

Supported Accommodation of Young People with Psychophysical Disorders as A Condition for Social and Pedagogical Inclusion

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Abstract

The relevance of the study is due to the need to overcome social exclusion of adolescents and young people caused by their health condition and restrictions on life in the context of inclusion trends in the worldwide social policy and practice. In this connection, the article aims to justify and search for hospital-substitute format of social and pedagogical support for young people with psychophysical behavior disorders of an autism spectrum disorder (ASD) type. The leading approach in the research of this issue is an integrative activity-based approach that allows comprehensive consideration of socio-political, organizational-pedagogical and technological opportunities for active inclusion of families with children and adolescents with ASD into joint activities in a social settlement. In the article, results of sociological, and psychological-pedagogical studies of the issue of social inclusion of individuals at risks of their exclusion from society are presented; various types of social integration practices are typologically disclosed; the author's structural-functional model of a supported living arrangement is substantiated; conditions and possibilities for its implementation by a public organization of parents having children with autism in the regional context as exemplified by a rural settlement are identified and shown. The information presented in the article is of practical value for specialists in social pedagogy and work, as well as for those who are trained for concrete competences of social support of families having children with disabilities. The results of the given socio-pedagogical project may be useful for the development of the social movement of parents.

Keywords: *social support of individuals, autism spectrum behavior disorders, social inclusion, social exclusion, structural-functional model of supported accommodation.*

Introduction

Social solidarity and cohesion in today's highly heterogeneous society are ensured by the inclusion of all citizens irrespective of their gender, age, social status, health condition and capabilities of the body into social life. To expand opportunities for social participation, a great variety of mechanisms are used; these are not only key social institutions (education, social protection, culture, law, health, business, etc.), but also everyday life practices. The basic condition for ensuring social inclusion is the formed public inclusive consciousness, i.e., the

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prevalence of values and norms according to which the human interaction is built and mutual understanding of people is achieved. Social inclusion is a process that requires certain efforts both of state and of public organizations. Among the latter, a considerable role is played by socially oriented non-profit organizations of parents of children and adolescents with disabilities, particularly with mental disorders of autism spectrum disorder type. It is this group of people that especially needs non-institutional support without being placed in a permanent care (boarding) institution. The latter is traditional for the Russian system of social service. In this regard, especially topical are hospital-substitute forms of living arrangements, their testing and scientific justification.

Abroad, the issue of social inclusion in forms that are understandable to the population regularly becomes the subject of government reports, scientific research and reports of large international organizations. In particular, there are academic peer-reviewed periodicals: *Journal of Social Inclusion*, *Social Inclusion*, *Zeitschrift fuer Inklusion*. In a number of countries national strategies of social inclusion are implemented and their implementation is monitored. The political course for social inclusion has been adopted by Great Britain, Canada, Australia and the countries of the European Union (EU). In the EU, special methodology for the assessment of social protection and social inclusion that is based on peer review has been developed (see: [Employment, Social Affairs and Inclusion]). The peer review is a key tool of the so-called “open method of coordination” and of the formation of the inclusive policy, culture, education and a variety of inclusive life practices (Borodkin, 2000).

Literature Review

Foreign and domestic researchers, primarily sociologists studying the issues of the inclusion of people with disabilities are actively turning to the classical studies of the stratification structure of society based on different sociological approaches: economic, political and functionalist.

The conception of social exclusion which replaced the conception of poverty in the 90-s offered a new view of the problem of social injustice, restricted access to the resources of society and discrimination of the rights of people with specific needs. In the era of ‘postmodernity indifference’ a new theory holds that one of the factors of the deprived state of a marginalized group is broken social ties, disrupted process of assimilation of social and cultural experience. In this context, the essence of the new social policy is determined; it must be directed not to the

entire society but to its more local communities that are expected to be considerably active, aiming to overcome their social disadvantage and to satisfy both basic and specific (intermediate) needs (Karmysheva, 2015). The concept of social inclusion has been actively studied by western sociologists since the 70-s of the 20-th century. At present it is used to denote new forms of social stratification. Contemporary researchers in sociology point out that the previous class stratification divided people in vertical layers. Today, we are talking about horizontal differentiation between 'insiders' and 'outsiders' (Abrahamson, 2001).

