

PEHPP 2019**Pedagogical Education: History, Present Time, Perspectives****RESOURCES OF ALTERNATIVE COMMUNICATION IN
SOCIALIZATION OF CHILDREN WITH SEVERE
DEVELOPMENTAL DISABILITIES**

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Abstract

The article is devoted to the problem of socialization of children with severe and multiple developmental disabilities. The results of studying the state of the speech-communicative sphere of children with severe and multiple developmental disabilities are described. Diagnostic technology and the results of studying the parents' readiness for interaction in the process of socialization of children who do not own verbal communication methods are presented. The article reveals a communicative technology addressed to children who do not have the ability to "read" the communicative meanings of signs and symbols and correlate plane images with objects. The results of the study of the parents' readiness to use alternative and supplementary communication technologies in the conditions of family education of children with SMDD are presented. The frequency of occurrence of social stigmatization and narrowing of the socio-cultural space of families is revealed. The contradictions between the need to socialize non-speaking children with severe and multiple developmental disabilities and the insufficient willingness of parents to use alternative and supplementary communication methods are revealed. The rehabilitation resources of alternative communication are revealed in relation to the category of children with severe and multiple disabilities. Actively tested individually-oriented means of alternative communication are described that make it possible to increase the efficiency of socialization of children with severe and multiple developmental disabilities. The risks and conditions for the effective use of this technology with children with severe and multiple developmental disabilities are presented.

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Keywords: Children with severe and multiple developmental disabilities, alternative and supplementary communication, verbal and communicative abilities of children.



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1. Introduction

The problem of helping children with severe and multiple developmental disabilities (hereinafter SMDD) is actively studied in a multidisciplinary field of research. Scientific materials in the field of neurology, psychiatry, special psychology, pedagogy, defectology, etc. allow us to talk about a certain consistency in the ideas about the essence of the syndrome of severe and multiple developmental disabilities. The syndrome is complex, its obligatory part is severe or deep mental retardation, combined with blindness or low vision, deafness or hard of hearing, disabilities of the musculoskeletal system or somatic disabilities in various combinations (Goldbart & Caton, 2010; Goldbart, 2017; Opredeleeniye TMNR, 2018; Vereshchaga, Moiseeva, & Paykova, 2017; Von Tetzchner & Martinsen, 2000).

In the United States, the term “severe and multiple learning disabilities” is used to refer to violations of this category - deep multiple developmental difficulties. In England and Australia, the term “profound and multiple learning difficulties”, literally, “deep multiple learning difficulties” (Ryazanova, 2018).

2. Problem Statement

The objectives of this article stem from the understanding of severe and multiple developmental disabilities as a cruel barrier to the socialization of a child, a special extremely unfavorable situation for the development of his brothers and sisters, stigmatization of the family, and a significant narrowing of the boundaries of its socio-cultural life.

Obviously, children with severe and multiple developmental disabilities require constant intensive support in all vital areas: in self-care, movement, substantive activities, communication. However, our analysis of domestic and foreign sources revealed clear research emphasis in the field of organizing health care, education, social protection and alternative communication of children with SMDD (Goldbart, 2017; Hewett, Firth, Baber, & Harrison, 2011; Nind & Hewett, 1994; Tsarev et al., 2014; Vereshchaga, Moiseeva, & Paykova, 2017). Meanwhile, the problem of socialization and social communication of children with SMDD seems to be insufficiently studied.

3. Research Questions

- 3.1.** What is the state of verbal and communicative abilities of children with SMDD;
- 3.2.** To what extent are parents ready for interaction in the field of socialization of children with SMDD?

4. Purpose of the Study

The aim of our study was the study of alternative communication resources in the context of the socialization of children with disabilities and their families.

5. Research Methods

The study involved 18 families undergoing comprehensive medical, social, psychological and pedagogical rehabilitation on the basis of the regional autonomous social service institution "Rehabilitation Center for Children with Disabilities" of the Novgorod Region.

