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FINANCIAL AND ECONOMIC ASPECTS OF THE PROBLEM OF CHILDREN WITH AUTISM SPECTRUM DISORDERS SOCIALIZATION

ASPECTOS FINANCEIROS E ECONÔMICOS DO PROBLEMA DA SOCIALIZAÇÃO DE CRIANÇAS COM TRANSTORNOS DO ESPECTRO DO AUTISMO

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Abstract. The relevance of this work lies in the need to create prerequisites for overcoming the gap between the relatively deep development of medical and social, pedagogical, psychological aspects and the slurring in understanding the socio-economic aspect of the problem of socialization of children diagnosed with autism spectrum disorder (ASD). The purpose of this article was to identify, based on the study of modern Russian and foreign studies, those conditions and circumstances that directly or indirectly set the direction and priorities in the formation of the socio-economic base for the socialization of a child with autistic disorder. And of course, this activity cannot be directed only at the child in isolation, it cannot but affect his parents. After all, such a family, in addition to their normal life activities, is also busy raising a “special” child with an ASD diagnosis. It should be taken into account that the socialization of such a child inevitably requires additional moral, physical, and, which for us is an independent subject of research, increased material and financial costs from parents. Final positioning concept is formulated in the paper.

Keywords: autism spectrum disorders (ASD), diagnosis, socialization, socio-economic aspects, financing, social support, programs, pedagogical aspects.

Resumo. A relevância deste trabalho reside na necessidade de criar pré-requisitos para superar a lacuna entre o desenvolvimento relativamente profundo dos aspectos médicos e sociais, pedagógicos, psicológicos e a dificuldade na compreensão do aspecto socioeconômico do problema da socialização de crianças com diagnóstico de autismo. transtorno do espectro (TEA). O objetivo deste artigo foi identificar, com base no estudo de estudos modernos russos e estrangeiros, aquelas condições e circunstâncias que direta ou indiretamente definem os rumos e prioridades na formação da base socioeconômica para a socialização de uma criança com autismo. transtorno. E, claro, esta atividade não pode ser dirigida apenas à criança isoladamente, não pode deixar de afetar os seus pais. Afinal, tal família, além de suas atividades normais de vida, também está ocupada criando uma criança “especial” com diagnóstico de TEA. Deve-se levar em conta que a socialização de tal criança requer inevitavelmente custos adicionais morais, físicos e, o que para nós é um objeto independente de pesquisa, aumento de custos materiais e financeiros dos pais. O conceito de posicionamento final é formulado no artigo.

Palavras-chave: transtornos do espectro do autismo (TEA), diagnóstico, socialização, aspectos socioeconômicos, financiamento, apoio social, programas, aspectos pedagógicos.

1. INTRODUCTION

The range of problems and tasks directly or indirectly related specifically to the economic difficulties faced by a family raising and socializing a child with a diagnosis of "Autism Spectrum Disorder" (ASD), until recently, was far from being at the forefront of public, research, scientific attention in Russia. Abroad, this topic became relevant a little earlier, but

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even there the socio-economic aspects of the problem still far from always fall into the focus of research interest.

Of course, in order to provide effective assistance to a child diagnosed with ASD, first of all, answers to questions of a medical, pedagogical, psychological and psychiatric order are required. At first glance, they and only they determine the volume, structure and regularity of funding. Therefore, medical-psychological, pedagogical aspects of the problem are more often the subject of scientific research. These tasks are occupied by researchers, practitioners, theorists working in the relevant fields of medical, pedagogical, psychological and psychiatric science.

Unfortunately, to date, the results in these areas of research cannot be recognized as unambiguously convincing and reliable. This does not allow adopting a specific, unified, effective intervention scheme that is guaranteed to ensure the socialization of a child with autism (Sheshko, 2022; Zhou et al., 2021; Goncharova et al., 2018).

