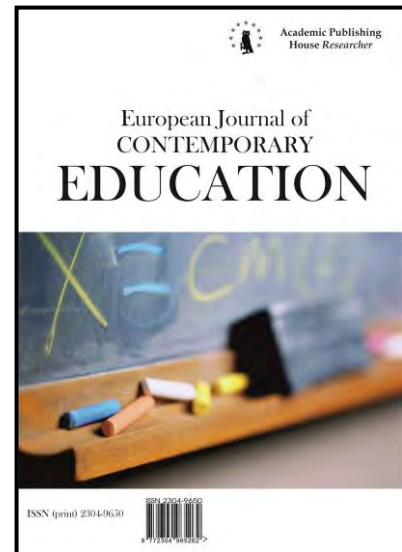




Copyright © 2020 by Academic Publishing House Researcher s.r.o.  
All rights reserved.  
Published in the Slovak Republic  
European Journal of Contemporary Education  
E-ISSN 2305-6746  
2020, 9(4): 935-947  
DOI: 10.13187/ejced.2020.4.935  
[www.ejournal1.com](http://www.ejournal1.com)

**IMPORTANT NOTICE!** Any copying, reproduction, distribution, republication (in whole or in part), or otherwise commercial use of this work in violation of the author(s) rights will be prosecuted in accordance with international law. The use of hyperlinks to the work will not be considered copyright infringement.



### **Achievements and Challenges of Autism Support System in Russia: A Multidimensional Stakeholder Survey**

Anton A. Varlamov <sup>a, b, \*</sup>, Ivan V. Skorokhodov <sup>a, b</sup>, Elena Yu. Skorokhodova <sup>c</sup>, Igor L. Shpitsberg <sup>b</sup>

<sup>a</sup> Pushkin State Russian Language Institute, Russian Federation

<sup>b</sup> **Rehabilitation Center for Children with Autistic Spectrum Disorders “OUR SUNNY WORLD”** (Non-Government, Non-Profit Organization), Russian Federation

<sup>c</sup> Russian State Social University, Russian Federation

#### **Abstract**

Autism spectrum disorder (ASD) is among the most common developmental disorders of great social significance. Adequate intervention can increase socialization of autistic individuals, both increasing their quality of life and decreasing financial burden. Initiatives to introduce modern standards of autism treatment and education in Russia were launched several years ago; unfortunately, there is little information on the perceived problems and barriers, which may hinder further development of autism support system. This paper presents the results of a stakeholder survey including both service receivers (parents of children with ASD) and service providers (professionals working with ASD children) from different regions of Russia. The study reveals that the quality of specialized services related to autism treatment is assessed much higher than the quality of inclusive education and accessibility of general education and other general services available to children and adults with ASD, highlighting the importance of implementing an inter-departmental system providing continuous support to people with ASD and facilitating their inclusion and social integration. The results also show that general attitude to distant diagnostics and education, on par to the estimates of quality of services related to distant education, are lower in non-capital regions, where the need for such services is higher due to lower accessibility of person-to-person services. The present study may be of use both for professionals in autism treatment and education, and for the specialists who may encounter persons with autism once in a while, as it brings a detailed estimation of several aspects of autism support both through the eyes of support receivers and providers.

---

\* Corresponding author

E-mail addresses: [antonvarlamov@gmail.com](mailto:antonvarlamov@gmail.com) (A.A. Varlamov), [iskor@live.com](mailto:iskor@live.com) (I.V. Skorokhodov), [aentar@gmail.com](mailto:aentar@gmail.com) (E.Yu. Skorokhodova), [igor@solnechnymir.ru](mailto:igor@solnechnymir.ru) (I.L. Shpitsberg)

**Keywords:** autism, stakeholder survey, inclusive education, telehealth, remote education, comprehensive support system.

### **1. Introduction**

Autism spectrum disorder (ASD) is a development disorder characterized by social and communicative impairments and restricted interests and behavior, as well as perception abnormalities ([American Psychiatric Association, 2013](#)). This term combines previously used diagnoses of **infantile autism, atypical autism, Asperger's syndrome, and pervasive development disorder**. It is one of the most common developmental disorders with average global prevalence about 1%, often having a strong negative impact on the quality of life of the affective individuals and their families, and thus has a crucial social significance ([Baxter et al., 2015](#); [Lugo-Marín et al., 2019](#)). The terms **“high-functioning autism” (HFA)** and **“low-functioning autism” (LFA)** are frequently used, referring to the absence or presence of intellectual disability accompanying ASD. LFA is considered more prevalent than HFA, with about 50 to 70 % of all the persons with autism having LFA ([Matson, Shoemaker, 2009](#)).

Low-functioning autism poses a great challenge, and treatment can have quite pessimistic outcomes, especially if the intervention was not delivered at early age ([Elder et al., 2017](#)). In the most unfavorable case, such a child is devoid of the opportunity to get any education and is constantly and totally dependent on either his or her relatives, or the social support services. In such a scenario not only the person with autism is excluded from the society, but his or her caregivers are obliged to spend most of their time and other resources to supervise and nurture him or her as well ([Montes, Cianca, 2014](#)). But the need for support is high not only for individuals with LFA. Persons with HFA often meet challenges in different aspects of their everyday life, mostly in social situations ([Tantam, 1991](#)), as they usually possess an impaired ability to comprehend nonverbal components of communication, such as gestures and facial expressions ([Amenta et al., 2014](#)), and figures of speech ([Rundblod, Annaz, 2010](#)). Altered sensory perception, particularly hypersensitivity which is quite common to people with autism regardless their intellectual development, also impedes the quality of everyday life ([Uljarevic, 2017](#)).

Support of people with autism incurs heavy costs on their families ([Knapp et al., 2009](#)) and state support system ([Ganz, 2007](#)). Autism, while incurable, is treatable; a well-timed and well performed intervention allows more individuals on the autism spectrum to participate in social and economic life, decreasing this burden. A study of early intervention cost-efficiency in Australia has shown a cost-benefit ratio of 11.4; the overall savings exceed 1 billion AUD ([Synergies Economic Consulting, 2013](#)). Thus, providing high quality treatment to the individuals with autism is not only humane, but it is beneficial in the most pragmatic sense. Several authors have called for a comprehensive system introduction uniting facilities of treatment, education and social support in order to improve the quality of life and social integration of people with ASD ([Alekhina, 2015](#); [Nesterova, Aysina, Suslova, 2016](#); [Shpitsberg, 2018](#)). Establishing good quality of inclusive education and increasing accessibility of general education for people with autism is paramount for such a support system, as it greatly promotes social inclusion for people with ASD ([Shpitsberg, 2018](#)). This approach seems the most promising taken into consideration the current condition of the Russian support system for the individuals with ASD.

