

# Disorders of Autistic Spectrum” In the Institutional and Discourse Space of the Russian Society: The Problem of Social Exclusion

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**Abstract:** Disorder of autistic spectrum has a high rate of spread in Russia and the world. Russian statistics is subject to deformities in relation to the disease. People diagnosed with an autism spectrum disorder and their families are socially excluded. It manifests itself in the institutional plane and in the discursive media space. In the institutional environment, positive changes occur to solve the problem: the work of public organizations and special - virtual and real - social media platforms are intensifying, the information space of messages and news about autism is increasing, the conservative state system is gradually transforming measures of social and educational policies in an inclusive manner. However, at the institutional level of the mass media and public opinion, a wary and often prejudiced attitude towards people and children with mental disorders continues to persist. Among all types of disabilities, mental disorders are the most discriminated. This prevents the implementation of measures of social inclusion by civil society institutions and the state. Intensive informational and educational work with the Russian population is required to overcome myths and stereotypes regarding children and adults with ASD.

**Keywords:** autism spectrum disorders, social inclusion, social exclusion, discourses, sociology of health and disease.

## I. INTRODUCTION

In social theory, exclusion is understood as a mechanism of restricting access to society's resources and discrimination of the rights of people with special needs, which objectively reduce the individual's capabilities. [Sen, 2000]

The processes of social exclusion are associated with tendencies of ignoring the difficulties of the existence of a group and the deprivation of fully or partially social, economic, political, and cultural (including educational) rights and opportunities. This process, on the one hand, can be considered by levels - macro (social policy, regulatory system), meso- (social groups, communities, organizations), and micro- (personal resources and capitals) [Eflova, 2015], as well as by the allocation of social space or a system of social institutions (family, education, state, media, etc.) and the discursive sphere, which has become more and more significant and pre-determining for basic social reality in the last decade [Newschaffer et al 2007; Boardman, 2011].

The spread of autism spectrum disorder is intensifying around the world in a way that is already defined as an

epidemic. This mental disorder of neural processes affects the field of social interaction and communication, determining the distinctive behaviors from those generally accepted in neurotypic individuals, and stipulating their special needs for social integration. In this regard, people with ASD and their close people become an object of social discrimination and exclusion. [Boardman, 2011].

## II. METHODS

The study used such a sociological method of collecting information as a qualitative (traditional) method for analyzing documents and secondary analysis of data of sociological opinion polls and the Medialogia information system.

## III. RESULTS AND DISCUSSION

Autism spectrum disorders are an acute problem in the modern world. According to WHO, 1 out of 160 children suffers from ASD. [The World Health Organization calls for a system of measures that will make the physical space and social environment more accessible and inclusive, points to a lack of access to services, support and the problem of stigma and discrimination against people with ASD.

In Russia, autism as an independent disorder began to be diagnosed only since 1999 in connection with the transition to statistical accounting according to the International Classification of Diseases of the tenth revision. [Furiaeva & Furiaev 2017; Hansen, et al, 2018] For a long time, people with autism were diagnosed stigmatically with schizophrenia or mental retardation. Since the early 2000s, the paradoxical situation with the diagnosis of ASD has persisted to the present: most people who were diagnosed with ASD in childhood were diagnosed with schizophrenia at the age of 18. In this regard, in the clinical recommendations of the leading Russian psychiatrists in 2015 (Autism spectrum disorders: diagnosis, treatment, observation Clinical recommendations (treatment protocol)), and then in the explanatory letter of the Ministry of Health of the Russian Federation published in October 2017, there were no age restrictions for autism spectrum disorders (“On establishing a diagnosis of autism after reaching the age of 18 for people with autism spectrum disorder”).

It is clear that under such conditions, statistics on the number of people with ASD in Russia are far from the true indicators.

At the moment, it is collected only by the regional health departments and, as of 2018, it records the incidence of 0.1% of the child population.

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The forecast value of the Ministry of Health of the Russian Federation is 1%. This means that about 90% of children with ASD in Russia are not taken into account by official statistics. [Ministry of Health] Ministry of Health: in 2018, more than 31 thousand children were diagnosed with autism <https://tass.ru/obschestvo/6287169>

There are several reasons and factors that determine this situation. Among them are an incorrect diagnosis (in particular, childhood schizophrenia), comorbidity of ASD (mental retardation is the main diagnosis in Russia), lack of medical and parental alertness for the disease (low awareness), and a number of others.