However, the already created and tested, modern complex means of psychological and pedagogical influence, as well as medical and psychiatric support for a child diagnosed with ASD, significantly and noticeably improve the processes of socialization of children with autistic disorders. This is convincingly presented in many, primarily foreign and in some Russian studies (Spitsberg, 2019; Goncharova & Merzlyakova 2020; Goncharova et al., 2018)

It is indicative that almost everywhere, no matter what side of the named problem researchers touch upon, purely medical, educational and pedagogical, rehabilitation and rehabilitation, sociological, demographic, neuropsychological, everywhere one can find indications of the high cost of comprehensive professional assistance in the development and socialization of a child diagnosed with ASD. And, despite the prevalence of such judgments, there are very few studies where the authors go from statements to a detailed study and justification of the optimality, necessity and sufficiency of the financial base for the life of a family with children with autistic disorders. Hence, it is difficult to determine how excessive or insufficient the current financial and economic support for such families is, how the volumes and structure of such financing are justified. At the same time, it cannot be argued that our state and society do not pay attention to these problems at all.

2. RESEARCH AND METHODS

Thus, a legislative framework has been created that opens up opportunities for the regional authorities to move towards the gradual overcoming of the most complex set of problems that prevent a considerable number of young Russian citizens who have been suffering from autism spectrum disorder since childhood from becoming active and full members of society (Belousov et al., 2022; Bogdanyan, 2014; Volkov, 2003). There are public, non-state charitable foundations to help such children (Belousov et al., 2022; Grinberg & Rubinshtein 2014). Public figures involved in the problem of socialization of autistic children are invited to hearings in State Duma committees (Dovbnya & Morozova, 2019). It raises issues of discrepancy in the principles of accounting, control, and evaluation of the effectiveness of the use of targeted funding by the relevant state institutions, where the costs of maintaining these institutions themselves are often significantly higher than the same costs for themselves for non-state charitable foundations.

According to modern terminology, which has developed in the process of development of state social security, such institutions are commonly referred to as "providers of social services." In the media (Doroshenko, 2013), at socially significant conferences, it has been repeatedly noted that non-state providers of social services do not have equal opportunities and conditions for their activities, in comparison with state institutions providing these services. The necessity of individualization of social services, involvement of non-state providers in the social security system, ensuring equal access of citizens to the relevant services provided by state and non-state providers (Efremova, 2016; Knyazeva & Lvova, 2015; Morozov & Chigrina 2022) is proved. In addition, it is stated the need to reduce the territorial remoteness of the service provider from children and their parents who need these services, providing the right to choose a provider (Morozov et al., 2017; Goncharova et al., 2018)

3. RESULTS

Scale and complexity of the problem of social support for children diagnosed with ASD. Economic aspect. An increasing number of specialists point to the accelerating growth in the number of children with autism spectrum disorder.

Dovbnya, & Morozova, (2019) draws attention to this. Analyzing the statistics of childhood autism, the authors compare the data they collected for a number of European countries and the United States. This statistics with enviable stability shows an increase in the number of children diagnosed with ASD. The authors analyze the possible reasons for this. And as one of these reasons is the improvement in the diagnosis of ASD in developed countries.

The authors report that the US Centers for Disease Control and Prevention published the following data at the end of 2021. Autism occurs in every 44th child, and in boys on average 4.2 times more often than in girls (Mukharyamova & Savelieva 2021; Nedovodieva et al., 2019; Semenov, 2017). This is more than 2% of the entire child population of the country (Simanov, 2008).

Russian statistics cited by Spitzberg (2019) testifies to almost the same thing. The author, comparing data for different countries, notes that almost everywhere where the system of early diagnosis is deployed, there is a steady increase in the number of children diagnosed with ASD by 10% - 17% every year (Solovyova, 2022).

According to the Ministry of Health of the Russian Federation, the prevalence of autism spectrum disorders in Russia is about 1% of the child population (Fakhrutdinov & Knyazeva, 2022; Jamalpour & Derabi, 2023; Jamalpour & Yaghoobi-Derab, 2022; Shariati et al., 2013).

). And if, as of 2021, the child population was more than 30 million, then the predicted number of ASD diagnoses in Russia will be more than 300,000 (Khaitova & Belousov 2021; Sheshko, 2022).