In Russian sociology the research of the issues of social exclusion-inclusion has started relatively recently. In particular, the essence of social exclusion and its methodology, as well as certain groups of the excluded people were and are studied by F.M. Borodkin (2000), V.N. Yarskaya and E.R.Yarskaya-Smirnova (2015), M.D. Napso (2016), J. Boardman (2011) etc. The conceptual definition of the concept of social inclusion originates from the idea of T. Parsons' (1993) conception about "the capital of diversity" which in his opinion should be formed in each country. Inclusion is part of the strategic tasks of many international organizations, as well as a fundamental category of social policy and public life (Soziale Inklusion als Grundlage Sozialer Arbeit, 2012). It is seen as a key condition for ensuring well-being, quality of life and expanding the opportunities for the development of all people. Here the main thing is not so much the functional necessity of including certain "elements" into the system. Of principal importance is the formation of special ethics of care and respect of diversity, which must become the core of social policy (Abrahamson, 2001, Kononova, 2016, Karmysheva, 2015, Yarskaya & Yarskaya-Smirnova, 2015). The task of successful social inclusion acquires a particular psychological-pedagogical relevance in relation to children and adolescents who are actively searching for their own meanings and opportunities for self-realization.

Russian psychological and pedagogical sciences build the understanding of the essence of individual development of a person with disabilities in the context of the basic methodological provisions of L.S. Vygotsky (2003) about social and cultural-historical conditioning of the inner world, general laws of development of all people and huge compensatory abilities of the body, provided there is a targeted socio-pedagogical accompanying and support. Modern social, general, and correctional pedagogy clearly articulate the task of developing inclusion culture in the educational and parent community, in organizing special studies, in creating experimental

models of the inclusion of children and adolescents with special needs into society not only in educational institutions but in everyday socio-cultural life as well.

In foreign pedagogy there is a separate conception existing for several decades; the main idea of it is the principle of preservation of identity of every community member as a basis for educational inclusion. This conception has gained popularity and spread as a social-pedagogical conception of diversity, heterogeneity (Heimlich, 2004, Herz, 2011, Hinz, 2013). It focuses on the pedagogical task of forming a cooperative community of children and youth with different needs, on stimulating various processes of living together, teaching and educating (Lafer, 2014).

Analysis of psychological-pedagogical research in the area of inclusive discourse, and of documents relating to people with disabilities over the past few decades, indicates a significant dynamics of the conceptual apparatus associated with education and psychological-pedagogical support of children and adolescents with disabilities. For a long time correction / special pedagogy that is concerned with the problems of the support of children with specific needs in an educational institution has been based on the concept of “deviation”. It determined the hierarchic dependence of four significant concepts: delay, disorder, damage and impaired development and respectively, the character and organization of the support. At the end of the 90-s of the 20-th century a new set of concepts is developed in special pedagogy, social pedagogy, and psychology; besides, thesaurus in the documents of the World Health Organization is changed. In the 80-s three interrelated concepts were used: defect, aggravation and disorder; and at the end of the 20-th century a new set of concepts is proposed: defect, activity and participation (Furyaeva, 2017). Education, training, organization of everyday life should be based not on a defect, but on the features of the inner world, on a person’s behavior, and on his/her position within the cultural context and social conditions. This becomes an additional pedagogical conceptual ground for the need in special support, in our case, a supported living arrangement that implies reduction of overprotection by parents, strengthening of independent social and individual behavior of children and adolescents with mental disability. Here adequate organizational work is needed, i.e. identification and testing of concrete content and adequate forms of social psychological-pedagogical assistance for and self-assistance of people with different limitations, particularly with behavioral disorders of an autism spectrum (Gundelfinger, 2016, *Leben mit Autismus in der Schweiz-eine Elternbefragung. Zwischenbericht fuer die Delegiertenversammlung*, 2013, *Mental Health and Social Exclusion: Unit Report*

Summary, 2004, Autismus-Therapie in der Praxis: Methoden, Vorgehensweisen, Falldarstellungen, 2017, Riedel & Clausen, 2016, Hall, 2010, Vermeulen, 2016).

