

Support of Children with Autism: Structural and Functional Model

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Abstract. This article presents structural and functional model of support of preschoolers with autism spectrum disorders in a consortium of scientific and educational organizations, which includes the main directions of its implementation in the Republic of Tatarstan. We have described its characteristics, key components and presented promising objectives for its implementation. The model we developed includes structural units represented by Institutes and Scientific Centers, kindergarten and a resource center of Kazan Federal University. This will allow to achieve the implementation of the following directions: conducting fundamental and applied scientific research in the field of studying and correcting autism spectrum disorders; methodological, expert and informational support of various activities of organizations helping people with ASD in the Republic of Tatarstan; creating special conditions for pre-school education, correction of developmental disorders and successful socialization of children with autism; preparing students with autism to switch to inclusive education in general education groups; providing affordable and high-quality education environment for preschoolers with autism when moving from one educational level to another; generalization and distribution of modern technologies of education and training of children with ASD.

1. Introduction

The need to provide supportive conditions for children with autism spectrum disorder (ASD) is stated in government programs, plans as topical issues of implementing measures to develop a system for helping children with ASD: State Program of the Russian Federation called "Accessible Environment" for 2011-2020 [1], Interdepartmental comprehensive plan on the organization of inclusive general and additional education and creation of special conditions of providing quality education for students with disabilities for 2018–2020 (approved by the Government of the Russian Federation 07.02.2018 N 987p-P8), Plan of measures for implementation of the Concept of the development of early care in the Russian Federation for the period up to 2020 [2]

Another relevant issue is associated with the development and implementation of regional models and programs that ensure the availability of quality education and successful socialization of children with autism, creation of innovative and experimental platforms aimed at spreading innovative experience of supporting children with autism in educational institutions.

However, at the current moment the Republic of Tatarstan has no scientifically based models for organizing comprehensive support for preschoolers with autism and their families in a consortium of

university and educational organizations, as well as regional innovation platforms broadcasting this experience.

2. Knowledge of the problem

Most of the researchers who study the support of children with ASD at various stages of social adaptation (Baenskaya E.R., Bratkova M.V., Kostin I.A., Libling M.M., Nikolskaya O.S., Frith U., Gray C., Hartley C., Bird L.-A., Monaghan P., et al.) state that the main characteristics of preschoolers with ASD which impede successful socialization and learning among normotypic peers are the following ones:

- pronounced difficulties of social and emotional interaction;
- difficulties with organizing one's own activities and behavior, behavioral disorders of different types;
- pronounced imbalance and specificity of the development of mental functions, general specificity of the development of cognitive activity;
- difficulties in establishing productive interaction with other people;
- the need for a specially organized educational space, special techniques and methods for teaching and providing psychological and pedagogical support for children with ASD. [3]

Based on an the analysis of 74 sites of regional public and state organizations, educational institutions and centers of different types, as well as publications in scientific journals by Nesterova A.A., Aysina R.M., Suslova T.F. (2016) we were able to identify the following necessary conditions for effective support of children with autism spectrum disorder:

- creation of a single integrated rehabilitation environment;
- formation of expert-informational and practical resources for consolidation of efforts, exchange and dissemination of successful experience of professionals and parents who raise children with ASD;
- protection of the rights and interests of children with ASD and their families;
- development of a mechanism of inter-institutional cooperation aimed at providing early support for children with ASD, creation of programs and models of inter-institutional cooperation;
- consolidation of efforts of specialists, parents and public organizations for solving problem issues associated with accessible education, equal rights of children with ASD for getting education and social assistance;
- development of models of inclusive education and their introduction into the educational space of regular schools, preschool and out-of-school educational organizations;
- introduction of a comprehensive multi-level rehabilitation, socialization and assistance in solving various problems of autistic children, their parents and caregivers;
- support of projects aimed at developing diagnostic and aiding (corrective, rehabilitation, educational, etc.) technologies;
- training personnel for working with autistic children and teams for helping parents of children with ASD in their education and training. [4].

Chereneva E.A., Volodenkova E.A. (2016) presented their innovative model for development of inter-institutional interaction of specialists for organizing integrated support for children with autism spectrum disorders in Krasnoyarsk Region. They have described the technologies of inter-institutional cooperation of domestic and foreign researchers and practitioners in development of ideas for helping people with autism as well as the experience of developing parental initiatives, the formation of research directions and a system for training professional personnel for working with children and adults with autism. The following institutions are involved in the implementation of the regional model: Ministries of Krasnoyarsk Region – social policy; education and science; healthcare; system of educational organizations; healthcare facilities; higher professional education; non-profit organizations (public organizations of parents of children with autism); commercial organizations supporting children with ASD [5]