“In our country, severely autistic person is a person who does not exist. However, since we in our social development have already overcome the level at which sick children are sunk in a basin, then such a person does exist physically. And since he is physically present, then he would have to be put and attached to anything. It can be put on a back burner where schizophrenics live in society. Poorly live, in an Auschwitz manner, but still, there is such a burner. If they don't fit in there, then they can be inserted into the nest with the strange name “mentally retarded”, after the Wechsler test, which does not distinguish any autistic person by intelligence. The autistic person can be ascribed deviation, burdened with the guilt of parents for bad education and for the fact that from the wrong end his mother gave him breasts in infancy. Ascribed anyhow, if only, God forbid, he would not show his extravagance and too special needs” (Men E. When school is a miracle // Snob. URL: <https://snob.ru/profile/28374/blog/76865>)

One of the key reasons, in our opinion, is the deep stigmatization and exclusion of people with mental disorders and their families, the reluctance to acknowledge the violation and especially the public disclosure of the diagnosis. In their comments to the posts of the Vychod Foundation regarding the discrepancy between the predicted and the actual statistics, Instagram users argue that the diagnosis with “F is a stigma in Russia”, “if you don't plan disability, then nobody goes to psychiatrists for an official diagnosis ...”, G-coded neurological conditions are more preferable, “Our children should queue up to neurologists” (<https://www.instagram.com/p/BnYqjhBnkKC/?igshid=1r5m0v4wkb9xi>)

Being, as a rule, in strong psychological stress and emotional stress associated with the manifestation of the disorder, many parents of children with ASD try to avoid aggravating an already difficult life situation and prefer to hide the diagnoses of children with ASD in various social environments. At the same time, the virtual space of social media allows them to more freely manifest the identity of the parents of a special child, look for ways to solve problems and take an open position when discussing issues, including those related to discrimination, violation of rights, and stigmatization of their children. It can be stated that in recent years, parental communities in various regions of Russia have been intensively united, institutionalized, and formalized as a powerful information subject in the discursive media space for upholding the rights of children with ASD. An example is the Autism-Regions Association established in 2017.

In recent years, the state has been developing social policy measures to help people and, primarily, children with ASD. In 2016, on the basis of the Moscow State Psychological and Pedagogical University, a Federal Resource Center was established to develop a comprehensive care system for

children with ASD in the Russian Federation; in 2019, grant support was provided to public organizations in more than 15 regions of the Russian Federation to develop a system of inclusive education, etc.

However, while civil society institutions are intensively working on the task of social integration of people with mental disabilities, the state takes measures in the framework of lawmaking, social and educational policies, then a consensus with the social media institute and public opinion about the goals and objectives, forms and integration tools has not been yet developed. It is obvious that without their support, social inclusion of people with ASD is not possible. Social integration involves first of all the inclusion of the individual in various social groups and relations through the organization of joint activities (gaming, educational, labor, leisure and a number of others).

What is the public opinion in Russia regarding people with mental disabilities? A survey of the All-Russian Center for the Study of Public Opinion, conducted in April 2019, showed that the majority of respondents chose “sympathy” (38%), “pity” (34%) when answering the question about attitude to people with mental disorders. Among those who choose these options, the proportion of the elderly is higher. At the same time, 26% said they were afraid of these people, 18% did not trust. 9% replied that society treats them with contempt. (<https://www.asi.org.ru/news/2019/06/04/vtsiom-opros/>).

A sociological study conducted in 2016 by the Higher School of Economics (HSE) showed that, of all categories of children with disabilities, Russians are less willing to co-educate neurotypic children and children with mental disorders and mental illnesses. Most of them advocate for study “of children with special needs (for example, autism)” in specialized schools (65%). 22% favors teaching children in a special (resource) class of a regular school, 7% advocates learning in ordinary classes. 6% of respondents found it difficult to answer. The authors of the study indicate that the distribution of answers to the question is not related to the socio-demographic characteristics of the respondents (gender, age, education, financial status). For comparison, we shall give as an example the distribution of answers of the surveyed parents of children with disabilities in relation to this category of health problems: 33% speak for special schools, 45% speak for special classes, 13% speak for ordinary classes in a regular school, and 9% find it difficult to answer. At the same time, the authors note that, in general, public opinion on assistance to children with disabilities undergoes significant positive transformations associated with an increase in the activity of citizens in providing assistance and intentions to provide it [Maich & Belcher 2014; Mendoza Velazco & Rivero Padrón, 2019; Loseke, 2003].

Thus, according to the results of the survey, 29% of Russians support the idea of inclusive education, of which the vast majority are in resource classes, which are currently open in small numbers only in large Russian cities. Periodically, information about bullying, violence or exclusion of children with ASD from preschool and school educational institutions appears in the media and on social media sites. In addition, until recently, a child with severe or multiple developmental disabilities during the passage of the



psychological-medical-pedagogical commission could be denied school on the wording "home-based education", "uneducable", "not subject to education". According to the letter of the Ministry of Education of the Russian Federation dated June 26, 2019, this state of affairs is unacceptable and for these students. Special individual educational programs should be developed (<https://pmpkrf.ru>). In general, this situation looks depressing compared to societies which provide about a third of people with ASD with not only school education, but continue their education after, and about 18% of people with ASD have a decent salary [Grigorenko, 2018; Alwahdani, 2019; Maich & Belcher 2014].