Research Methods

In the given research of the ways for social inclusion of young people with psychophysical disorders, in particular with behavioral disorders of autism spectrum, a historical method of the analysis of the practical experience of their social support in various countries and in RF regions was applied. As a subject of historical and theoretical analysis, legal and socio-pedagogical documents were used. The theoretical method of modeling allowed us to develop appropriate conditions for a socio-pedagogical experiment as a series of projects over five years to create a regional variant of social inclusion of young people with ASD as an autonomous rural settlement. The project included several stages associated with the creation of a parent voluntary movement, with organizing joint activities for the construction of buildings on a special territory. At the third stage, the joint activities of children with autism and their parents were filled with content to develop various types of leisure, cultural-creative, sports and recreation activities while actively seeking real financial opportunities. The fourth stage that is continuing today has determined two base lines of organizing the supported living arrangements: permanent and temporary accommodation of families with psychological-pedagogical comprehension of the change in the character of the social and individual behavior of all the participants. Monitoring methods consisting of questionnaire survey, interviewing, and included monitoring of social participation and behavior of children and young people with ASD, as well as of members of more than 100 families led to the conclusion about a positive influence of the regional format of the supported accommodation, "Social Homestead" /that the regional format of the supported accommodation, "Social Homestead" has a positive influence on the way the social inclusion of young people with psycho-physical disorders takes place.

Results and Discussion

In Russia autism as a separate disease began to be diagnosed only from 1999 in connection with the transition to statistical records according to the International Classification of Diseases, Tenth Revision. From the middle of the first decade of the 21-st century a considerable growth of the number of children with a diagnosed autism was identified. At the same time even elements of the care system for people with a disability of this kind were missing. This gave a powerful impetus to the development of active movement of parents of

ASD children, the formation of public organizations which clearly articulated the request for the creation of an aid system for people with ASD. As the main proportion of the diagnosed individuals were children of pre-school and primary school age, significant positive changes in the organization of the system of psychological-pedagogical assistance in the RF began to occur in the area of early intervention and pre-school education. At present the issue of the supported living arrangement for adults with ASD is becoming increasingly topical. Until recently, in Russia, it was impossible to build a system of the accompanied (supported) accommodation outside neuropsychiatric boarding schools. However, after the ratification by Russia in 2012 of the UN Convention on the Rights of Persons with Disabilities and, accordingly, with the need to implement the proclaimed principles of the attitude to people with disabilities, in particular the principle of social inclusion, in various regions of the Russian Federation, including the Krasnoyarskiy Krai (Territory), various forms of the supported living arrangements for individuals with specific psychophysical features are actively sought, living arrangement models are developed and tested, and the related infrastructure is created (Furyaeva & Markevich, 2016). In the framework of this study, the following tasks were set: to analyze the existing foreign and domestic practices of social and psychological-pedagogical support of adolescents and young people with ASD, to identify the state and dynamics of the regulatory support of their social inclusion, to develop and partially implement the structural-functional model of the supported living arrangement, as well as to organize psychological-pedagogical support of the process of inclusion of children with ASD and their families under the conditions of the created rural settlement, "Social Homestead". Analysis of existing practices of the supported living arrangements of persons with ASD shows that the modern Russian state, in comparison to other countries, mainly confines itself to targeted assistance instead of creating the conditions for a full and maximally possible independent life activity and realizing its human potential. A person with mental disorders faces a very complicated problem after his/her parents' death: to adapt to an independent life in society and to learn to take correct decisions in critical situations. If he/she is unable to do so then it is a question of the deprivation of legal capacity and placing him/her in a neuropsychiatric boarding school (NBS) since there are no institutional services of support of social inclusion. The analysis of legal documents adopted in Russia for the past 5-7 years shows a serious reform of the legislative framework in accordance with the principles of the Convention, which is taking place largely under the influence of the activities of public