Currently, Russian society as well as the professional community are struggling to improve the quality of support to the ones with ASD using the approaches proven effective in other countries: introducing inclusive education and comprehensive support systems, and raising both public and professional awareness. Still, a lot of issues, while being addressed, remain prominent. Some of them are common for every autistic society, such as inequity of access to therapy and education ([Manelis et al., 2013](#)), family burden ([Mikhailova, Gutshabash, 2016](#)), social stigma ([Borodina, Fisunova, 2017](#); [Nesterova, Khitryuk, 2018](#)). Other challenges are more characteristic for Russia. For instance, the very term **“детский аутизм” (childhood autism)** officially recommended by the Ministry of Health implies that ASD is only a childhood condition, so adolescents and adults with autism face more challenges in their attempts to get support ([Borodina, 2015](#)). A routine practice of changing the autism diagnosis to other psychiatric diagnoses (intellectual disability, schizophrenia, schizoaffective disorder etc.) after the patient reaches 18 years affects not only the direct victims of this practice but the whole community, as it corrupts the data on autism prevalence in Russia, which are available currently only through

extrapolations of relatively small cohort studies (Ivanov et al., 2018). A lack of structured and statistically sound information on different aspects of everyday life of people with autism and their relatives affects the general understanding of the situation, hindering the improvement of the support system. In such situations stakeholder surveys are an accessible and a reasonably reliable source of information. Usually such surveys are focused only on one narrow group: adults with autism (Gotham et al., 2015) or parents and caregivers of autistic children (Heiman, 2002; Ryan, Quinlan, 2018), or teachers and therapists (Buell et al., 1999). Such polls are useful when a small set of issues is being researched. Broader issues require broader and more diverse sample, because different participants of autistic community have different experiences and neither of them should be rejected (Pellicano et al., 2014). Parents of children with disabilities, including ASD, are more prone to burnout and depression (Dumas et al., 1991; Ryan, Quinlan, 2018), so their answers, while sincere and insightful, may be negatively biased to some extent. On the other hand, opinions of specialists on the efficacy of facilities they work at may be biased towards higher ratings. Stakeholder surveys are useful as a source of information both on the general attitude to the issues in question and on group differences within the community. We were particularly interested in differences between the support receivers and support providers because lack of understanding between those two parties may decrease efficiency of their collaboration, which is a centerpiece of successful autism treatment (Ryan, Quinlan, 2018).

Differences between the Russian regions were an object of interest as well. Regional inequity in access to support and its quality is a known issue (Juárez et al., 2018; Murphy, Ruble, 2012). Its complex nature was noted in (Skinner, Slifkin, 2007): while the quality and variety of services for children with ASD are lower in rural areas, they are also less accessible due to lower social and economic status (SES) of its residents. This is true for Russia as well. The SES of Moscow and Moscow Oblast is by far better than rest of the country (Mayorova et al., 2018), which brings in higher quality of education (Grigoryev et al., 2016), life expectancy (Shkolnikov et al., 2019), human development index (Bobkov, Gulyugina, 2012) and overall quality of life (Sobol, 2018) in the capital region. We were curious if this pattern transfers to the estimation of different aspects of autism support and to what extent. This issue is especially relevant to Russia due to its population geography. Although only 25% of Russians live in rural areas, another 25 % live in small towns, which are not much different from a village in terms of social infrastructure. Moreover, about 66 % of Russian space (i.e. more than 11 million km<sup>2</sup>) are low density territories. This vast land is populated by roughly 7 million people with an average density of .6 people per km<sup>2</sup>. Distant education, diagnostics, and therapy seem particularly promising for those areas (Juárez et al., 2018; Sutherland et al., 2018), so we included a block of questions covering different aspects of telehealth and tele-education.

The paper presents the results of a multidimensional survey assessing **stakeholders' opinions** on support system for people with ASD in Russia, focusing on special education, inclusion, general education, and e-learning, and covering several other aspects of social support to people with ASD and their families. We specifically aimed

- 1) To obtain the estimates of different aspects of support of individuals with ASD and their families in Russia from service providers and service receivers;
- 2) To receive opinions on the current state and the prospects of remote diagnostics and distant education for children with ASD, as well as for using online solutions for raising awareness to ASD-related problems, disseminating good practices and parental education;
- 3) To assess the differences between different groups of stakeholders in their perception of different aspects of support system for people with ASD in Russia.

## **2. Methods and participants**

134 respondents participated in the survey. Respondents were asked to specify their relations to the ASD community, their total experience with the ASD, and their geographic region. 61 respondents were parents of individuals with ASD, 70 were specialists in ASD education or therapy, 8 were both, 11 were neither. The last group included mostly activists of related communities (parent organizations, charities etc.). While persons with ASD were also welcomed to participate in the survey, only 1 of them responded. This respondent was not included in a separate group. The experience was defined by four options: less than a year (18 respondents), one to three years (36 respondents), three to five years (29 respondents) and more than 5 years

(51 respondents). Pilot analysis of the responses suggested grouping the respondents further into two supergroups: less than 3 years (54 respondents) and more than 3 years (80 respondents). **Parents had significantly greater experience than other respondents** ( $\chi^2=7.23$ ,  $p = .007$ ). The respondents came from 33 of 85 Russian federal subjects. They were regrouped as follows: capital region, which included Moscow and the surrounding it Moscow Oblast (54 respondents), and non-capital regions (80 respondents), as the shares of separate non-capital regions were relatively small; this grouping reflects the above stated disparities in education quality and general life quality. All the respondents gave their informed consent before participation in the study.

The survey was conducted via Google Forms and consisted of 43 questions of different types divided into five sections (Table 1). Most questions (31) were a 5-point Likert scale where 1 was the most **negative answer** (“**extremely low**” for questions about estimation and “**completely dislike**” for questions about the attitude) and 5 was the most positive. Six were multiple choice questions allowing to choose several options. An open question concluded each of the six sections of the survey.

Statistical analysis was conducted using Statistica 8.0 software. As the score distribution for the most items was not normal, the between group analysis for ranked variables was performed using Mann-Whitney U test and within group analysis was performed with Wilcoxon signed-rank test. **Nominal variables were analyzed with Pearson’s Chi-square analysis.**

### 3. Results

Mean ratings for all the Likert-type questions for the general sample and for different stakeholder groups are shown in Table 2 with the significance level of the resulting differences. Below in this section we present the most noteworthy results relevant to the study aims.