At the same time, of course, one cannot ignore the fact that the unambiguity and finality of the diagnosis is still not a settled matter. Research in this direction is underway. And children who do have ASD can often be misdiagnosed. However, children with other developmental disabilities may also be misidentified as having an autism spectrum disorder.

Until now, in neuropsychology and psychiatry, the issue of separating children with mental retardation and children with distortions or features of this development remains debatable. However, the data of various studies on this subject, despite medical discrepancies, differ only in the magnitude of growth rates. And the very fact of an increase in the number of children diagnosed with ASD is not denied today anywhere and by no one.

The complexity of socializing intervention, which involves the simultaneous and continuous work of several specialists at once, such as a teacher, psychologist, psychiatrist, gastroenterologist, audiologist, neuropathologist, is today declared as a necessity. Moreover, complexity as the only way of effective socialization today is empirically proved in scientific works devoted to this issue.

As Spitsberg (2019), the use of complexity makes it possible to achieve a level of 50% success in the socialization of children diagnosed with ASD versus 2% who receive this assistance not in a complex manner. Solovyova (2022) details the complexity, recommending that several specialists work with the child: a neurologist, a psychiatrist, a gastroenterologist, and an audiologist. A similar complexity as a promising way of developing, socializing intervention of an adapting child to life in society is indicated by Nedovodiev et al. (2019).

Attempts to make economically sound cost calculations, taking into account the complexity of the intervention aimed at the socialization of a child diagnosed with ASD, as well as the growing scale of the problem, are made in the study of Cakir, et al., (2020).

The authors estimated and predicted the expected amount of social expenditures of households with children with autism spectrum disorders, spent specifically on the complex developmental and socializing intervention of specialists in different areas. Here, in addition to medical and psychiatric support, such types of assistance as social and psychological group communicative training, correctional developmental pedagogy, specialized physical education classes, and even vocals are mentioned (Zhao & Wangqian 2022; Zhao et al., 2021).

The authors took an interval of forty years as a promising and long period of time. The costs of a comprehensive developmental intervention were calculated and predicted between 1990 and 2029. Data were summarized for fifty US states. The number of cases diagnosed with ASD was estimated, which was multiplied by the annual direct complex costs, adjusted for the increase in the number of children with such disorders. As a result, the costs by 2029, according to researchers, will amount to 15 trillion. US dollars. At the same time, the authors stipulate that they took into account the linear increase in the number of children diagnosed with ASD. And at the end of the study, data began to appear on the acceleration of this growth, i.e., on an increment that is more similar to an exponential rather than a linear dependence (Abolkheirian et al., 2022; Bieleninik, & Gold, 2021).

Befkadu, et al., (2022), provide a methodologically sound and empirically validated estimate of the cost of standard care for children with autism spectrum disorders in Europe. The estimate is based on the analysis of a large international sample. Of particular interest are the data that researchers rely on as they move from cost estimates per child to estimates of total costs and related investments that take into account the number of children diagnosed with ASD, as well as a forecast of an increase in their number in the future. Choosing between predicting a linear or progressive increase in the number of children with autistic disorders, the authors tend to, as they themselves write, to the “pessimistic scenario”, preferring to predict an almost exponential increase in the number of “special” children. (Cakir et al., 2020)

In other words, a steady increase in the number of autistic children is observed everywhere in the world. And, at the same time, the prices for the services of specialists are growing, and the very complexity of the developmental intervention is also becoming more complicated. That is, the scale of the problem is growing, which means that costs are growing in almost all indicators. Here it is necessary to predict, plan and anticipate the variability of investments. Then these investments will turn out to be truly effective, although the effect will appear only after a decade and a half or even two and a half decades.

The analysis carried out leads to the following conclusions:

- The sooner, the more rational, the more justified the comprehensive and systemic social support for children diagnosed with ASD is deployed, the more benefits will be gained by the region, the state where it is implemented.
- when calculating the total costs of the complexity of socializing intervention intended for a child diagnosed with ASD, and also, given the scale of the problem in its dynamics, one has to focus on the inevitability of increasing costs. If this is taken into account, then the rationalization of the structuring of these costs in their future becomes even more justified, and the costs will become more efficient (Quilendrino et al., 2022).

