

CURING DISABILITY IN CONTEMPORARY RUSSIA: REHABILITATION PRACTICES AND THE PLACEBO EFFECT

ANNA KLEPIKOVA

DEPARTMENT OF ANTHROPOLOGY, EUROPEAN UNIVERSITY AT ST.PETERSBURG

The paper is based on the materials of an ethnographic research project involving interviews with parents of children with developmental disabilities, primarily intellectual disabilities, multiple disabilities, and autism. Though in contemporary humanistic pedagogy and psychology developmental disabilities are viewed in terms of difference and diversity, Russian public and professional discourse on disability is dominated by a medicalised approach and the majority of parents adhere to this view. This article analyses the patterns of rehabilitation and treatment of children with disabilities in the family context. It views the effectiveness of various popular therapies offered to children with disabilities through the lenses of the placebo effect theory. It shows that the assessment of both biomedical and alternative treatment outcomes by parents of children with disabilities are subject to the placebo effect, and this effect is maximized by various symbolic elements of treatment, such as price, prestige, or popularity of a certain drug, method or institution. The placebo effect, together with other factors, accounts for the commercialization of the disability services sphere.

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Artykuł powstał na podstawie materiałów zgromadzonych w trakcie realizacji projektu badawczego, w ramach którego prowadzono wywiady z rodzicami dzieci z niepełnosprawnościami rozwojowymi, szczególnie intelektualnymi, wielorakimi oraz autyzmem. Mimo że we współczesnej pedagogice i psychologii humanistycznej niepełnosprawności rozwojowe postrzegane są w terminach różnic i różnorodności, rosyjski dyskurs publiczny i profesjonalny o niepełnosprawności jest zdominowany przez zmedykalizowane podejście, podzielane przez większość rodziców. Artykuł analizuje wzorce rehabilitacji i leczenia dzieci z niepełnosprawnościami w kontekście rodzinnym. Rozpatruje skuteczność różnych popularnych terapii dzieci z niepełnosprawnościami poprzez pryzmat teorii efektu placebo. Pokazuje, że ocena rezultatów leczenia, tak biomedycznego, jak i alternatywnego, dokonywana przez rodziców dzieci z niepełnosprawnościami, podporządkowana jest efektowi placebo, a efekt ten potęgują różne symboliczne elementy terapii, takie jak cena, prestiż bądź popularność danego leku, metody czy instytucji. Efekt placebo, wraz z innymi czynnikami, przyczynia się do komercjalizacji sfery pomocy osobom niepełnosprawnym.

Key words: disability, developmental disabilities, autism, medicalisation, biomedicine, alternative medicine, placebo effect

INTRODUCTION

This paper analyses the practices of rehabilitation targeted at children with intellectual disabilities, multiple disabilities and autism in present-day urban Russia commonly used by their parents in order to treat them. It aims at viewing the effectiveness of various therapies, rehabilitation methods and curative procedures, as perceived by the parents, through the lenses of the placebo effect theory¹.

The introductory part the article will discuss the connections of the placebo effect theory to anthropology. Afterwards it will describe the current approaches to and discourses on disabilities in Russia, highlighting medicalisation trends, and then, based on the ethnographic material, analyse the popular therapeutic strategies and methods applied to children with developmental disabilities. It will discuss the role of the level of trust for certain institutions in parents' choice of therapies and the commercialization of the disability rehabilitation sphere. This article lies within the framework of medical anthropology, and does not touch upon pedagogical methods of rehabilitation, focusing on the use of official biomedicine and non-biomedical or alternative medicine methods. It also leaves aside the topic of physical rehabilitation.

In the narrow medical sense, the placebo effect is understood as the non-specific effects of biomedical therapies, usually treated as something to be controlled and minimized in clinical research (Thompson *et al.* 2009). In the 19th and the beginning of the 20th century the word “placebo” itself was used as a pejorative term referring to an inert and inactive drug or substance. The medical interest towards the placebo effect started to grow in the 1920–1930s accompanied by the development of pharmacology. It was then that it became clear that the results of clinical trials depended on the participants' awareness of whether the patients were receiving an active drug or a placebo, and the first double-blind experiments were then conducted (Shapiro and Shapiro 1997b, 28–174).

