Socio-economic effectiveness of children with autism spectrum disorders rehabilitation

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Abstract. The gist of this article boils down to the possibilities of creating favorable conditions for organizing medical-psychological, pedagogical, social and educational adaptation of children with autism spectrum disorders. The purpose of the study is to determine the socio-economic effectiveness of rehabilitation measures for children at an early age. The authors identified problems of financial support for adaptive and educational technologies for children with autism spectrum disorders. The main directions in improving the system of providing social services to the population from the standpoint of their accessibility and quality to preserve the country's demographic fund have been identified. These directions contribute to the implementation of the national projects "Demography", "Healthcare" and help to implement the guarantees and rights of their citizens, to create new jobs through incentives the social services market, the creation of an extensive, penetrating system of social services, and the efficient use of budget funds. Keywords: socio-economic efficiency, costs, autism, cost, morbidity, guarantees, disability

1 Introduction

In modern society, medical and demographic problems come to the fore due to the increasing level of pathological health conditions of the population. Today, all over the world there is an increase in the number of children with autism spectrum disorders. Moreover, this pathology first was identified in children dating back to the mid-sixties and was quite rare at that time (on average, about 3 cases per 10,000 children). It is known that children with autism are born all over the world, regardless of race, religion or socioeconomic status of families. Data published in 2021 and 2023 confirm this. However, the latest research also shows that in some regions of the United States, children in African American and Hispanic families are diagnosed less often and later, and are more likely to be diagnosed with intellectual disability. Possible explanations are that poverty, higher rates of preterm birth, and African American families are less likely to use diagnostic services and have less access to assistance programs. In states where the process of identifying autism is well established and access to services is higher for all groups of the population, this trend is not observed [1].

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According to the Ministry of Health of the Russian Federation, the prevalence of autism spectrum disorders in Russia (as well as in the world) is about 1% of the child population. According to Rosstat of the Russian Federation for 2023, the child population is about 31 million, which means that the projected number of ASD diagnoses in Russia is more than 300 thousand [2]..

The problems of rehabilitation of children with autism spectrum disorders are discussed in the works of foreign and domestic scientists O. Ivar Lovaas, Manelis N.G., Klimas D.G., Khaustova A.G., Bystrova Yu.A., Brazhnikova A.N., Karpenkova N.V., Rizzi D., Dubari A. and many others [3 - 8].

At the same time, it is necessary to note the fact that the methodology for identifying autism in children with autism spectrum disorders in the early stages is constantly being improved and increasing attention from medical and pedagogical specialists, as well as parents, is being paid to observing deviations in the psychosomatic state of the child. However, today there are no effective confirmed methods of instrumental medical diagnostics, which often complicates diagnosis at an early age due to the characteristic signs of behavioral abnormalities in the child's life, which can be detected through close observation. Despite the high level of interest of medical, pedagogical and social specialists in the domestic literature, there are practically no studies in the field of assessing the socio-economic effect of rehabilitation measures. However, these measures presuppose the future involvement of the individual in the process of social reproduction.

Thus, in modern society, economic issues related to the system of planning, analysis, assessment and rational use of economic resources for diagnostic, treatment and educational technologies in the rehabilitation process of autism in childhood are relevant and, in our opinion, will be the objects of close attention research by economists, financiers and sociologists.

2 Materials and Methods

The materials and research base were the works of foreign and domestic scientists in the field of economic, socio-pedagogical and medical knowledge. In order to analyze and calculate various economic indicators, statistical, accounting, reporting, information, and analytical official sources in the field of implementation of rehabilitation and treatment and diagnostic technologies in Russia and abroad were used. The authors in their work relied on the study of enormous practical experience in organizing educational and psychological-pedagogical services for the rehabilitation of children with autism in Yekaterinburg and the Sverdlovsk region. When processing and systematizing information and analytical material, methods of grouping, detailing, synthesis, historical and logical research method, as well as methods of economic and statistical analysis were used.

3 Literature review

In world practice, the Swiss psychiatrist Eugen Bleuler introduced the terminological concept of "autism" in 1911. Bleuler defined autistic thinking as an infantile desire to escape unsatisfactory realities and replace them with fantasies and hallucinations [9]. The term "autism" acquired its modern meaning in the 40s of the last century thanks to psychiatrists Leo Kanner and Hans Asperger, who described in sufficient detail the behavioral characteristics of people who have certain difficulties in interacting with other people [10, p.65; 11, p. 93].