#### 3.1. Special and general education

The ratings were obtained for different types of organizations providing special education and general support to people with ASD and their families. Parental organizations and non-governmental institutions got similar ratings of 3.37 and 3.27 respectively, while the state support facilities were rated significantly lower, at 2.14. The efficiency of interactions between organizations was also rated poorly with a score of 2.36. Parents tended to rate the state support facilities more critically than non-parents (1.77 vs 2.47,  $U = 1359$ ,  $p = .0001$ ), while the specialists rated it somewhat better than non-specialists (2.43 vs. 1.84,  $U = 1490$ ,  $p = .0008$ ). Even the state-employed professionals gave better scores to private and non-governmental facilities compared to state-own facilities: 3.21 vs 2.57 ( $T = 96$ ,  $Z = 3.14$ ,  $p = .002$ ); this difference in the efficiency assessment was even more pronounced in the ratings of their private-employed peers’: **3.48 vs 2.17** ( $T = 20$ ,  $Z = 4.56$ ,  $p < .00001$ ). All the items were rated significantly higher in the capital region in comparison to non-capital regions. The respondents with an experience of 3 and more years tended to give lower scores; this tendency reached statistical significance for both state and private institutions ( $U = 1680.5$ ,  $p = .023$  and  $U = 1727$ ,  $p = .041$  respectively). More detailed analysis of experience groups showed a negative correlation between experience rate and scoring ( $r = -.22$ ,  $p = .009$ ).

The basic accessibility of education for children with ASD was estimated rather low (2.17). **Again, the parents’ ratings were significantly lower than for non-parent stakeholders** ( $U = 1644.5$ ,  $p = .009$ ). We used two different questions to distinguish the attitude towards the concept of inclusive education per se and towards its current implementation. The concept of inclusive education itself was rated rather positively (3.58), particularly by the parents (3.98 vs. 3.29 for non-parents;  $U = 1489.5$ ,  $p = .001$ ). The attitude of the service providers was lower (3.35), and the specialist from the government facilities were significantly more critical to the concept of inclusive education than their peers from private sector (3.12 vs. 3.95;  $U = 460.5$ ,  $p = .005$ ). The current implementation of inclusive education got much lower average scores of 1.91 (no significant between group differences for this item), revealing that promotion of inclusive education still faces many barriers. The nature of this barriers as reflected in the answers on the most prominent challenges in establishing education accessibility for children with ASD. 90.9 % of the respondents named unpreparedness of teachers to work with autistic children, 89.4 % named lack of auxiliary specialists (such as tutors, psychologists, therapists etc.), 73.5 % named lack of supportive equipment and environment (such as alternative communication systems, rooms of sensory relaxations etc.), 65.2% named lack of adapted teaching materials, 56.8 % named negative attitude **of other children or their parents. No respondents picked an option “None of the above”** that would indicate that these challenges are irrelevant. Some items revealed regional differences:

the respondents from the capital region significantly less frequently indicated a lack of auxiliary specialists ( $\chi^2 = 7.18$ ,  $p = .007$ ) and of adapted equipment and environment ( $\chi^2 = 4.46$ ,  $p = .035$ ) as major problems. The respondents from the capital region were somewhat more prone to highlight negative attitude of classmates and their parents than the other respondents (66.7% vs. 52.5%), but this difference did not reach statistical significance ( $\chi^2 = 2.24$ ,  $p = .13$ ). There also were infrequent mentions of negative attitude of teachers and school administration (2 of the total sample).

In response to the question asking to highlight the areas of education least adapted towards the needs of autistic children 88.6 % of the respondents noted social skills, 69.7 % noted basic school subjects, and 63.6 % noted self-care skills.

The respondents showed no differences on the issues of the most efficient form of education for children with HFA and LFA. For children with HFA, 28.1 % recommended full inclusion, 6.6 % voted partial inclusion with individual schedule and support, 7.6 % were for separate education in special schools. 1.5 % voted for home education, 2.2 % had other opinions. As for children with LFA, 45.5 % recommended assisted inclusion, 4.2 % voted for special schools, 6.8 % recommended home education, and only 2.3 % opted for full inclusion. 5.2 % had other opinions (mostly stating an opinion that an education form should be chosen according to a child's individuality).

### **3.2. Family support and parental education**

The overall level of family support was rated 2.19, psychological support for parents got 2.04, and financial support scored 2.17. Parents rated the first two items significantly lower than the other respondents: 1.77 vs 2.52 ( $U = 1309$ ,  $p < .0001$ ) and 1.61 vs 2.40 ( $U = 1220$ ,  $p < .0001$ ). Parental awareness of ASD-related problems got 2.6, and the overall efficiency of awareness-improving initiatives scored 2.41. Parent responders showed a high level of self-criticism, as their rating on this matter was significantly lower (2.31 vs 2.81,  $U = 1656.5$ ,  $p = .011$ ). The efficiency of awareness-improving initiatives was rated significantly higher for the capital region (2.63 vs. 2.24,  $U=1657.5$ ,  $p = .022$ ).

### **3.3. Social support, accessibility of general social services**

In general, the quality and accessibility of general services for people with ASD was rated lower than the quality and accessibility of autism-related services. Overall availability of medical services for children with ASD was rated at 2.44. The difference between parents and other participants had statistical significance (2.15 vs. 2.67,  $U=1684$ ,  $p = .015$ ). Overall awareness of medical staff was rated 1.93 with no group differences. The items related to problems of adults with autism were rated particularly negatively. The current level of employment of adults with ASD was rated at 1.51. State programs of employment support scored 1.52, while non-governmental programs got 2.06. Residents of capital region were more optimistic in their rating of non-governmental initiatives (2.48 vs. 1.80,  $U=4515$ ,  $p < .0001$ ). The awareness of law enforcement and judiciary professionals of ASD-related problems was rated at abysmal 1.45 with no differences between groups.

There was a statistically significant difference in ratings according to the experience group: respondents with more than 3 years of experience gave lower scores to most of the items ( $p$  levels ranging from .04 to .002).

### **3.4. Distance education and diagnostics**

The general concept of providing distance education and diagnostic services for children with ASD was rated 2.78 with no significant group differences. The current level of efficiency of distance services was rated at 2.14. The respondents from the capital region were more positive in their estimates (2.36 vs. 2.00,  $U = 1653$ ,  $p = .032$ ). Positive rating of existing distance support differed between respondents depending on their experience: more experienced participants rated the current state lower, at 1.90, while less experienced participants rated it at 2.51 ( $U = 1441$ ,  $p = .002$ ). The respondents assessed the current education system as poorly prepared to implement distant services for the children with ASD, the total average was 1.87. Specialists were slightly more optimistic in comparison with the other respondents, as well as the capital residents, but for both comparisons the results were barely significant (2.01 vs. 1.70,  $U = 3728.5$ ,  $p = .047$ , and 2.06 vs. 1.74,  $U = 1719$ ,  $p = .046$ , respectively). On the issue of general efficacy of remote diagnostics of ASD the opinions divided. 23,5 % of the respondents entirely disapproved the concept, 46.3 % approved remote diagnostics as a tool for screening and/or progress control, 27.3 % approved remote diagnostics for situations where a person-to person diagnostics is unavailable, and only 3 %

completely approved remote diagnostics. The overall preparedness of the public health system to integrate remote diagnostics was rated very low, at 1.47 with no group differences.

#### **4. Discussion**

This survey had several areas of interest. First, we intended to assess current opinions on basic challenges of people with ASD and their families. Next, we planned to analyze the difference between different groups of stakeholders and their views of the situation.