At the first empirical stage, 2 subject groups were identified. The first group consisted of 18 children with SMDD at the age of 7 to 10 years. In five cases in the SMDD syndrome, children had mild sensory (visual) disorders, and in the remaining cases, musculoskeletal disorders of varying severity. The degree of intellectual disability of all children qualifies as severe.

The second group was represented by adults. It included 26 parents and grandparents (of which 16 mothers, 4 fathers, 4 grandmothers, two grandfathers) accompanying children during rehabilitation. The selection of diagnostic tools was determined by the need, on the one hand, to get an idea of the state of verbal and communicative opportunities of children with SMDD, and on the other hand, to get an idea of the readiness of families for effective interaction in the field of socialization of children (Goldbart, 2017; Hewett et al., 2011; Ryazanova, 2018). The current state of verbal and communicative abilities of children we identified in the framework of conceptual representations (see I.L. Ryazanova on assessing the communication skills of children with SMDD). Diagnostic technology has been used as a toolkit (Nind & Hewett, 1994).

Processing the results made it possible to generalize the idea of the state of verbal-communicative capabilities of children in nine parameters: 1) the ability to enjoy communicating with others and sharing a communicative space with them; 2) the ability to focus on another person; 3) the ability to perform actions in turn; 4) the ability to understand communicative gestures; 5) the ability to respond to the emotional tone of the voice; 6) the ability to isolate meanings from intonation and facial expressions of the speaker; 7) the ability to understand non-verbal communication and contextual language; 8) the ability to understand certain individual words and abstract symbols without the support of the context; 9) the presence of expressive speech. For each of the nine parameters presented above, the child could get from 0 to 2 points (0 points - the parameter is unformed, 1 point - the elements of formation; 2 points - the communicative parameter is formed).

In order to study the readiness of parents and grandparents for effective interaction with specialists in the field of socialization of children using alternative communication, a survey was conducted. For this, a questionnaire was developed containing three semantic blocks of questions: 1) questions regarding the quality and ways of understanding by parents of the communicative needs and capabilities of the child; 2) issues related to the presence / absence of social stigmatization of the family; 3) questions revealing the parents' ideas about the possibility of using alternative communication methods for the socialization of the child.

6. Findings

Criteria analysis of the results revealed significant differences between the children in the experimental group. In the interests of predicting and implementing further verbal-communicative assistance to children with SMDD, the concept of the levels of formation of the verbal-communicative

capabilities of a child with SMDD (sufficient, insufficient, markedly insufficient) was introduced.

A sufficient level of verbal-communicative development, suggesting the presence of expressive speech, was not detected in any child.

Seventeen children showed an insufficient level of verbal-communicative development. These children enjoyed communication and could share the communicative space with adults. For some time they focused on another person. They could perform simple actions in turn. They understood simple instructions. Moreover, the elements of expressive speech that they have often had an echolalistic character. For example, an eight-year-old boy, trying to interrupt the research situation and return to his favorite pastime - rocking on a rocking horse, repeated the phrases "the mushroom does not speak" and "aunt Tonya should go to work" many times. Communicative gestures (for example, nodding, did not always mean "yes", "good", "understood", "agree", often they could be interpreted as motor automatism).

In nine children, the level of verbal-communicative development was interpreted as markedly insufficient. Children did not only have elements of expressive speech, but also experienced expressed difficulties in shaping its impressive side. The sounding speech was not a communicative signal for them, the children did not read the emotional tone of the speaker's voice, his facial expressions, hardly concentrated their attention on the communicative partner.

Understanding the parental answers to the questions of the first block allows us to conclude that nineteen parents allow only one-way communication with the child: ("He can neither say nor show," "We understand her without words," "Nobody but me cannot talk to Masha"). Four parents exaggerate the children's communicative abilities: ("Our son is silent, but he understands everything," "We hope he will speak by ten years old"). Three of them are deeply worried about their children's "speechlessness", they associate this condition with a lack of local specialists or with a lack of time for studying with a child ("There is no speech therapist in our village," "They didn't do anything with Gosha in the kindergarten," "I have no time to teach her, I have two more little ones").