At the same time, it is necessary to note the invaluable contribution of scientists from the young Soviet state to the global practice of identifying children with autism spectrum

disorders. Thus, the works of the Soviet psychiatrist G.E. Sukhoreva devoted to issues of child psychiatry. Back in 1925, she identified and described pathological abnormalities in children and defined the syndrome of autism. At the beginning of the last century, the results of scientific research of the Soviet state were poorly integrated into the system of world scientific thought. Sukhareva's scientific works were not available for the English-speaking space; therefore, A. L. Kanner is considered the discoverer of autism in Western countries and in the USA [12]. In the 1950s, in an attempt to explain the causes of autism, psychologist Bruno Bettelheim developed the "cold mother theory," which in modern medical science is considered a persistent misconception and is criticized by modern scientists in matters of cause-and-effect relationships in making this diagnosis [13].

Based on research and literature reviews, the prevalence of birth of children with autism spectrum disorders in the modern world is 62/10,000 of the population, i.e. according to average calculations, one child out of 160 children born suffers from this pathology with possible further disability. In addition, it is necessary to note the generalized average data of a large number of studies in Western Europe, the USA, Russia and China, which vary significantly in the estimates of the obtained statistical indicators of the prevalence of this pathology. In economically undeveloped countries of the world, such studies have either not been carried out at all, or are partial, so statistical data are speculative, or are completely absent. Thus, scientific research in the field of identification and rehabilitation of children with autism spectrum disorders is carried out in countries with dynamically developing economies, while in countries with low levels of socio-economic indicators such research is not carried out at all.

In 2023, Morozova T. and Dovnya S. published research data from the US Centers for Disease Control and Prevention, according to which autism occurs in every 36 child at the age of 8 years, with boys on average 3.8 times more likely than girls. The frequency of detection in childhood increases every year throughout the world, regardless of race, religion and socio-economic status of families. [14].

Table 1. Ratio of detection of the number of children with autism spectrum disorders per 1 child aged 8 years [15].

2004 year	2006 year	2008 year	2010 year	2012 year	2014 year	2016 year	2018 year	2020 year	2023 year
1 : 166	1 : 150	1 : 125	1 : 100	1 : 88	1 : 66	1 : 59	1 : 54	1 : 44	1 : 36

As evidenced by the data in Table 1, every year there is a decrease in the detection of children with this pathology at the age of 8 years by almost 4 times, which may indicate timely early diagnosis in infancy. Diagnostics presupposes timely rehabilitation measures, ultimately leading to the child's adaptation to modern living conditions and the possibility of further involvement in social reproduction in adulthood, as well as full independent social services.

In modern Russia, the work of domestic scientists in the field of medicine, psychiatry, pedagogy and sociology, such as Mukharyamova L.M., Zangieva I.K., Lesnykh K.A., Savelyeva, is also devoted to the problems of early diagnosis and rehabilitation of children with autism spectrum disorders Zh.V., Dvoryaninova V.V., Fedoseeva E.S., Gorbunova E.V., Khaidov S.K. and many others [16 - 20]. Thus, the problems of rehabilitation and correction of mental behavior of children with psychosomatic health disorders at an early age are receiving increasing attention both from scientists and from federal and regional executive authorities. As evidenced by the results of foreign and domestic scientists, more than 50% of all those rehabilitated in childhood enter adulthood without any special deviations in mental health, are included in social production, start families, etc. That in modern society, in conditions of demographic imbalance and "staff shortage" in almost all

sectors of the Russian economy (especially in the real sector of the economy), is especially relevant.

4 Results

According to the monitoring of the Analytical Resource Center for organizing support for children of the autism center, the total number of people with autism spectrum disorders in Russia is recorded; the figure varies at the level of 1.1% of the total population of the country, which is about 300,000 inhabitants. However, as noted earlier, most of this population is no different from healthy people after adequate rehabilitation measures have been taken. At the same time, attention is drawn to the fact that there is an increase in the coverage of socio-psychological, medical and educational assistance for newly identified patients in childhood, which contributes to more effective adaptation and integration into the system of social and everyday activities of the child. In addition, one should not forget about the socio-economic effect in future periods of time, when a child, having received an education and a profession, is involved in the formation of the labor market, bringing a significant economic effect to the state, as well as to his own family.