Several trends were easy to notice. First, as expected, parent responders were more pessimistic; the differences gained statistical significance in 21 out of 32 closed questions (see [Table 2](#)). One may presume that, adding to the above-mentioned problem of parental depression and burnout, there also is a clear effect of demand and supply. A receiver of a service usually rates it lower than the supplier ([Ramseook-Munhurrun et al., 2010](#)). Another between-group difference that may be related to burnout is an effect of experience (more experienced participants were significantly more critical in their judgements). In our sample parents had greater experience than nonparents and it can partly account for the difference in ratings but the effect of experience was quite prominent within both parent and non-parent groups; this corresponds to the data confirming that specialists and therapists are as susceptible to the issue of burnout as parents ([Hurt et al., 2013](#)). Our findings point out that the burnout problem should be taken into account, and specific initiatives should be promoted to counter this problem more efficiently. A more optimistic explanation of the findings that can partly account for the experience effect is related to the fact that the situation with the support of autistic individuals in Russia has substantially increased within the last decade, so lower scores of more experienced respondents may reflect their memories of issues that are less relevant nowadays.

The difference between the capital region and the rest of Russia is another serious issue. Higher estimates may be explained by better quality of available services, which is consistent with previous findings obtained for other countries ([Murphy, Ruble, 2012](#); [Skinner, Slifkin, 2007](#)). This, however, does not explain better attitude to the concepts of remote diagnostics and distance learning. Higher overall quality of life and better access to the state-of-the-art education, treatment, and diagnostic technologies may account for more positive estimates of the capital region respondents. The survey data were collected before the COVID-19 related lockdown and subsequent disruption of different everyday routines, including school education and treatment.

**The study of parents' evaluation of remote therapy sessions for their children with ASD held in May and June 2020** shows that after experiencing this format of treatment people become more enthusiastic towards it. 97.6% of parents reported progress in condition of their children and expressed their desire to continue remote sessions ([Shpitsberg et al., 2020](#)). We hope that the skepticism demonstrated by the respondents from non-capital regions will be eventually overcome by the demonstration of opportunities provided by distant education and distant treatment sessions. Nevertheless, the facilitators of distant services should note that the respondents from non-capital regions (that presumably are in greater need for distant services due to poorer access to person-to person services) showed greater aversion towards distant practices. At present this attitude may pose a barrier of its own and it should be taken into consideration while planning any measures to introduce distant education and remote treatment practices.

Some aspects of support system were rated similarly by all the stakeholders. The highest ratings were assigned to the issues directly related to autism treatment, the lowest — to the issues of other components of everyday life and support. Some issues scored particularly low (less than 2): current state of inclusive education (1.92), awareness of judiciary and security forces professionals (1.45) and of general medical professionals (1.93) about problems of children with ASD, employment level of adults with ASD (1.51) and state employment support (1.52), and readiness of current healthcare system to introduce remote diagnostics and treatment. Most of the questions related to the issues of adults with autism were also scored particularly low reflecting the vulnerability of this group. It reveals that, while some substantial progress has been made in autism treatment and promoting the system of special education services for children with ASD and their families, the providers and professionals in general social services are much less prepared to deal with specific problems of autistic individuals. These findings concur with the results of previous studies of teachers training in dealing with students with special needs ([Aysina et al., 2020](#)) and quality of medical services provided to the children with ASD ([Piskunov et al., 2018](#)).

These issues have to be properly addressed in order for the system of support to be more comprehensive, continuous, and fully efficient – otherwise the efforts of autism treatment professionals will be undermined by the low readiness of the society to incorporate people with ASD. It would require increasing the awareness of such professionals and promoting principles of universal design to ensure that people with ASD have proper access to general social services and do not have to face inclusion barriers.

It is also worth noting that similar unanimity of stakeholders was found for the recognition of relatively higher efficiency of non-governmental support institutions and parent organizations compared to slower adapting state-owned institutions. The experience of Russian non-governmental organizations may be used not only in setting an example of good practices, but as leverage for further progress achieved by more efficient collaboration of state-run and non-governmental institutions. The development of a framework of continuous comprehensive interdepartmental support for people with ASD and other mental disabilities is probably one of the first successful examples of such a collaboration. This framework was developed by the specialists of Our Sunny World, one of the leading Russian non-governmental ASD treatment facility. It applies across the whole lifespan and provides different kinds of support, from early diagnosis and intervention to sheltered employment and assisted living. This framework was first put into action in 2017 in Khanty-Mansi Autonomous Okrug – **Yugra by the Governor’s decree** ([The Government of Khanty-Mansi Autonomous Okrug-Yugra, 2017](#)). Later, it was introduced in Nizhny Novgorod Oblast (September 2019) ([The Government of the Nizhny Novgorod Oblast, 2019](#)) and Chuvash Republic (June 2020) ([The Government of the Chuvash Republic, 2020](#)), and several other regions showed their willingness to adopt this framework.

## 5. Conclusion

The survey data provided an overview of stakeholders’ opinions on the current state of autism support situation in Russia. The respondents were generally quite critical in their assessment, the parents of children with ASD being the most pessimistic. The highest ratings were given to the facilities that have individuals with autism as their prime audience, the lowest – to the services that have to deal with autistic individuals as with a part of general populace. It underscores the need for more efficient interdepartmental and private-public cooperation, raising awareness of providers and professionals in general social services, and pleads for promotion of universal design principles across all the systems providing social services. The experience of Russian private facilities may be a helpful asset for further development of support systems for people with ASD.

## 6. Funding and acknowledgments

The research was funded by a Russian Government contract, project FZNM-2020-0005, **“Transformation of human cognition and communication in the digital era”**. The authors would like to thank K.O. Nasakin (Chuvash Regional Public Organization for Helping Children with Autism Spectrum Disorders “Krilia”), E.V. Bagaradnikova (Regional public organization to help children with autism spectrum disorders “Contact”), and A.V. Khaustov (Federal Resource Center for Organization of Comprehensive Support to Children with Autism Spectrum Disorders) for their support and assistance in data acquisition.