The far-reaching consequences of placebos were first demonstrated by Henry Beecher in his well-known paper “The Powerful Placebo” (Beecher 1955). He showed that placebos could produce powerful therapeutic effects, and they are especially high in the treatment of pain (see also Morris 1997). They can also bring about side effects analogous to the supposed side effects of an active drug. Papers cited by Beecher, as well as later research, have shown that numerous medical conditions, among them nausea, cough, “common cold”, headache, blood pressure, asthma, gastritis, ulcers, nervous and psychiatric disorders, and others, are subject to therapeutic placebo effect.

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Beecher, as well as other researchers (for example, Lasagna *et al.* 1954), then suggested that the psychological constitution of the patient played the key role in the manifestation of placebo effect. However, later it became clear that such psychological factors were not as relevant.

Further research demonstrated that the very context of treatment and its social characteristics contributed to the effect. Patients' sex, age, diagnosis, clinical records, or psychological constitution were not as important here as the levels of belief they exercised towards the treatment, which in turn depended on the doctor's communicative style, enthusiasm, and persuasiveness. The doctor-patient relationship and interaction, on the whole, influence the results of therapy tremendously. One of the placebo effect theories suggests that the effect is due to attributing natural positive changes, or changes that are due to any other factors, to certain medication or medical procedures (Shapiro 1969; Frank and Frank 1973; Gibbons and Horhmath 1981; Ross and Olson 1981).

Thus, through an anthropological perspective the placebo effect can be perceived as a broader phenomenon than the therapeutic effect of saline solution, sugar pills, or sham surgery. It involves the effect produced by any therapeutic interactions and the symbolic elements of treatment. As Daniel Moerman puts it, "participating in any healing process, regardless of its content, can lead to healing" (Moerman 2000, 52). The effectiveness of therapeutic methods used within religious healing and rituals, ethnomedicine and other medical systems alternative to biomedicine are believed to be mostly built on the placebo effect. As Arthur and Elaine Shapiro claim, the history of medicine, prior to modern evidence-based biomedicine, involving the Hippocratic-Galenic theory or animal magnetism with its methods of theriac, blood-letting and dehydration, or fat of puppy dogs, is largely the history of placebo effect (Shapiro and Shapiro 1997a, 2). However, the results of biomedical treatment can also be highly related to the placebo effect.

The words and actions of a shaman or healer are infused with symbols and meaning. As Claude Levi-Strauss has shown in his classic essays "The Effectiveness of Symbols" and "The Sorcerer and His Magic" (Levi-Strauss 1963), the effect of a shaman's ritual is to a large extent rooted in its performative elements, including the performative linguistic elements of the text he pronounces. Sham surgery or laying on of hands show effective results due to the performativity, but the same happens in the modern biomedical clinic. The white coat, the organization of a medical room or a hospital, the order of actions and interaction in the medical room are interpreted as strong symbolic elements in the framework of the modern urban culture. The doctor's prognostic speech acts and her verbal instructions to a large extent determine the patient's expectations and behaviour, and thus the results of the treatment, because the results are largely mediated by a patient's beliefs and expectations. For a patient who does not belong to modern urban culture and usually goes to a healer when she is ill the

symbolism of the biomedical clinic might not be as effective (see Hahn and Kleinman 1983; Thompson *et al.* 2009).

Apart from the doctor's role, her status, reputation and authority, various other symbolic elements might be important in the therapeutic process. Placebo trials have shown that the colour and size of a pill, the price of the medication or the popularity of the brand played the role in the outcome of treatment. Thus, during the experiments, the placebo branded as a famous aspirin brand resulted more effective than unbranded placebo aspirin (Moerman 2002, 47–48; Moerman and Jonas 2002)².