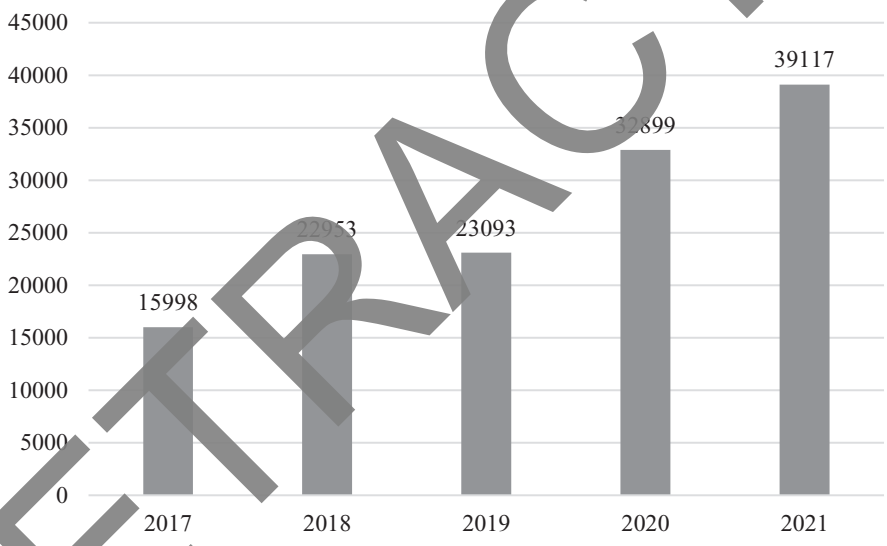

Fig. 1. Number of students with ASD in the Russian Federation [21].

One cannot but rejoice at the increase in the number of children covered by various rehabilitation and educational programs, presented in Table. 2. Thus, in 2021, 39,117 people were covered by educational programs, which is approximately 18% less than in the previous year. If we compare it with the base year 2017, then the growth of this indicator was more than 2 times. However, it should be noted that the number of children with ASD and the incidence of autism spectrum disorders vary greatly in different regions of Russia, as evidenced by the data in Table 2.

Table 2. Dynamics of the number of students with ASD by federal districts [21].

Districts of the Russian Federation	2018 year	2019 year	2020 year	2021 year	2022 year
Central Federal District	5175	6006	11526	13476	17216
Southern Federal District	3111	3215	4065	4463	4485
Northwestern Federal District	1262	1485	1833	2173	2451
Far Eastern Federal District	1201	995	1716	1803	2070
Siberian Federal District	2870	3339	3789	4879	5678
Ural Federal District	2472	2618	3260	3650	4115
Volga Federal District	3760	4493	5291	6449	7709
North Caucasus Federal District	895	942	1419	2224	2164

As the data in Table 2 shows, in all federal districts there is a uniform small (12-18%) increase in the number of children with ASD in the education system. The greatest dynamics were revealed in the Central Federal District - 27%, which undoubtedly may be due to the uneven distribution of demographic indicators on the territory of the Russian Federation. Thus, in the Central Federal District there is a high level of population concentration. The Volga Federal District and the Siberian Federal District added 19% and 16%, respectively. This situation may indicate the development of a system for identifying children at risk of developing ASD and diagnosing ASD in the regions of these districts, as well as the readiness of the constituent entities of the Russian Federation to include such children in the education system. In the Southern District, the smallest dynamics in the increase in the number of children with ASD was revealed, which amounted to less than 1% compared to last year - only 22 people. Unfortunately, the North Caucasus District, which last year showed a 50% increase in the number of children with ASD, this year even decreased its figures by 3%. Thus, the obtained monitoring results in the Russian Federation are in some way at odds with the indicators of world statistics, which record the incidence rate of this pathology at 1 in 100 in the general child population. The current situation may indicate an insufficient level of diagnostic screening of young children, as well as the uneven prevalence of early diagnosis and observation methodology in different regions of the Russian Federation.