## Appendix

**Table 1.** The survey layout

#	Item	Type
General questions		
1	Please provide your estimation of overall efficiency of organizations of parents of children with ASD	Likert scale
2	Please provide your estimation of overall efficiency of state services of support of children with ASD	Likert scale
3	Please provide your estimation of overall efficiency of private services of support of children with ASD (NGOs, charities, private therapy centers)	Likert scale

4	Please provide your estimation of overall efficiency of interactions between different services supporting children with ASD	Likert scale
5	Please provide your comments on the issues of general support for children with ASD	Open question
Issues of education availability and quality		
1	Please provide your estimation of education accessibility for children with ASD	Likert scale
2	Please provide your opinion of the idea of inclusive education	Likert scale
3	Please provide your estimation of the current realization of inclusive education	Likert scale
4	Please choose the most prominent challenges in establishing education accessibility for children with ASD: 1) unpreparedness of teachers to work with autistic children; 2) lack of auxiliary specialists (such as tutors, psychologists, therapists etc.); 3) lack of supportive equipment and environment (such as alternative communication systems, rooms of sensory relaxation etc.); 4) lack of adapted teaching materials; 5) named negative attitude of other children or their parents; 6) None of the above; 7) Own answer.	Choose all that fit
5	Please choose the subject areas in the most need of adjustment for children with ASD: 1) Basic school subjects; 2) Social skills; 3) Self-support skills; 4) No adjustment is needed; 5) Own variant	Choose all that fit
6	Please select the most promising form of education for children with HFA: 1) Full inclusion; 2) partial inclusion with individual schedule and support; 3) separate education in special schools; 4) Home education; 5) Own answer	Choose one
7	Please select the most promising form of education for children with LFA: 1) Full inclusion; 2) partial inclusion with individual schedule and support; 3) separate education in special schools; 4) Home education; 5) Own answer	Choose one
8	Please provide your comments on the issues of education accessibility for children with ASD	Open question
Issues of autism treatment and diagnostics availability and quality		
1	Please provide your estimation of the overall quality of treatment of children with ASD	Likert scale
2	Please provide your estimation of treatment accessibility for children with ASD	Likert scale
3	Please provide your estimation of state autism treatment efficiency	Likert scale
4	Please provide your estimation of diagnostics accessibility for children with ASD	Likert scale
5	Please provide your estimation of the overall autism diagnostics quality	Likert scale
6	Please provide your estimation of ASD diagnostics quality in the specialized state institutions	Likert scale
7	Please provide your estimation of medical services accessibility for children with ASD	Likert scale
8	Please provide your estimation of awareness of medical professionals about practices of interaction with children with ASD	Likert scale
9	Please provide your comments on the issues of medical support for children with ASD	Open question
Issues of family support		



1	Please provide your estimation of the overall quality of support of families with children with ASD	Likert scale
2	Please provide your estimation of psychological support of parents of children with ASD	Likert scale
3	Please provide your estimation of financial support of families with children with ASD	Likert scale
4	Please provide your estimation of parent awareness on interaction with children with ASD	Likert scale
5	Please provide your estimation of awareness raising among parents on interaction with children with ASD	Likert scale
6	Please provide your estimation of the overall status of employment of people with ASD	Likert scale
7	Please provide your estimation of the state employment programs for people with ASD	Likert scale
8	Please provide your estimation of the non-governmental programs of facilitation of employment of people with ASD	Likert scale
9	Please provide your estimation of awareness of judiciary and security forces professionals about practices of interaction with persons with ASD	Likert scale
10	Please provide your comments on the issues of financial, occupational, and legal support for children with ASD and their families	Open question
Remote education, treatment and diagnostics		
1	Please provide your opinion on the concept of remote education and treatment of children with ASD	Likert scale
2	Please provide your estimation of the current level of remote education and treatment development	Likert scale
3	Please provide your estimation of the readiness of the present education system to remote work with children with ASD	Likert scale
4	Please provide your opinion on remote ASD diagnostics (e. g. by a video call): 1) Completely approve, it is effective and more convenient for the child; 2) Somewhat approve, remote diagnostics is acceptable if there is no physical possibility of direct contact; 3) Somewhat approve, remote diagnostics is insufficient for diagnosis establishment, but may be used for screening or progress control; 4) Completely disapprove, ASD cannot be diagnosed without a direct contact 5) Own answer	Choose one:
5	Please provide your estimation of the present public health system readiness to remote ASD diagnostics	Likert scale
6	Please provide your opinion of remote education of parents of children with ASD on the issues of interaction and treatment	Likert scale
7	Please provide your estimation of availability of remote education of parents of children with ASD on the issues of interaction and treatment	Likert scale
8	Please provide your estimation of efficacy of remote education of parents of children with ASD on the issues of interaction and treatment	Likert scale
9	What is the best approach to support children with ASD in remoted and isolated regions? 1. To use existing medical and educational facilities; 2. To establish branches of specialized state and private ASD support organizations; 3. To use remote support; 4. It is impossible, they should move to more accessible areas; 5. Own answer	Choose all that fit:
10	Please provide your comments on the issues of remote support of children with ASD	Open question
Please provide your comment on the issues that were left untouched by the questionnaire		Open question

**Table 2.** Mean rates and SDs (in parentheses) of the questions with Likert scales by groups. Prof. – professionals, Capital – Capital region. Asterisks denote statistical significance of the group differences: \* – p<.05, \*\* – p<.01, \*\*\* – p < .001