Answers to the questions of the second block show that the majority of families (22 out of 26 respondents) feel social stigmatization, narrowing of the socio-cultural space, they feel the formality of measures to ensure the accessibility of the environment for children with SMDD. Let's give examples of answers: ("I'm embarrassed to go out with my granddaughter, she screams, everyone turns around, almost shows at us", "Gosha and I went to my friend once, so he started throwing scissors, pillows, books from the windows, now we don't go anywhere", "Everything is only well arranged for wheelchairs, but ours is running, he would have some kind of quiet place", "Yes, I know that she has good eyesight, but it seems that she doesn't see anything, stumbles upon everything"). Only in four cases parents did find the family's social space wide enough, did not feel pronounced stigmatization, actively use the accessible environment ("We travel everywhere with him, fly by plane", "Guests often come to us", "Now there is a lot of information, social advertising is working, society is used to our children").

Parents' opinions about the possibility of using alternative and supplementary communication tools (ASC) also turned out to be different. Some families (12) tried to use some versions of the ASC, but did not see the communicative results: "We tried alternative communication methods, but without success", "Dima tears cards, and he cracks the laminated ones", "We had two communicative albums, but I can't explain to my daughter how to handle them". Five families have never turned to AAC funds: ("My daughter

doesn't need any alternative communication, she will show everything with my hand what she needs - juice, chocolate bar or a phone", "I know about communicators, but they are very expensive, and I am raising a child alone", "No, we have not heard about this"). Nine families have some positive experience using ASC funds, but they need accurate targeted selection of funds: "Only no pictures", "He does not understand the tables," "Something small, some objects to fit in the hand."

Alternative and additional communication as a means of socializing people with disabilities (DA) has been widely studied in recent decades. Alternative communication implies that a person communicates with the interlocutor without the use of speech (Slovar zhestovyyh yazykov SPREADTHESIGHN, 2019). Supplementary communication means communication that complements speech. The term "supplementary" emphasizes that training in alternative forms of communication has a dual purpose: to support the development of speech and provide an alternative form of communication if a person still does not develop the ability to speak, as well as provide communication in that environment (store, transport, etc.), in which they do not understand the specific speech of the interlocutor. Alternative and supplementary communication (ASC) combines the most diverse means of communication, designed for different modalities of a person: visual, gesture, subject (Haidt, Allon, Edwards, Clark, & Kushman, 2011; Von Tetzchner & Grove, 2003). Tools can have varying degrees of technical complexity (Haidt et al., 2011; Von Tetzchner & Martinsen, 2000).

In the framework of our study, we developed and, from September 2017 to August 2019, we are actively testing individually-oriented means of alternative communication, which can increase the efficiency of socialization of children with severe and multiple developmental disabilities.

7. Conclusion

Thus, it became obvious that verbal-communicative difficulties are the most pronounced in the composition of the SMDD syndrome. We have received confirmation that intellectual disturbances, combined with sensory or motor ones, violate the fundamental foundations of communication and distort its ontogenesis.

Diagnostic findings talk about the contradiction between the need to socialize non-speaking children with severe and multiple developmental disabilities and the insufficient willingness of parents to use alternative and supplementary communication methods.

The materials accumulated during the testing process make it possible to draw preliminary methodological conclusions:

- There are high risks associated with a possible shift in emphasis from the interaction of communication partners to means of communication.
- Due to the violation of symbolic activity, some children can master only the elements of ASC.
- There is a need for dosed application and maximum individualization of ASC.
- When selecting ASC funds, it is necessary to take into account the child's preferences regarding modality (visual, auditory, tactile).

- The conditions for the positive dynamics of the verbal-communicative development of children with SMDD are the systematic nature of the work and sufficient readiness of parents to use ASC funds in the process of socializing the child.

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