Research works by Khaustov A.V., Shumskikh M.A. indicate that 71% of children with autism spectrum disorders in Russia are educated at the levels of primary, basic and secondary general education. A much smaller proportion of children at risk of developing ASD is covered by early help - 1.5% of their total number, which once again confirms the conclusion about the improvement of the screening system for children at an early age. In addition, as the authors note in Russia, the minimum number of adolescents and adults with ASD are included in the system of secondary vocational and higher education: 1.1% and 0.033%, respectively, of the total number of people with ASD [22].

On December 23, 2013, the State Duma of the Russian Federation adopted the Federal Law "On the Basics of Citizens in the Russian Federation No. 442-FZ". According to this Law new principles for organizing the social service system should be formulated, which include: individual programs for the provision of social services; inclusion of non-state (commercial and non-profit) organizations and individual entrepreneurs in the social service system; the principle of equal and free access of citizens to social services; the principle of proximity of the social service provider to the place of residence of the recipients; the right of recipients to choose social service providers; formation of tariffs based on per capita standards for financing social services.

Thus, the new law made it possible to organize social services at the level of the best world standards. Since abroad these tools are the main ones in organizing social services.

Despite the fact that each region promptly reported on the development of standards and tariffs for social services, the approved procedure for paying compensation for the work of non-state providers, the creation of regional registers of social service providers, despite the fact that the regions annually report on funds disbursed by social service providers, in almost all regions, the situation remains where no one has yet been concerned about the legal, organizational and administrative barriers for recipients of social services that have persisted for 8 years. In our opinion, the main barriers to the accessibility of receiving social services are the following: 1) The difficulty of obtaining a complete list of social services in an individual program for the provision of social services;

2) Insufficient number of providers actually working and providing social services to the population in the register;

3) Barriers to the emergence of new providers of social services around recipients, the development of a social services market in which recipients can choose their own provider. Bodies authorized by ministries still "manually" regulate entry into the register of social service providers. The necessary organizations "enter" the register. "Unnecessary" delays entry deadlines;

4) Barriers include piecemeal, rather than hourly, rates, complex reporting on paper (the need to maintain a separate staff for preparing reports), etc.

Social adaptation of children and adults with autism objectively requires coordination of the efforts of doctors, teachers and social workers, which undoubtedly affects the level of costs in the pricing system for a range of these services. In addition, individual rehabilitation and educational programs must be approached in a differentiated manner, which will ultimately affect the cost of these activities. In addition, the lack of time-based per capita funding standards does not allow for the introduction of effective accounting and control of the timeliness and completeness of service provision, and does not allow for an analysis of the sufficiency of social assistance to people guaranteed to them by the state. Existing reporting of volumes of services provided cannot be controlled. This is how social service was organized in Russia in the 20th century during the Soviet Union. This order in the Sverdlovsk region continues to exist today for 99% of the volume of funding for social services.

Thus, the current financing system does not allow providers of social and educational services to keep track of budget expenditures for each recipient of services or their group, since state providers of social services, in accordance with budget legislation, have direct budget funding and are not tied to the number of service recipients served and the duration of their service (in hours). Reports on social services are made not for analyzing the efficiency of spending money, but for preparing a report. The financing of the public provider of social services and the preparation of a report on social services are not entirely linked in meaning.

At the same time, most non-governmental suppliers, also established with the involvement of government organizations, receive funding in the form of grants for the organization itself. The size of grants to support small and medium-sized businesses is

determined without taking into account the per capita standards for financing social services established in the region.

Only a small part of non-state social service providers is subsidized according to per capita funding standards. They are the ones who keep track of state budget expenditures for each recipient of services or group of providers. The cost of providing services from such providers in the region, according to expert estimates, is about 1% of the budget funds allocated in the regional budget for the provision of social services. In other words, social service providers in the region do not have equal funding conditions.

5 Discussion

A fundamental solution to accelerate the formation of a competitive market for social services, in our opinion, is the participation of the Sverdlovsk region in the implementation of the Federal Law "On the state (municipal) social order for the provision of state (municipal) services in the social sphere" dated July 13, 2020 No. 189-FZ It is being introduced gradually in Russian regions. In order for the Sverdlovsk region to begin work in the social sphere according to the principles of this progressive law, it is necessary for the regional authorities to take the initiative.