#	Parents (N=61)	Non-parents (N=73)	Prof. (N=70)	Non-prof. (N=64)	Capital (N=54)	Non-capital (N=80)	More experienced (N=80)	Less experienced (N=54)	Total
General									
1	3.29 (1.1)	3.34 (1.1)	3.39 (1.01)	3.25(1.08)	3.61*(.76)	3.13*(1.16)	3.28(1.03)	3.39(1.07)	3.32(1.04)
2	1.77***(.99)	2.47***(.82)	2.43***(.97)	1.84***(.89)	2.39*(.9)	1.99*(.99)	1.98*(.85)	2.4*(1.09)	2.18(.98)
3	3.13(1.04)	3.46(1.24)	3.48(1.03)	3.13(1.24)	3.89***(.69)	2.92***(1.23)	3.15*(1.13)	3.56*(1.13)	3.31(1.15)
4	2.1***(1.01)	2.58***(.98)	2.5(1.02)	2.2(1.01)	2.78***(.79)	2.08***(1.06)	2.23(.94)	2.56(1.11)	2.35(1.02)
Issues of education availability and quality									
1	1.93**(.83)	2.42**(.95)	2.41*(.95)	1.97*(.85)	2.28(.79)	2.15(1.02)	2.14(1)	2.3(.88)	2.22(.93)
2	3.98***(1.11)	3.29***(1.23)	3.35*(1.23)	3.88*(1.18)	3.78(1.14)	3.49(1.27)	3.53(1.2)	3.72(1.24)	3.6(1.23)
3	1.77(.64)	2.01(.81)	2.01(.75)	1.78(.72)	2(.78)	1.84(.72)	1.85(.85)	1.98(.68)	1.92(.74)
Issues of family support									
1	1.77***(.84)	2.52***(1.03)	2.49***(1.03)	1.84***(.89)	2.3(.84)	2.1(1.12)	2.09(.97)	2.31(1.08)	2.19(1.02)
2	1.61***(.71)	2.4***(1)	2.3***(1)	1.75**(.84)	2.11(.77)	1.99(1.07)	1.91(.89)	2.22(1.04)	2.04(.96)
3	1.97(.89)	2.33(1.13)	2.37*(1.09)	1.94*(.94)	2.06(.92)	2.24(1.12)	2.15(.99)	2.19(1.12)	2.17(1.04)
4	2.31*(1.06)	2.81*(.84)	2.86**(.77)	2.28***(1.09)	2.74(.87)	2.48(1.03)	2.59(.9)	2.57(1.09)	2.6(.98)
5	1.97***(.98)	2.75***(.95)	2.83***(.93)	1.92***(.95)	2.63*(.85)	2.24*(1.13)	2.3(1)	2.54(1.09)	2.41(1.04)
6	1.36*(.61)	1.63*(.77)	1.59(.77)	1.42(.64)	1.57(.69)	1.46(.73)	1.44(.63)	1.61(.81)	1.51(.71)
7	1.39(.61)	1.6(.74)	1.57(.73)	1.44(.64)	1.57(.66)	1.46(.71)	1.48(.64)	1.56(.77)	1.52(.69)
8	1.97(1.02)	2.16(.85)	2.09(.83)	2.06(1.04)	2.48***(.88)	1.8***(.86)	1.93*(.88)	2.3*(.96)	2.06(.93)
9	1.41(.69)	1.47(.69)	1.44(.67)	1.44(.71)	1.48(.72)	1.41(.67)	1.41(.65)	1.48(.75)	1.45(.69)
Issues of autism treatment and diagnostics availability and quality									
1	2.46*(.98)	2.92*(.88)	2.89*(.83)	2.52*(1.04)	3.00**(.75)	2.51***(1.02)	2.56*(.94)	2.93*(.93)	2.71(.95)
2	2.25***(.98)	2.84***(.94)	2.77*(.95)	2.34*(1.01)	2.93***(.72)	2.33***(1.09)	2.35***(1.02)	2.89***(.88)	2.56(1)
3	1.87***(.92)	2.52***(1.06)	2.53***(1.07)	1.89***(.91)	2.5**(.86)	2.04***(1.12)	2.06*(.97)	2.46*(1.11)	2.24(1.04)
4	1.98***(.88)	2.79***(1.05)	2.71***(1.08)	2.11***(.94)	2.61(.81)	2.3(1.18)	2.2***(1.01)	2.76***(1.04)	2.4(1.06)
5	2***(.82)	2.73***(.96)	2.69***(.97)	2.08***(.86)	2.48(.79)	2.34(1.07)	2.21*(.9)	2.67*(1.01)	2.39(.97)
6	2.26***(1.2)	2.88***(1.03)	2.94***(1.08)	2.22***(1.11)	2.85*(1.04)	2.43*(1.19)	2.38***(1.1)	2.93***(1.15)	2.56(1.14)
7	2.15***(.93)	2.67***(1.12)	2.67***(1.11)	2.17***(.95)	2.33(.85)	2.5(1.19)	2.33(1)	2.59(1.14)	2.44(1.06)
8	1.8(.87)	2.01(1.05)	1.97(1.06)	1.86(.87)	1.89(.9)	1.94(1.02)	1.86(.85)	2(1.13)	1.93(.97)
Remote education, treatment, and diagnostics									
1	2.77(1.22)	2.78(1.2)	2.83(1.24)	2.72(1.17)	2.85(1.16)	2.73(1.24)	2.71(1.18)	2.87(1.24)	2.78(1.02)
2	1.92*(1)	2.33*(1.01)	2.36*(1.01)	1.91*(.99)	2.36*(.94)	2*(1.06)	1.9***(.92)	2.51***(1.07)	2.14(.91)
3	1.74*(.93)	1.97(.9)	2.01*(.92)	1.7*(.89)	2.06*(.92)	1.74*(.9)	1.76(.88)	2.02(.96)	1.87(.67)
5	1.36(.66)	1.53(.67)	1.53(.65)	1.38(.68)	1.5(.67)	1.43(.67)	1.38(.62)	1.57(.72)	1.47(1.23)
6	3.92(1.29)	3.77(1.17)	3.8(1.2)	3.88(1.27)	3.98(1.09)	3.74(1.31)	3.89(1.31)	3.76(1.1)	3.81(1.1)
7	2.33*(1.06)	2.77*(1.1)	2.69(1.1)	2.44(1.1)	2.87***(1.01)	2.36***(1.12)	2.4*(1.19)	2.81*(.91)	2.56(1.11)
8	2.74(1.24)	2.81(.99)	2.84(1.02)	2.7(1.19)	2.89(.97)	2.7(1.18)	2.71(1.21)	2.87(.92)	2.78(.95)

## References

- Alekhina, 2005 – Alekhina, S.V. (2015). Proekt po sozdaniyu kompleksnoj pomoshchi detyam s RAS v Rossii. [The project for development of comprehensive support for children with ASD in Russia]. *Autizm i narusheniya razvitiya*. 13(2): 3-7. DOI: <https://doi.org/10.17759/autdd.2015130201> [in Russian]
- Amenta et al., 2014 – Amenta, S., Ferrari, C., Balconi, M. (2014). Facial Expression Decoding in Autistic and Asperger Children. In Vinhood B. Patel, V. R. Preedy, C.R. Martin (Eds.), *Comprehensive Guide to Autism* (pp. 1885-1904). New York, NY: Springer New York. DOI: [https://doi.org/10.1007/978-1-4614-4788-7\\_114](https://doi.org/10.1007/978-1-4614-4788-7_114)
- American Psychiatric Association, 2013 – American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. Arlington. 2013. 970 p. DOI: <https://doi.org/10.1176/appi.books.9780890425596.744053>
- Aysina et al., 2020 – Aysina, R.M., Nesterova, A.A., Suslova, T.F., Khitryuk, V.V. (2020). Attityudy pedagogov v otnoshenii inkluzivnogo obrazovaniya detej s RAS: obzor otechestvennyh i zarubezhnyh issledovanij [Teachers' attitudes towards inclusive education of children with ASD: A review of Russian and foreign research]. *Obrazovanie i nauka*. 21(10): 189-210. DOI: <https://doi.org/10.17853/1994-5639-2019-10-189-210> [in Russian]
- Baster et al., 2015 – Baxter, A.J., Brugha, T.S., Erskine, H.E., Scheurer, R.W., Vos, T., Scott, J.G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*. 45(3): 601-613. DOI: <https://doi.org/10.1017/S003329171400172X>
- Bobkov, Gulyugina, 2012 – Bobkov, V.N., Gulyugina, A.A. (2012). Neravenstvo kachestva i urovnya zhizni naseleniya regionov [The inequality of the quality and standards of life of the population of the regions]. *Ekonomika regiona*. 2: 170–178. DOI: <https://doi.org/10.17059/2012-2-15>. [in Russian]
- Borodina, 2015 – Borodina, L.G. (2015). Smena diagnoza RAS posle 18-ti let: mnenie psihiatra [Changing the diagnosis of ASD after the age of 18: an opinion of a psychiatrist]. *Autizm i narusheniya razvitiya*. 3(48): 41-43. [in Russian]
- Borodina, Fisunova, 2017 – Borodina, L.G., Fisunova, A.S. (2017). Problema tolerantnosti k licam s psihicheskimi rasstrojstvami v sovremennom rossijskom megapolise [The problem of tolerance to persons with mental disorders in a modern Russian megapolis]. *Autizm i narusheniya razvitiya*. 15(1): 49-53. DOI: <https://doi.org/10.17759/autdd.2017150105> [in Russian]
- Buell et al., 1999 – Buell, M.J., Hallam, R., Gamel-McCormick, M., Scheer, S. (1999). A survey of general and special education teachers' perceptions and inservice needs concerning inclusion. *International Journal of Disability, Development and Education*. 46(2): 143-156. DOI: <https://doi.org/10.1080/103491299100597>
- Dumas et al., 1991 – Dumas, J.E., Wolf, L.C., Fisman, S.N., Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, down syndrome, behavior disorders, and normal development. *Exceptionality*. 2(2): 97-110. DOI: <https://doi.org/10.1080/09362839109524770>
- Elder et al., 2017 – Elder, J.H., Kreider, C.M., Brasher, S.N., Ansell, M. (2017). Clinical impact of early diagnosis of autism on the prognosis and parent-child relationships. *Psychology Research and Behavior Management*. 10: 283-292. DOI: <https://doi.org/10.2147/PRBM.S117499>
- Ganz, 2007 – Ganz, M.L. (2007). The Lifetime Distribution of the Incremental Societal Costs of Autism. *Archives of Pediatrics Adolescent Medicine*. 161(4): 343-349. DOI: <https://doi.org/10.1001/archpedi.161.4.343>
- Gotham et al., 2015 – Gotham, K., Marvin, A.R., Taylor, J.L., Warren, Z., Anderson, C.M., Law, P.A., Lipkin, P.H. (2015). Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data. *Autism*. 19(7): 794-804. DOI: <https://doi.org/10.1177/1362361315583818>
- Grigoriev et al., 2016 – Grigoriev, A., Ushakov, D., Valueva, E., Zirenko, M., Lynn, R. (2016). Differences in educational attainment, socio-economic variables and geographical location across 79 provinces of the Russian Federation. *Intelligence*. 58: 14-17. DOI: <https://doi.org/10.1016/j.intell.2016.05.008>
- Heiman, 2002 – Heiman, T. (2002). Parents of Children With Disabilities: Resilience, Coping, and Future Expectations. *Journal of Developmental and Physical Disabilities*. 14: 159-171. DOI: <https://doi.org/10.1023/A1015219514621>