organizations. In particular, one of the most important changes concerns the institution of legal capacity, the introduction of a differentiated system that broadens the alternative, "capable and incapacitated," which is reflected in the Federal Law No. 302-FZ of 30 December 2012 "On Amendments to Chapters 1, 2, 3 and 4 of the first part of the Civil Code of the Russian Federation ". It introduces a new type of the restriction on capacity, in particular, due to a mental disorder. Corresponding changes within the framework of the update of the Civil Code of the Russian Federation are included in articles 29, 30, 33, 36. The adopted law is designed to align the model of the support and protection of people with mental disorders with Article 12 of the Convention, which that contains the principles according to which people with disabilities may enjoy their legal capacity, as well as with the principle of proportionality in Part 3 of Article 55 of the Constitution of the RF (Minutes of the Board under the Government of the Russian Federation on guardianship in the social sphere of 27.05.2015. (item 3) and from 25.06.2015. (item 5), 2015).

Law № 302-FZ introduces the notion of limited legal capacity with a view in order to fix the actual level of legal capacity, taking as a basis the incomplete legal capacity of minors from 14 to 18 years old. In this case a person with specific needs can independently make household and other small transactions, and at legally significant moments, to carry out his/her actions with the consent of the guardian. The main objective of the innovation is to provide support in taking a decision in the amount that is required by the person, taking into account his/her ability to understand the meaning of his/her actions and control them. The law developers regard the limited legal capacity as a fluid variable structure, depending on the improvement or worsening of the condition of a person with partial capacity. The degree of independence in making certain actions is a dynamic value and it has a wide range: from complete independence to a full control on the part of the guardian. When needed, it is possible to additionally explain and simplify the information to a degree that will allow the person to take an independent decision. The law came into force on March 15, 2015. But in order for the law to become fully operational, it is necessary to amend a number of legislative acts that regulate the limitation of legal capacity in a variety of spheres, such as suffrage, professional activity, marriage and the upbringing of children and many others. In addition, it will be required that changes be introduced into the Civil Procedure Code of the Russian Federation that regulates actions of courts in making

decisions related to the limitation of legal capacity due to mental disorder. Without these alterations a flexible approach to changing the volume of the limited capacity is impossible.

In the middle of 2015, on the basis of the protocol decisions of the Council under the Government of the Russian Federation on the issues of guardianship in the social sphere, pursuant to Article 19 of the Convention, the Fund for Children in Difficult Situations developed the conception of ensuring the independent living of graduates of boarding schools for mentally retarded children of the system of social population protection (supported accommodation) in the first years of their discharge from the institutions, as well as children with disabilities over 16 and young people of 18+ with mental disorders who are brought up in families (The concept of a pilot project to provide independent living graduates of orphanages for mentally retarded children, social protection of the population (accommodation support) in the first years after their release from institutions, 2016). The basis of the conception are the results of the analysis of domestic and foreign experience of introducing hospital-substitute forms and technologies such as supported accommodation, supported daytime activities and supported employment. These forms and technologies are seen as the basic tool for deinstitutionalization and reforming of the boarding school system in Russia. Testing of the concept is defined as the implementation of a pilot project in different regions of the RF, including the Krasnoyarsk Krai (Territory). The project involves the creation and testing of conditions for implementing hospital-substitute forms and technologies, as well as the development of the principles and mechanisms for the inclusion of hospital-substitute forms and technologies into the state system of social service in order to broaden the spectrum and improve the quality and variability of social services.