Status and prospects for improving the financial and economic base of socializing intervention necessary for children diagnosed with ASD

The unsatisfactory state of the financial base of families with children with autistic disorders is stated, albeit in very different contexts, by almost all researchers. In whatever genre, in which country, on which sample these studies would not be conducted, the conclusion is the same everywhere. Families with children with autism spectrum disorder are statistically significantly more likely than ordinary families to experience financial difficulties. And these difficulties are not only directly caused by the need to pay for the services of specialists who carry out the developmental and socializing intervention necessary for a "special" child. The insufficiency of the financial base is also formed from the indirect influence of such reasons as, for example, the depression of the emotional background in the family, which, in turn, weakens the labor motivation of parents and leads to a decrease in their earnings.

Among domestic studies on this topic, the work of Halterman & Montes, (2008). The authors of the study interviewed pediatricians, neurologists, psychiatrists (N = 400) and psychologists and educators working with autistic children (N = 470). Respondents represented 67 subjects of the Russian Federation. Psychologists and educators rated the accessibility of the social environment for families with autism (shops, cinemas, etc.) low: 42.4% for 1 point out of 5, 28.1% for 2 points, 22.7% for 3 points, and only 5.7% - by 4 points, 1.1% - by 5 points.

Of the participants in the study, 47.7% believe that the tasks of ensuring territorial and financial accessibility for families where early assistance is needed for their children diagnosed with ASD have not been resolved. 35.9% of respondents believe that these problems for families in need of such assistance have been partially resolved. And only 5.6% of survey participants believe that these problems have been completely resolved. A significant proportion of respondents - 17.4% - answered that there is no special support for families with children diagnosed with ASD in their region, and 10.2% indicated that they did not know about such support at all. And these are the answers of doctors specializing in childhood diseases, and not parents, who may well show ignorance (Goncharova & Merzlyakova 2020). These are the data for Russia.

The unwillingness of other employers to hire specialists whose children require increased attention and, therefore, will distract their parent from work to a greater extent, also does not contribute to the growth of the well-being of such a family. Surely, problems of this kind are inherent in any society in any country. Empirical confirmation of this in domestic works could not be found. And foreign studies testify to the realism of such hypotheses.

These judgments are confirmed, for example, by a study by Lavelle, Tara, et al. (2014). It states the empirically found fact that the financial and economic burden of households where children with ASD are growing is statistically significantly higher than in ordinary families, not only due to payment for the services of socialization specialists, but also due to a decrease in the attractiveness of members of such a family as workers. In the job market. In other words, not every employer is ready to hire a specialist who has a child with an autism spectrum disorder. And again, despite the use of quantitative methods in the study, numerical indicators of the results of the study as factors influencing the effectiveness of social assistance to the child, as well as the impact on the social well-being of his parents, are not given (Goncharova & Merzlyakova 2022). Researchers limit themselves to the conclusion that the economic burden of households with children with autism is underestimated in society.

Montes & Halterman (2008) investigated the problems of finding a job for parents of children with autism in the United States, as well as the difficulties associated with caring for such children. The authors organized a survey of almost fifteen thousand parents invited to the survey through addresses obtained from a database of 16282 children. As a result, 97% of parents declared that they regularly receive material assistance, medical and psychiatric services, and social support for their children in the relevant institutions at the place of residence. And, at the same time, such parents were seven times more likely than parents with ordinary children to say that the problems of caring for a child negatively affect their employment. The article raises the question of finding special measures to help parents in finding a job that is acceptable to them, that really corresponds to the level and content of their professionalism (Lavelle et al., 2014; Liao & Li, 2020).

An analysis of a number of studies similar in subject matter to those cited above showed that everywhere researchers are focused on detailing and clarifying the structure of the financial insufficiency of the budget of households where children with ASD are growing up.