- Hurt et al., 2013 – Hurt, A.A., Grist, C.L., Malesky, L.A., McCord, D.M. (2013). Personality Traits Associated with Occupational ‘Burnout’ in ABA Therapists. *Journal of Applied Research in Intellectual Disabilities*. 26(4): 299-308. DOI: <https://doi.org/10.1111/jar.12043>
- Ivanov et al., 2018 – Ivanov, M.V., Simashkova, N.V., Kozlovskaya, G.V., Makushkin, E.V. (2018). Epidemiologiya riska vozniknoveniya rasstrojstv autisticheskogo spektra u detej 16–24 mesyacev zhizni (dannye po Rossii za 2015–2016 gg.) [The epidemiologic study of the risk of autism spectrum disorders in children of 16-24 months in Russia, 2015–2016]. *Zhurnal Nevrologii i Psikiatrii Im. S.S. Korsakova*. 118(5): 12. DOI: <https://doi.org/10.17116/jnevro20181185212> [in Russian]
- Juarez et al., 2018 – Juárez, A.P., Weitlauf, A.S., Nicholson, A., Pasternak, A., Broderick, N., Hine, J., Warren, Z. (2018). Early Identification of ASD Through Telemedicine: Potential Value for Underserved Populations. *Journal of Autism and Developmental Disorders*. 48(8): 2601-2610. DOI: <https://doi.org/10.1007/s10803-018-3524-y>
- Knapp et al., 2009 – Knapp, M., Romeo, R., Beecham, J. (2009). Economic cost of autism in the UK. *Autism*. 13(3): 317-336. DOI: <https://doi.org/10.1177/1362361309104246>
- Lugo-Marin et al., 2019 – Lugo-Marín, J., Magán-Maganto, M., Rivero-Santana, A., Cuellar-Pompa, L., Alviani, M., Jenaro-Rio, C., Canal-Bedia, R. (2019). Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders*. 59: 22-33. DOI: <https://doi.org/10.1016/j.rasd.2018.12.004>
- Manelis et al., 2013 – Manelis, N.G., Medvedovskaya, T.A., Subbotina, E.V. (2013). Analysis of the problems in preschool educational institution with the creation of special educational conditions for children with ASD. Results of the survey. *Autizm i narusheniya razvitiya*. 41(2): 1-9.
- Matson, Shoemaker, 2009 – Matson, J.L., Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*. 30(6): 1107-1114. DOI: <https://doi.org/10.1016/j.ridd.2009.06.003>
- Mayorova et al., 2018 – Mayorova, A.N., Panasenko, S.V., Nikishin, A.F., Ivanov, G.G., Mayorova, E.A. (2018). Analyzing regional differences in the condition and development of trade in Russia. *Entrepreneurship and Sustainability Issues*. 6(2): 927-938. DOI: [https://doi.org/10.9770/jesi.2018.6.2\(30\)](https://doi.org/10.9770/jesi.2018.6.2(30))
- Mikhailova, Gutnabash, 2016 – Mikhailova, N., Gutshabash, M. (2016). Povsednevnyj stress i koping roditelej, vospityvayushchih detej s autizmom [Daily stress and coping in parents of children with autism]. *Problemy sovremennogo pedagogicheskogo obrazovaniya*. (53–10): 294-302.
- Montes, Cianca, 2014 – Montes, G., Cianca, M. (2014). Family Burden of Raising a Child with ASD. In Vinood B. Patel, V. R. Preedy, C. R. Martin (Eds.). *Comprehensive Guide to Autism* (pp. 167-184). New York, NY: Springer New York. DOI: [https://doi.org/10.1007/978-1-4614-4788-7\\_4](https://doi.org/10.1007/978-1-4614-4788-7_4)
- Murphy, Ruble, 2012 – Murphy, M.A., Ruble, L.A. (2012). A Comparative Study of Rurality and Urbanicity on Access to and Satisfaction with Services for Children with Autism Spectrum Disorders. *Rural Special Education Quarterly*. 31(3): 3-11. DOI: <https://doi.org/10.1177/875687051203100302>
- Nesterova et al., 2016 – Nesterova, A.A., Aysina, R.M., Suslova, T.F. (2016). A positive socialization model for children with autism spectrum disorders: comprehensive and interdisciplinary approaches. Part 2. Russian experience in social-psychological support of children with ASD and their families. *The Education and Science Journal*. (3): 140-155. DOI: <https://doi.org/10.17853/1994-5639-2016-3-140-155>
- Nesterova, Khitryuk, 2018 – Nesterova, A.A., Khitryuk, V.V. (2018). Stigmatizatsiya i predrassudki v otnoshenii roditeley, vospityvayushchikh rebenka s rasstroystvom autisticheskogo spektra [Stigmatization and prejudice towards parents of children with autistic spectrum disorders]. *Vestnik MGOU. Seriya: Psikhologicheskie nauki*. (4): 50-61. DOI: <https://doi.org/10.18384/2310-7235-2018-4-50-61> [in Russian]
- Pellicano et al., 2014 – Pellicano, E., Dinsmore, A., Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*. 18(7): 756-770. DOI: <https://doi.org/10.1177/1362361314529627>
- Piskunov et al., 2018 – Piskynov, M.V., Skorokhodov, I.V., Varlamov, A.A., Shpitsberg, I.L. (2018). Kachestvo meditsinskih uslug pri rasstroystvah autisticheskogo spektra v otsenkakh potrebiteley [Quality of medical services in children with autism spectrum disorder assessed by customers]. *Rossiyskiy psikiatricheskiy zhurnal*. (3): 10-15 [in Russian]
- Ramseook-Munhurrun et al., 2010 – Ramseook-Munhurrun, P., Lukea-Bhiwajee, S., Naidoo, P. (2010). Service Quality in the Public Service. *International Journal of Management and Marketing Research*. 3(1): 37-50.