Integrated model for organization of psychological and pedagogical support for children with ASD implemented on the basis of Federal Resource Center for organization of comprehensive support for

schoolchildren with ASD includes two formats of interaction between educational organizations and PPMS centers: in PPMS center, children receive help that they cannot get from schools (for example, classes with a defectologist); PPMS center performs resource functions in methodological support of school support service. According to A. Haustov, the functionality of such a model currently seems to be the most promising one. [6]

Development of a model of multidisciplinary medical support for children with autism spectrum disorders (ASD) will begin in 2019 with the efforts of the National Medical Research Center for Child Health of the Ministry of Health of the Russian Federation with active participation of the Center for Autism Problems. [7]

Our analytical review of domestic experience of supporting children with ASD showed that the presented models of psychological and pedagogical support of people with ASD in educational institutions, the experience of Russian regions in introducing and testing various forms of support for children with ASD and their families are mainly aimed at schoolchildren with ASD. However, there is no single comprehensive system of special support for children with ASD in preschool educational institutions, no tools and mechanisms for implementing inclusive education for preschoolers with ASD are developed, and no technologies of continuity during the transition to the next stage of learning are described.

3. Structural and functional model of support of preschoolers with autism spectrum disorders

The Republic of Tatarstan has 492 kindergartens with compensatory groups which bring up 16 thousand preschoolers. [8.] Since 2017, new groups for children with autism have been opened on the basis of 5 preschool organizations in Kazan. In 2019, a new kindergarten will be opened at the Kazan (Volga) Federal University, which will offer all necessary conditions for education of children with autism. The key mechanism for achieving accessibility and individualization is associated with formation of educational process in the university-kindergarten consortium and creation of adapted educational programs for preschoolers with autism spectrum disorders.

Organization of inclusive kindergarten as a innovative structural department of KFU is determined, on the one hand, by changes in society attitudes towards people with special needs and their families, and the legislation of the Russian Federation, which poses new requirements for constructing a system of inter-institutional cooperation for working with children. However, there is still no single unified system of integrated support for children with autism spectrum disorder on the territory of the Republic of Tatarstan [9]. On the other hand, there is a problem associated with training specialists who would be able to carry out professional activities in the conditions of new and alternative pedagogical systems using innovative technologies in new forms of education. This makes the task of creating innovative and experimental sites aimed at introducing interactive forms of educational process by immersing students in practical defectological activities particularly relevant.

The core of the model is represented by the structural units: "Resource Center for the Development of Children with Disabilities", Department of Defectology and Clinical Psychology of the Institute of Psychology and Education, Scientific and Clinical Center for Precision and Regenerative Medicine of the Institute of Fundamental Medicine and Biology, Situation Analytical Center of KFU, Center for Innovative Development of KFU, kindergarten as a structural unit of KFU, and basic educational sites that teach children with autism. They are united by a common concept and mission of organizing a system for integrated development of children with ASD and their future adaptation. These structures perform a number of organizational functions (goals, tasks, identification of subjects and objects of socialization, etc.), as well as substantive issues (directions of socialization, technologies, principles of support, competence of specialists, etc.).

The current model includes the implementation of the following areas: creation of special conditions for providing preschool education, correction of developmental disorders and successful socialization of children with autism in a consortium of university and educational organizations, implemented on the basis of the principles of applied behavior analysis; preparation of pupils with autism for the transition to inclusive education in regular education groups and to the world of

normotypic peers; ensuring affordable and high-quality education for preschoolers with autism during the transition from one educational level to another in accordance with the requirements of federal state educational standards, which is an important condition for their successful education and socialization; generalization, implementation and dissemination of modern technologies and experience in the upbringing and education of children with ASD, psychological and pedagogical support for families that raise people who belong to this category; conducting fundamental and applied research in the field of studying and correcting autism spectrum disorders, teaching and socializing children with ASD; methodological, expert and informational support of organizations working with people with ASD in the Republic of Tatarstan.

Thus, this model reflects the interests of all participants of the educational process, providing the conditions for successful socialization – both of normotypic children and kids with autistic spectrum disorders.

Below are the key directions of work for each structural unit.

The main objective of the *Resource Center for the Development of Children with Disabilities* is the development of a comprehensive care system for children with autism spectrum disorders in the Republic of Tatarstan. Implementation of this goal involves solving the following tasks:

- carrying out activities aimed at supporting, educating and developing children with disabilities and parents who raise such children;
- providing consultations and resource support to preschool educational organizations, general educational organizations, organizations of higher and professional education, development centers, other organizations involved in education and development of children with disabilities;
- support for fundamental and applied research in the field of education and support of children with disabilities;
- implementation of educational activities for education and development of children with disabilities, training of parents who raise children with disabilities, education of general public about the problems associated with life of children with disabilities;
- analysis and accumulation of information about the best world managerial, pedagogical, psychological, medical practices aimed at supporting, developing and educating children with disabilities, their successful adaptation and socialization in society.