As for the tasks of designing and organizational and administrative steps aimed at reasonably overcoming "barriers" and "failures" related to the causes of financial difficulties identified in the general "landscape" of problems of socialization of children with a diagnosis of ASD, there is almost nothing on this topic in publications made available for study. At best, other authors limit themselves to appeals to the authorities, to society, and only formulate the task of taking measures to implement targeted and diverse socio-economic support for families where “special” children grow up.

As an illustration, we can cite several of the most revealing and notable works of recent times.

So, Abolkheirian, et al., (2022), on samples of various sizes, from several dozen families to several hundred, comparing the data obtained, show that the emotional state of parents whose children have the diagnosis of ASD is statistically significantly more depressed, depressed than the emotional state of the parents of ordinary children. This emotional state, in turn, inevitably affects children, which reduces the effectiveness of a comprehensive socializing intervention and leads to additional funding for such an intervention (Goncharova et al., 2018; Ou et al., 2015).

The authors conclude that special psychological and social support is needed not only for "special" children, but also for the parents of these children. Before the calculations, at least indicative, which would show how much additional funding aimed at correcting the emotional background of families with autistic children is minimally necessary, the researchers did not get.

Smythe, et al., (2021), studying early intervention in children with developmental disabilities in low- and middle-income countries, set out to find and justify, as they wrote, "arguments for action". The authors insist that it is necessary to take concrete steps to support families with children with developmental disabilities, including those diagnosed with ASD. The number of such children, whose age has not exceeded five years, according to the authors, is about 53 million in the countries of the Asia-Pacific region alone. The authors did not touch upon Russia in their studies. Discussing possible ways of financial and social assistance to families of children with developmental disabilities, Smythe et al., (2021) mention the strategic "Program for Responsible Care" of the World Health Organization (WHO), the United Nations Children's Fund (UNICEF) and the World Bank. According to the authors of the study, this program is quite effective. Briefly characterizing its essence, Smythe et al., (2021) report that the program has five basic guidelines that make up its strategic basis. These include:

- centralized management of financial flows invested to overcome problems;
- Priority in the direction of investments is given to a specific family with children with developmental anomalies, including a diagnosis of ASD, and not to organizations providing social services that distribute material assistance;
- direct financing of specialists providing child-social services;
- control, monitoring of the movement of financial flows at all stages up to the final consumer;
- financing of innovative developments, as well as their implementation.

All this, according to the authors, contributes to the growth in the number of socialized, professionally active citizens who had an ASD diagnosis in childhood. Their labor activity in a relatively short-term (from 15 to 25 years) perspective will increase the general well-being of the country whose authorities consistently and relentlessly acted in the named strategic directions. How exactly the centralized management of such programs is carried out, what are the costs of such administration of programs, the authors do not specify.

In addition, at the empirical level, Smythe et al., (2021) revealed the significance of the difference in the financial condition and budget structure of families with "ordinary" and "special" children. Families from the control and experimental groups were compared, selected so that the income level of representatives of both groups was not statistically significant.

As a result, as expected, the difference in financial burden due to spending on children is always not in favor of families with children with autistic disorders. Moreover, the less wealthy a family with a “special” child is, the greater the difference in its expenses compared to the same family from the control group (Montes & Halterman 2008; Mugno et al., 2007; Zhao et al., 2021).

Probably, the tasks of administering assistance programs for families with children diagnosed with ASD are solved in each specific case in its own way. And the precedents for discussing rational ways to solve such problems, firstly, are vanishingly small, and secondly, they need to be scrupulously and critically studied, bearing in mind an adjustment for the characteristics of the region where the assistance program is being deployed.

