*" has concluded cooperation agreements with some Saint Petersburg schools, and has developed programs of network interaction.

Nevertheless, in spite of the positive experience of socialization of children with SMDD in the charitable public organization "*Perspektivy*", many education institutions have not yet created all the necessary conditions in the sphere of staff training and equipment provision for this kind of activity, which, to our mind, brings about certain difficulties for education of this category of children. These difficulties may be caused by the following factors:

1) absence of effective barrier-free environment for children with disabilities, which does not allow them to learn in the same group with typically developing peers;

2) inadequate equipment of education institutions with modern special teaching facilities (special desks, lift, didactic material for defectology, logopedics and psychology classrooms, adaptive physical training gym equipment, massage room equipment, etc.);

3) shortage of competent highly-qualified specialists in the sphere of work with children with SMDD;

4) absence of the necessary normative-legal basis for inclusion of such specialists as tutors in the staff, and the absence of salient definition and distribution of responsibilities among such pedagogical workers as tutor, assistant tutor, childcarer.

Thus, the problem of socialization of children with SMDD, including their preparation for schooling needs, on the one hand, ample realization of not only the programs of state support for this category of schoolchildren but also of cooperation programs with non-commercial institutions. It also needs an active position on the part of the parents. On the other hand, there emerges an urgent need to enhance mutual interaction between state-maintained education institutions and public associations ensuring continuity in the system of support for children

with SMDD and their parents (lawful representatives).

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