Kindergarten, as a structural unit of KFU, offers implementation of new effective forms of education for preschoolers with autism.

The Lekoteka short-term resource group is organized for children aged 3 - 7 years who cannot attend regular state educational organizations due to health issues or developmental conditions and who need psychological and pedagogical help. Lekoteka works in two shifts from 7.30 to 12.30 and from 13.30 to 18.30. Children in this group study together with their parents.

The “Special Child” short-term resource group is organized for children with ASD of 5-7 years of age who receive education which in a prolonged period may be comparable with education of peers without health limitations. The “Special Child” group operates in two shifts from 7.30 to 12.30 and from 13.30 to 18.30. Children in this group work without their parents, and receive assistance from tutors.

Children with ASD get enrolled in the structural unit after application from parents (legal representatives) and getting decision of psychological, medical and pedagogical commission (hereinafter PMPC). The enrollment implies the conclusion of an agreement between educational organization and parents (legal representatives), which determines the terms of child’s stay at the structural unit.

The maximum occupancy of the structural unit is 6-7 children with ASD and their parents / legal representatives. The work of the structural unit involves parents (legal representatives).

For each pupil, special adaptive educational programs will be developed based on the principles of applied behavior analysis [10]. These programs will take into account the results of specialized comprehensive testing on life skills, academic and social competencies of children.

The activities of the *Department of Defectology and Clinical Psychology of the Institute of Psychology and Education* are aimed at implementing the following directions:

- Preparation and distribution of publications on topical issues concerning complex psychological and pedagogical support for children with ASD and their parents.
- Scientific testing of innovative technologies for accompanying children with ASD and diagnostic assessment methods.
- Implementation of research projects and grant programs, including the ones involving the students of 44.03.03, 44.04.03 specialization (special (defectological) education).
- Development of diagnostic techniques for creating personalized recommendations for implementation of individual educational routes.
- Testing of screening methods for diagnosing the state of health indicators of educational process subjects alongside with teachers of the Institute of Fundamental Medicine and Biology.
- Conducting scientific and practical conferences, seminars, round tables on the development of giftedness of preschoolers and provision of comprehensive assistance to people with ASD.
- Development of software and methodological support for the activities of organizations and specialists providing education and support for gifted children and children with ASD (training courses, workbooks, manuals, etc.).

The main goal of the involvement of the *Scientific and Clinical Center of Precision and Regenerative Medicine of the Institute of Fundamental Medicine and Biology* in the model of integrated support for children with ASD is to ensure not only continuous psychological and pedagogical support, but also a medical support, in particular in what has to do with subtyping of autism and allocation of biomarkers.

Table 1. Functional characteristics of the model for support of children with ASD.

Functions	ANO "Resource Center" Kindergarten	Departments of institutes, scientific centers of KFU
	Development of adaptive general educational program	
<i>Diagnostic</i>	Assessment of functional capabilities and determination of support strategy	Study of autism biomarkers, diagnosis
<i>Correctional and Developing</i>	Implementation of adaptive educational program based on principles of applied behavior analysis	Development of adaptive educational program based on the principles of applied behavior analysis
<i>Consultative</i>	Home visits, consultations with parents	Supervision of teachers and specialists
<i>Educational</i>	Parent Training	Professional Development Courses for Specialists

The mission of the *KFU Situational Analytical Center* in the implementation of this model is to provide relevant statistical and analytical information on promising areas for the development of education and science in order to introduce modern educational practices for children with autism at KFU sites. The center's activities are aimed at solving the following tasks: analysis of the current situation, forecasting of domestic and world trends in the study of autism; study of the best domestic and world practices on the development of the education system for people with autism; analysis and

development of recommendations on application of the best domestic and world educational practices for educating people with autism.

The activities of the *Center for Innovative Development* are aimed at providing help in the development of social projects with their expert evaluation, participation in competitive and grant programs, as well as information support.

In addition to the key structural units, we have identified 4 functions that these structures perform, but each with respect to its own areas of activity: diagnostic, correctional and developmental, advisory, educational. The content of each function is presented in table 1.

4. Conclusion

The above structural components of the model will allow us to implement innovative technologies and effective methods developed by KFU scientists in order to provide qualified comprehensive help to children of a preschool age with autism spectrum disorders, to carry out interagency interaction of KFU structural units in organizing the system of support for people with autism spectrum disorders.

Thus, by combining the resources of preschool institutions and higher education organizations, we can timely identify children with ASD, organize complex psychological and pedagogical support at the early stages of education, which are most important for compensating and correcting developmental disorders and preventing secondary developmental deviations.

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