Based on the above, the following conclusions can be drawn:

- The economic burden of households with children with autism spectrum disorder is underestimated in society.
- Families with children diagnosed with ASD are statistically significantly more likely than ordinary families to experience financial difficulties.
- The insufficiency of the financial base of a family with children with autistic disorders is formed not only due to additional costs for the socialization of such a child, but also from the indirect influence of the oppressed emotional background in the family, since this weakens the labor motivation of parents and leads to a decrease in their earnings.
- The unwillingness of other employers to hire a specialist whose children are diagnosed with ASD and, requiring increased attention to themselves, will obviously distract their parent from work, forcing the specialist to accept less professionally responsible and, therefore, less paid work, which also lowers the level the welfare of his family.
- The task of providing psychological and socio-organizational support not only to children with autistic disorders, but also to the parents of these children, is relevant, however, has not yet passed into the plane of practical solutions.
- A convincing, evidence-based financial and economic algorithm, based on which it is advisable to provide assistance and support to a family with children diagnosed with ASD, does not exist today.
- A precedent for the deployment of a targeted, long-term comprehensive program of financial and economic support for families with children with autistic disorders can be the Responsible Care Program supported by the World Health Organization (WHO), the UN Children's Fund and the World Bank.
- Deployment of long-term targeted comprehensive programs of socio-economic support for families with children diagnosed with ASD can contribute to an increase in the number of socialized, professionally active citizens, whose labor activity in the future from 15 to 25 years will create the effect of increasing the overall welfare of the country.

4. CONCLUSION

The urgency of bridging this gap is further enhanced by the fact that the number of children with autism spectrum disorder is steadily growing throughout the world, not excluding Russia. Obviously, within the framework of this theoretical study, it is only possible to take the first step towards substantiating the most rational ways and methods for the expedient formation of a socio-economic base that provides socialization activities for children diagnosed with ASD. An analysis of domestic and foreign studies conducted in recent years on topics directly or indirectly related to the socio-economic aspects of the problem of socialization of children diagnosed with ASD showed the following.

The most relevant, although not often in the focus of attention of researchers, have become such questions as:

- Socio-economic, as well as emotional, administrative and organizational support for families with children with autism spectrum disorders;
- Financial and economic component that ensures the complexity and necessary duration of the developmental, corrective, socializing intervention required by a child with autistic disorders;
- Problems of targeted financing of the system of socializing and developmental interventions needed for children diagnosed with ASD, which provides for the growing scale of the problem.

Early diagnosis and the maximum possible early comprehensive socialization intervention prescribed for a child with ASD are two components of a single condition for the effectiveness of all activities for the socialization, development, and adaptation of children with autistic disorders. To comply with this condition, a socio-economic justification of the necessary and sufficient funding is required. With such an organization of social support for families with children diagnosed with ASD, it is possible to avoid forced surges in increasing future costs, given the growing scale of the problem worldwide.

Although there are proposals in a number of works to focus on the deployment of assistance programs in general for a family where a child with an ASD is growing up, and not focus only on the problems of this child, nevertheless, in the practice of social work, this approach has not yet become dominant, has not moved to the level of practical solutions.

The lack of a financial base, even the “threat to food security”, as it is called in some studies (Karpur, et al, 2021), creates an oppressed emotional atmosphere in the family. A child diagnosed with ASD, because of this, has additional difficulties in accepting developmental intervention. And parents, because of the oppressed emotional family background, which is empirically shown, lose their labor motivation. In addition, employers often shy away from hiring a specialist whose child has an autism spectrum disorder. The reason is that the employer expects such an employee to be more focused on family problems than on professional activities. This leads to the conclusion that families with children diagnosed with ASD need comprehensive social and organizational support, the financing of which has yet to be developed.

Taking into account the multifactorial nature of the accompanying financial, economic, social, organizational and administrative circumstances, which differently affect the level of effectiveness of the entire work on the socialization of children diagnosed with ASD and the validity of financing each individual element of this work, bearing in mind the growing scale of the problem, we can draw the following conclusion.

It is not only economically, but also politically beneficial to focus on the creation of a long-term targeted comprehensive program of systemic support for families with children diagnosed with ASD. In this case, complexity will have to be understood more broadly and systematically. The concept of complexity should include not only the range of tasks of attracting specialists to provide the intervention necessary for the child. This should also include the tasks of comprehensive social support for the family of this child as a whole. Only such an approach will provide, due to the socialization of today's children with autistic disorders, a genuine, in 15-25 years, increase in the number of professionally active citizens whose labor activity will create the effect of multiplying the general welfare of the country.

CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

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