Any medical system is a symbolic system (see Kleinman 1973) that affects an individual's state of bodily or mental health not only through particular medications, but through the cultural meanings embedded in the healing encounters and processes. Medical practices, healing methods and the effectiveness of these methods are rooted in the cultural ideologies and are related to the cultural ideas on body, mind and self, social organization, religious and moral notions, rituals and mythology, and so on. Thus treatment is aimed not just at particular individual and her body, but rather at the social system an individual is incorporated into (see Scheper-Hughes and Lock 1983). Our own materials, presented further, are illustrative in regard to these theoretical points.

It is worth mentioning that anthropologists first described a phenomenon polar to placebo effect. It was called the nocebo effect and referred to the facts of death or illness induced by social suggestion (Maus 1926; Cannon 1942). This effect also includes the phenomenon of mass hysterias, pseudo-epidemics, and self-diagnosis based on folklore symptoms (see, for instance, Hahn 1997, Justman 2015 for an extensive exploration of the nocebo effect). The nocebo effect, as well as the placebo effect, are directly related to the subject of this paper, particularly to the epidemiology of autism.

Thus, autism as a diagnostic category was included into the International Classification of Diseases and came into medical practice in the 1980s. It can still be considered a “new” diagnosis, in comparison with, for example, “mental retardation”, which in medical classifications had been distinguished from “acquired” mental disorders like schizophrenia since the first half of the XIX century. Children who were previously mostly diagnosed with learning disabilities or “childhood schizophrenia” in many cases now tend to receive the diagnosis of autism. These diagnostic trends have partly determined the statistical growth in autism among the child population in recent years, which in turn triggers the mood of panic among the parents' community. According to the popular folk data that can be easily found in the social media, by 2025 every second child will be diagnosed with autism. The wide-spread reflections about the causes of autism often entail eschatological narratives on vaccination, toxic food,

2 More interdisciplinary research on placebo phenomenon can be found in Harrington 1997.

or environmental pollution. Together with another popular diagnoses like ADHD, autism thus falls into the category of modern epidemics, partly brought forward by the nocebo effect.

The situation in Russia partly reflects these trends. On the other hand, autism, according to psychiatrists, neurologists and other expert informants, is highly underdiagnosed in Russia, as community psychiatrists remain hugely unaware of its symptoms and manifestations. At the same time, it is gradually becoming a “fashionable”, “romantic” and more desired diagnosis in comparison to highly stigmatized “mental retardation”. According to some experts, autism in Russia is sometimes overdiagnosed because parents talk the psychiatrists into diagnosing their child with autism instead of mental retardation. Self-diagnosis, which in this case refers to when parents diagnose their child with autism, plays an important role here.

MEDICALISING DEVELOPMENTAL DISABILITIES

This paper is based on a year-long ethnographic research conducted in three major Russian cities, during which we collected approximately 100 interviews with parents of children with developmental disabilities (most of them were biological parents, but we included several adoptive families too), as well as 40 interviews with specialists and experts who work with children with disabilities or their parents (special education teachers, psychologists, psychiatrists, and others). Our study focused on families with children or adolescents and adults diagnosed with learning disabilities, Down syndrome, cerebral palsy and autism, mostly accompanied by intellectual disabilities, and severe multiple disabilities. We mostly reached the families through NGOs and rehabilitation centres that provided support for people with disabilities and their parents, which of course meant that the selection was rather specific: thus, we could not reach families who lead a more isolated life, minimizing their contact with public or private disability services.

Such diagnoses are chronic conditions that usually imply and lead to disability status. From the point of view of modern humanistic approaches to children and people with disabilities, such conditions cannot be cured or “corrected”, though various educational methods and environmental adjustments can improve a person’s functionality. The humanistic approach suggests that such disabilities should be perceived and treated in terms of differences, rather than deviations from the norm, and appreciation of diversity. It claims that disability is an essential, integral part of a person’s identity, that should be rather subject to social adaptation and inclusion, than to medical rehabilitation. In Russia such ideology is shared and promoted by a number of professionals who work with people with disabilities, including some psychiatrists and neurologists, disability activists and self-advocates. Contemporary activist discourse in Russia, in

line with the international trends, follows the diversity model approach to disability and tends to view developmental disabilities as permanent conditions that are related to a person's selfhood.