Rundblad, Annaz, 2010 – *Rundblad, G., Annaz, D.* (2010). The atypical development of metaphor and metonymy comprehension in children with autism. *Autism*. 14(1): 29-46. DOI: <https://doi.org/10.1177/1362361309340667>

Ryan, Quinlan, 2018 – *Ryan, C., Quinlan, E.* (2018). Whoever shouts the loudest: Listening to parents of children with disabilities. *Journal of Applied Research in Intellectual Disabilities*. 31(April 2017): 203-214. DOI: <https://doi.org/10.1111/jar.12354>

Shkolnikov et al., 2019 – *Shkolnikov, V.M., Andreev, E.M., Tursun-zade, R., Leon, D.A.* (2019). Patterns in the relationship between life expectancy and gross domestic product in Russia in 2005–15: a cross-sectional analysis. *The Lancet Public Health*. 4(4): e181-e188. DOI: [https://doi.org/10.1016/S2468-2667\(19\)30036-2](https://doi.org/10.1016/S2468-2667(19)30036-2)

Shpitsberg, 2018 – *Shpitsberg, I.L.* (2018). Sistema nepreryvnogo soprovozhdeniya lyudei, imeyuchshikh osobennosti razvitiya [The continuous support system for people with developmental challenges]. *Kompleksnaya sistema mezhvedomstvennogo, mezhdisciplinarnogo dolgosrochnogo soprovozhdeniya cheloveka s mentalnymi osobennostyami: po materialam Mezhdunarodnoi konferentsii "Lyudi s sindromom Dauna i drugimi mentalnymi osobennostyami: pravo na buduchshee"* (pp. 7-30). Moscow: Downside Up. [Electronic resource]. URL: <https://downsideup.org/ru/catalog/doc/kompleksnaya-sistema-mezhvedomstvennogo-mezhdisciplinarnogo-dolgosrochnogo> [in Russian]

Shpitsberg et al., 2020 – *Shpitsberg, I.L., Skorokhodov, I.V., Varlamov, A.A.* (2020). Implementing a Nation-Wide Continuous Support System for People with ASD and Their Relatives in Russia: Current Problems and Perceived Barriers. *INSAR 2020 – Virtual Meeting* (p. 811). Seattle, USA: International Society for Autism Research.

Skinner, Slifkin, 2007 – *Skinner, A.C., Slifkin, R.T.* (2007). Rural/Urban Differences in Barriers to and Burden of Care for Children With Special Health Care Needs. *The Journal of Rural Health*. 23(2): 150-157. DOI: <https://doi.org/10.1111/j.1748-0361.2007.00082.x>

Sobol, 2018 – *Sobol, T.S.* (2018). Sovremenny uroven i kachestvo zhizni naseleniya v Rossii [Modern level and the living quality of the Russian population]. *Vestnik Moskovskogo universiteta imeni S. Yu. Vitte. Seriya Ekonomika i upravlenie*. 25(2): 7-14. DOI: <https://doi.org/10.21777/2587-554X-2018-2-7-14> [in Russian]

Sutherland, 2018 – *Sutherland, R., Trembath, D., Roberts, J.* (2018). Telehealth and autism: A systematic search and review of the literature. *International Journal of Speech-Language Pathology*. 20(3): 324-336. DOI: <https://doi.org/10.1080/17549507.2018.1465123>

Synergies Economic Consulting, 2013 – Synergies Economic Consulting. (2013). Cost-Benefit Analysis of Providing Early Intervention to Children with Autism. Synergies Economic Consulting Pty Ltd: Brisbane. 42 p.

Tantam, 1991 – *Tantam, D.* (1991). Asperger syndrome in adulthood. In U. Frith (Ed.), *Autism and Asperger Syndrome* (pp. 147-180). Cambridge University Press: Cambridge

The Government of the Chuvash Republic, 2020 – The Government of the Chuvash Republic (2020). O Konceptcii kompleksnogo soprovozhdeniya lyudej s rasstrojstvami autisticheskogo spektra i drugimi mentalnymi narusheniyami v Chuvashskoj Respublike na 2020–2022 gody i plane meropriyatij po ee realizacii [The Framework of integrative support of people with autism spectrum disorder and other mental disorders in the Chuvash Republic in years 2020–2022 and its implementation roadmap]. [in Russian]

The Government of Khanty-Mansi Autonomous Okrug-Yugra, 2017 – *The Government of Khanty-Mansi Autonomous Okrug-Yugra* (2017). O Konceptcii kompleksnogo soprovozhdeniya lyudej s rasstrojstvami autisticheskogo spektra i drugimi mentalnymi narusheniyami v Hanty-Mansijskom avtonomnom okruge – Yugre do 2020 goda [On the Framework of integrative support of people with autism spectrum disorder and other mental disorders in Khanty-Mansi Autonomous Okrug-Yugra till the year 2020]. [In Russian]

The Government of the Nizhny Novgorod Oblast, 2019 – The Government of the Nizhny Novgorod Oblast. Ob utverzhenii Konceptcii kompleksnogo soprovozhdeniya lyudej s rasstrojstvami autisticheskogo spektra i drugimi mentalnymi narusheniyami v Nizhegorodskoj oblasti [Enaction of the Framework of integrative support of people with autism spectrum disorder and other mental disorders in the Nizhny Novgorod Oblast]. 2019. [in Russian]

Uljaevic et al., 2017 – *Uljaevic, M., Baranek, G., Vivanti, G., Hedley, D., Hudry, K., Lane, A.* (2017). Heterogeneity of sensory features in autism spectrum disorder: Challenges and perspectives for future research. *Autism Research*. 10(5): 703-710. DOI: <https://doi.org/10.1002/aur.1747>