As for the media, there are conflicting trends, as well as in the whole space of media culture. [Autism spectrum disorder, Pros and cons of character portrayals of autism on TV and film]. On the one hand, the amount of informational materials on the problem of autism is growing. If in 2000, according to the Medialogia information system, which includes 37 thousand of the most significant media sources, there were no publications mentioning the categories of "autism" and "autism spectrum disorder", then, starting in 2001, the number of media materials on this problem grew and by the end of 2018 amounted to more than 40 thousand. Of all the publications recorded by the system (156 thousand), about 39% are reprints of published texts. Most often, reports on ASD were published in the sections on society and the social sphere (about 60.3 thousand), on health and medicine (about 36.5 thousand), on science and education (18 thousand), as well as in topics about power (13.5 thousand) and culture (11 thousand). The format of the messages was mostly consistent with the news (100 thousand), about 35 thousand publications were of analytical nature. The most mentioned words in the context in addition to "autism" and "ASD" were "child", "center", "parent", "school", and "rehabilitation". The term "ASD" was distributed in media as follows: about 13 thousand - newspapers, about 1 thousand - magazines, about 13 thousand - news agencies, 11.7 thousand - Internet, 3.2 thousand - television, 0.7 thousand - radio, about 8 thousand - blogs. We also point out that the majority of Russians are satisfied with the coverage of problems of children with disabilities - 45.1% in 2016 (versus 28% in 2010) [Zaitsev, 2014; Villalobos, 2018]. A positive aspect in the work of the media is not only the actualization of the problem and the intensification of information flows, but also the provision of platforms for the effective integration and activities of parent communities and public organizations [VTsIOM Kulagina, 2019].

On the other hand, one can detect the destructive contribution of the mass media, which impedes the development of the processes of integration of people with ASD in Russian society. It is connected with the principles of the media and the criteria for selecting news (sensationalism, hypertrophy, etc.), which should be more or less relevant to individual beliefs due to the culture of this society. In Russian culture, people with mental disorders in Russian society are surrounded with myths and stereotypes: they are considered to be aggressive, dangerous, and have intellectual disabilities. It is clear that this is a very heterogeneous group of people with very different diagnoses, behavior and degree of intelligence. Even people with the same diagnosis of ASD can dramatically differ from each other [Selomo, & Govender, 2016].

However, media discourse often reflects attitudes in society and contributes to the reproduction and reinforcement of stereotypes. An example is the situation described by a member of the Human Rights Council under the President of the Russian Federation, E.A. Topoleva-Soldunova, when, after a meeting on the reform of psycho-neurological boarding schools and distributed custody of persons with mental disabilities under the Government of the Russian Federation, the journalistic community responded with "a plenty of publications with the headlines "Nuts will be released tomorrow! What shall we do?". They in these headings reflect the opinions and concerns of most of the society" (A HRC's special meeting on human rights issues in the PNI. URL: <http://president-sovet.ru/presscenter/news/read/5603/>).

According to a pithy expression of the Russian employer, who created jobs for people with mental disabilities, "no one treats those with mental disabilities as people. They are like a dog for society, who can be kept better or worse. But this is a huge number of people, and they are all very different". (Rubnikovich M. Nobody's fool: it is time for society to reconsider its attitude towards people with mental disorders // Izvestia. 2019. February 21. URL: <https://iz.ru/846268/mariia-rubnikovich/durakov-net-obshch-estvu-pora-peresmotret-svoe-otnoshenie-k-liudiam-s-psikhicheskimi-rasstroistvami>)

#### IV. SUMMARY

A neurotypic individual has an inherent desire to interact socially. For a person with ASD, it is the key deficit, which micro and macro-institutional structures of society must eliminate in every possible way. With early and intensive intervention, this deficit can be largely compensated, and behavior can be corrected.

Effective integration of people with ASD into Russian society requires effective interaction between various institutions of the Russian society — various institutions of civil society and the state — is necessary. At the moment, in Russian society there is an "exclusive" state of public opinion, unfriendly informational accents of the media, inertia and "dispersal" of actions of state institutions. All this and a number of other factors hinder the intensification of the processes of social inclusion of children and people with ASD in Russian society.

#### V. CONCLUSION

Intensive and systematic informational and educational work with the public and media representatives is necessary to overcome myths and stereotypes regarding people with ASD. Obviously, social inclusion of people with ASD is impossible without the support of media institutions and public opinion.

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