In parents' narratives, however, a child's disability is primarily constructed as illness, a diagnostic category that needs to be established and cured. With some exceptions, a parent's story is usually a story of struggle for appropriate or desirable diagnosis, dodging between different specialists and rehabilitation methods, and searching for "the magic pill" that will eliminate the disease once and for all. The fact that their child is not capable of fulfilling expected life scenarios and thus does not correspond to social norms is a source of extreme stress for parents and extended family. The situation is exacerbated by quite high levels of stigmatization experienced by children with disabilities and their families, absence of any systematic psychological or informational support for families raising children with disabilities in Russia, and a lack of possibilities for integration and inclusion for people with disabilities, especially in the spheres of education and employment. Thus, rehabilitating the child up to the point that they become "normal" is the idea that underlies the help-seeking strategies of many parents.

According to anthropological theory, knowledge and notions about the causes of disease or disability have a crucial impact on how the disease or disability is conceptualised, constructed and cured. It has something to do with the levels of stigmatization and exclusion a person and their family suffer, because the causal theories can be related to the ideas of blame, sin and moral punishment (Foster 1976; Kleinman 1980, 71–118; Kleinman 1988; Whyte 1995). Thus, the idea that a child could be "corrected back to the norm" is more characteristic of parents who have children with cerebral palsy or autism, than with Down syndrome or other diagnoses with a known and clearly established reason, which is a chromosome mutation in this case. Cerebral palsy is often viewed as a pathology that developed as a result of birth trauma or medical error, while the reasons for autism are still unclear, a single gene or mutation, responsible for it, has not been discovered, and the fact that it usually starts to clearly manifest itself when a child is around three years old provides fertile ground for various causal theories to proliferate. In both cases parents often presume that a child has experienced a period of normative development, at least prenatally, as with cerebral palsy, which gives rise to the idea that the child could be reset to "the norm" again.

A medicalised approach to disability is also characteristic of medical professionals, naturally, system of special education, various disability services and Russian society at large. Contemporary Russian society offers children with disabilities and their families a variety of medical and rehabilitation practices, proliferating the point of view that disability might be repaired and fixed, and further reconstructing it as a medical, rather than a social, problem. This paper will further discuss several institutions popular among parents that offer rehabilitation and therapies for children with developmental disabilities.

REHABILITATION PRACTICES AND INSTITUTIONS

When family learn that there is something wrong with the child, either they have some obvious impairments, or vague behavioural deviation from the conventional norm, they tread upon the rehabilitation road by visiting a variety of different specialists who could, as they hope, could clarify the nature of the impairments and determine the “correct” diagnosis. The long chains of specialists who propose or disprove diagnoses may include paediatricians, special education teachers, psychologists, speech therapists, massage therapists, and they never fail to include psychiatrists and neurologists.

Psychiatrists and neurologists usually tend to immediately prescribe children with intellectual and behavioural problems biomedical drugs, such as, on the one hand, antipsychotics, tranquilizers and antidepressants, and nootropics on the other. The first group of drugs are aimed at alleviation of symptoms, such as agitation, hyperactivity or “stimming”³, that are usually seen as socially disturbing, or aggression or self-aggression that, apart from being perceived as a violation of social norms, might be dangerous or harmful. The aim and effect of nootropic drugs is usually described as “boosting the neurons”, “nourishing the vessels”, “stimulate the brain cells”, and so on. Both groups of drugs are described by psychiatrists or neurologists as remedies to prompt speech, improve attention and concentration and “pull the child together”.

One of our experts is a private psychiatrist and a representative of humanistic psychiatry and distances himself from the current trends in mass psychiatry, that are partly determined by the Soviet legacy. He comments that using the abovementioned popular explanations of drug effects psychiatrists and neurologists are enacting,

“the quasi-medical, pseudo-scientific rhetoric. There are dozens of nootropic drugs, it’s an extensive drug class, and the only thing that they actually have in common is that they don’t work at all”.

Our expert claims that metaphors and “mythological notions” that are used by doctors to explicate how the drug works have a prognostic effect, and the drugs are in fact placebos.