To be included into the national project we have carried out a preliminary analysis of available diverse practices of the support and rehabilitation of individuals with mental disorders in different countries and in more than 20 regions of the RF. They implement regional programs on the terms of social partnership of local authorities and socially-oriented non-profit organizations (NGOs). All the considered practices use a general common psycho-pedagogical approach to the organization of the lives of people with psychophysical disorders, in which the principles of social activity, individual approach, labor rehabilitation and maximum available independence are combined. At the same time different forms of supported accommodation are used. As a rule, practices of supported accommodation exist either on the initiative of the public (parent organizations or specialists) or on the basis of religious communities and organizations.

This situation has formed historically for because traditionally philanthropists and religious organizations engaged themselves in the charity support of disabled people. Often, the supported accommodation is provided by enthusiasts without permanent financing. However, today the attitude of the Russian state to social inclusion of the disabled people is considerably changing. Increasingly, state bodies and institutions are oriented toward creating decent living conditions and including persons with psychophysical disabilities into society in cooperation with public organizations. The outcomes of our analysis of Russian and foreign practices of the supported accommodation for individuals with mental disorders are presented in Table 1 where alternative forms of the supported accommodation are highlighted and characterized by the kind of support and the form of arrangement.

Table 1

Formats of the alternative supported accommodation for individuals with psychophysical disorders

Supported accommodation			
Temporary		Permanent	
Training	Crisis	By the character of support	By the arrangement form
Daily	Due to illness or related to health issues	Situational	In a city (a flat of one's own, specialized flats, specialized centers and houses)
Short-term (periodic)	For rest and recovery of psycho-emotional resources	Regular	In a rural environment (separate private houses, specialized houses, homesteads)
By courses (single or periodic)	To solve urgent household and other personal issues	Permanent	In autonomous settlements

Note. Source: the authors.

The approximate optimal number of people for different formats of the supported accommodation must not be more than 15, optimally up to 10. In flats and ordinary houses the number of young people with mental disability reaches the maximum of 5 people. In autonomous settlements the number of tenants depends on the scale of the settlement. At the same time it is not practical to create large-scale settlements with more than 50 residents, the optimal number is 25 people. It should be noted that every form of the living arrangement of adults with psychophysical disorders has the right to exist. It has its own target audience, its priorities and unique features. A complex of different formats represents an integral system that

gives the right to choose, and meets the needs and specific features of all people with psychophysical disorders without exception.

In the framework of our research, based on the results of the conducted analysis, as well on our own experience of the work of Krasnoyarsk regional public organization, “Society of the Support for Families having Disabled Children with Autism Spectrum Disorders “Svet Nadezhdy (Light of Hope)” a special settlement was created in a rural area, social homestead ‘Dobraya’ (Kind). Preliminary, a structural-functional model was developed which is an integrated system as a set of regular, functionally related components. The developed and implemented in practice structural-functional model includes the target, content, procedural and control-evaluation components that reveal organization of the process of the supported accommodation, and form and determine the interaction of its elements. Each component has its functional significance, contents and relationship with other components, elements and conditions for functioning of the whole model. Highlighted are strategic and tactical conditions presented in Table 2.

Table 2

Conditions for the implementation of the structural-functional model of the supported accommodation as exemplified by the social homestead, "Dobraya (Kind)"

Strategic conditions	Tactical conditions
Social and psychological-pedagogical characteristics of a target group	<ul style="list-style-type: none"> • Territorial features of the location
The form of living arrangements in accordance with alternative form classification	<ul style="list-style-type: none"> • Diversification of the activities and variability of the supported accommodation forms
Sources of financing (creation, development and current activities)	
Social environment and interaction with local community	<ul style="list-style-type: none"> • Openness and richness of the environment

Note. Source: the authors.