In our opinion, the idea of the Federal Interdepartmental Program for Social Adaptation of Children and Adults with ASD will allow children and adults to receive timely, specialized, accessible assistance through per capita financing mechanisms for the recipient of assistance in a sufficient amount for their social adaptation. And the region will receive additional funding within the framework of this federal program, and will allow the State to preserve the country's demographic fund, contribute to the implementation of the national projects "Demography", "Healthcare", implement the guarantees and rights of its citizens, create new jobs through stimulating the social services market, create an extensive, penetrating system of social services, and effectively spend budget funds.

The current accounting system for social services in the Sverdlovsk region is not transparent, and the tariffs for their provision are set in a monopolistic manner and do not provide full compensation for the costs of non-state providers. This fact is easily confirmed when analyzing the activities of any social service provider subordinate to the Ministry of Social Policy for any period of time. To do this, it is enough to compare information on the amount of budget funding allocated to such an organization for a calendar year with the number of social services provided by it during this period. The cost of one service will be thousands of times higher than the cost of the same service according to the Resolution of the Regional Energy Commission of November 18, 2015 N 162-PK "On approval of marginal tariffs for social services based on per capita standards for financing social services in the Sverdlovsk region, provided by social service organizations, under the jurisdiction of the Sverdlovsk region."

Changing the system of financing social service providers for the purpose of rehabilitation of children with ASD, in our opinion, is the most urgent task today, since it is not reasonable to expect a decrease in the incidence of this nosological form of the disease in modern society, citing the growth of this pathology in medical statistics. . At the same time, starting from 2022, the region has experienced a shortage of labor resources in almost all sectors and sub-sectors of the national economy due to the rapid development of the real sector of the economy. Due to the tasks set by the Government of the Russian Federation in the long term, focused on the further development of real sectors of the economy, the issue of training personnel for their implementation will become even more acute.

It is necessary to take into account not only the economic effect from the position of the state, but also the individual socio-economic effect from the position of an individual, adapted to the realities of living space (which can be simply invaluable in financial terms).

Assessing the economic efficiency associated with the involvement of rehabilitated children in social reproduction, based on the level of gross regional product in the Sverdlovsk region in 2022 (which averages about 880 thousand rubles per worker), it is not difficult to determine the economic effect during labor activity of 1 worker, which will vary within 35 million rubles.

6 Conclusions

In the context of deteriorating medical and demographic indicators in the country, including in the Sverdlovsk region, it is necessary to pay close attention to creating favorable conditions for organizing medical, psychological and pedagogical rehabilitation of children in the early stages of the development of pathological conditions. To do this, it is necessary to take several steps at the regional level:

1. Assessment of existing practices in the regions, study of the regulatory framework. Comparing it with foreign countries in countries where social services are at a high level. Development of recommendations by experts, and not by the relevant regional ministries themselves.

2. Introduction of government orders and time-based economically feasible tariffs in government orders.

3. Motivations of social service providers. Today in the regions, social service providers working within the framework of government orders are motivated by administrative methods. In developed countries, the main motivator is competition. Non-state suppliers are in a competitive market and they are literally "chasing" every potential recipient. The owner of the organization is interested in having more service recipients in the company, each of them feeling as good as possible, living as long as possible and not having the desire to change supplier. Today we propose the formation of a competitive market for social services within the framework of government procurement (to expand the effect of the law of July 13, 2020 No. 189-FZ "On state (municipal) social procurement..."). Moreover, the involvement of non-state providers of social services to fulfill government orders.

4. Development of measures to motivate social workers (for example, high salaries and personal licensing).

5. Automation. Information system for recording time-based services and calculating payment deductions to the social service provider.

6. Monitoring the satisfaction of service recipients. It is necessary to review the existing regulations for measuring the degree of satisfaction of recipients of social services and the regulations for the work of regional authorities with citizens' complaints about social services. Today, an independent assessment of the conditions for the provision of services, carried out in most regions of Russia in accordance with Article 23.1 442-FZ, is frankly imitative in nature.

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