At present the social homestead as an alternative social and psychological-pedagogical form of the supported living arrangement of individuals with ASD is at the stage of the development of not only different elements of the infrastructure but of the character of social inclusion of children with special needs and their relatives into joint diverse activities. The social pedagogue, as well as the parents, included into the process of the psychological-

pedagogical support of their children's life activity pay special attention to the establishment of an atmosphere of trust and acceptance of all the participants living together in the settlement, as well as of guests from the nearest settlement and town. Trusting relationship weakens the hypertrophied intrafamily relationships and helps children and adolescents to adapt to a new place of living. Based on O.S. Gazman (2002) and his disciples' concept of socio-pedagogical support the social pedagogue in close cooperation with parents studies the specific features of the development of concrete life situations, identifies deficits in the social and everyday behavior of each adolescent, and the degree of his/her independence. On the basis of the results of fixed included observations, conversations, and discussions in the focus group an individual program of socio-pedagogical support is made. Its effects show that children and young people with mental disorders regularly express a wish to visit the homestead and perceive it as their second home. In the natural environment it is possible to organize creative and labor activity of children with ASD who in urban conditions are prone to inadequate social behavior. They traditionally demonstrate lack of interest both in joint actions and in individual lessons. As the specially arranged observations show, part of hyper-patronized and hyper-dependent adolescents and young people gradually reduce their excessive need for their parent's constant presence; the level of their independence rises and over professional work skills develop.

A significant positive influence on the character of the social inclusion of children and adolescents with special needs is made by a special subprogram called "Peredyshka (Time-out)" for which training accommodation conditions were created. A major argument in favor of the conclusion about the successful course of social inclusion is a constant considerable annual increase in the number of parents who regard the social homestead as a future place for permanent accommodation of their maturing children. Parents express readiness to get involved in the project financing for enlarging the social homestead and building additional infrastructure.

Conclusion

Considerable growth of the number of young people with severe psychophysical disorders of the Autism Spectrum Disorder type in Russia and abroad stimulated political decisions, scientific (sociological, psychological-pedagogical) research, as well as taking concrete practical actions for organizing social inclusion both on the institutional and public level. The latter is reflected in a noticeable growth of parent initiatives, and creation of non-profit

public organizations that implement various projects for overcoming social exclusion of young people.

Prior to developing a special structural-functional model of the supported living arrangement in the concrete conditions of the Krasnoyarskiy Krai (Territory) an in-depth analysis was made of the descriptions of the existing foreign and domestic practices of organizing the supported accommodation for individuals with psychophysical disorders. The outcome is a classification table of kinds and forms of the supported accommodation for people with psychophysical disorders.

In the framework of our research together with Krasnoyarsk regional public organization, “Society of the Support for Families with Disabled Children Having Autism Spectrum Disorders, ‘Svet Nadezdy (Light of Hope)’ a structural-functional alternative model of the supported living arrangement was developed and partially implemented; it consists of target, content, procedural and control-evaluation components; implementation of this model, as shown by a five-year socio-pedagogical experiment, implies creation of the identified strategic and tactical conditions to ensure successful social inclusion of young people aged 14-19. For further successful development of the given project it is recommended that attention should be paid to the development of the integrated program of the psychological-pedagogical support of the families having a child with ASD, to active inclusion of the trained tutors from among students of humanities, as well as to organizational-pedagogical cohesion and strengthening of the parent community.

Acknowledgements

The paper has been prepared with the financial support of the Krasnoyarsk Krai (Territory) Fund for the support of scientific and scientific-technological activity, project №15/17, “Humanitarian technologies of the work with children and adolescents at risk of social exclusion”. The authors also express their deep gratitude to all the members of Krasnoyarsk regional public organization, “Society of the Support for Families with Disabled Children Having Autism Spectrum Disorders, “Svet Nadezhdy (Light of Hope)”, as well as to the regional non-profit organization delivering services in the area of the social support for individuals with Autism Spectrum Disorders and their families, “Social Homestead (Kind)” for providing information on implementing a set of projects, for the opportunity to actively participate in their implementation and organization of a special socio-pedagogical research.

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