The same expert, as well as other experts interviewed, including one high-level representative of public psychiatry, also object to “ubiquitous” prescription of antipsychotic drugs to small children. These drugs, as they claim, are meant to help adult people with acquired mental disorders like schizophrenia. They demonstrate numerous side-effects and can hinder a child’s intellectual development and have a detrimental impact on their personality. Their administration might be efficient or inevitable to a small percentage of children with disabilities who experience severe psychotic behaviour. However, community psychiatrists in Russia, according to our experts, demonstrate

3 Auto-communicative self-stimulation using movements and gestures that look “strange” and socially unacceptable, but is thought to be a means of self-comfort for a child with autism.

negligence towards these nuances, tend to over-medicalise children with developmental disabilities and remain hugely unaware of educational methods of rehabilitation.

Some parents, however, link positive changes in child's development with the intake of antipsychotics, stating something like "Risperidone⁴ has boosted speech at once". Many notice the effects linked to nootropics intake:

"He got injections [of nootropics]. The active ingredient was of **high purification degree**. The drugs were **from Italy or the USA**. [...] Professor prescribes himself! He's an active member of **the New-York Academy of Science**, a citizen of honour in **the Maryland state**. He's got **patents everywhere!** But this guy he works in Yoshkar-Ola⁵ [...] We were sceptical at first. But the child started to progress. He became more independent, more active. Like he didn't eat with a spoon himself, and now he does, actively! The self-care skills get rolling!" (Eugenia⁶, mother of a child with autism).

As the highlighted phrases illustrate, the effectiveness of an antipsychotic or nootropic drug is usually recognized when it is prescribed by a "famous", high-status or foreign doctor, or when the drug itself is foreign or exclusive (compare with branded aspirin mentioned in the introduction). Further progress in a child's development are seen as the results of such treatment.

More often, however, in case of antipsychotics, tranquilizers, anticonvulsants and the like the story of drug intake is told as a story of never-ending, interlacing side-effects, of chaotic administration of medication by the doctor, of restless experimentation with dosage regimen. The motivation behind the administration of this or that drug or dosage by the doctor remains vague for parents, prescriptions often seen as unreasonable. It often leads to a situation where parents completely refuse to give their child any drugs or improvise with dosages without consulting with any representatives of biomedical professionals, thus invoking the self-treatment practices. In case of self-administration or self-cancellation of drugs by parents the effect is viewed as immediate and maximized.

The parents' stories are usually built on the criticism of Russian psychiatry and neurology, and medical services at large. Thus, the administration of antipsychotic drugs is in many cases seen as useless and harmful, ruining a child's "normal" intellectual development or even the supernatural abilities they are claimed to have possessed.

As a rule, all parents of children with disabilities pass through a period of trust towards official psychiatry and biomedicine, and follow all the instructions and prescriptions. However, when their child fails to show expected improvements, when various undesired symptoms, interpreted as medical side-effects, start to manifest themselves, and when doctors fail to explain to parents what is going on, what logics stands behind the treatment, what

4 Popular atypical antipsychotic

5 A town with a population of about 200 000 people in the central part of Russia.

6 All names used are pseudonyms.

consequences to expect, a period of doubt and hesitation sets in. Parents start to distrust official biomedicine and psychiatry, as well as biomedical treatment, or refuse it completely and turn to alternative methods of rehabilitation.

Usually parents learn about the alternative methods of rehabilitation and healing by surfing through the internet, mostly at specialised parents' forums or Facebook pages. The discussions at such forums often look like a flow of advice that list a whole spectrum of doctors or institutions, including centres, offering non-biomedical therapies. However, it is not uncommon that some such methods are advised by representatives of official medicine, like paediatricians or neurologists, and it is relatively often that they are also recommended by special education teachers. Such popular methods include the Tomatis procedure, "bioacoustic correction" of the brain and dolphin therapy.

The Tomatis procedure is a type of sound or music therapy that has become popular across the world as a method for improving speech and language skills by stimulating the connection between the middle ear and the brain. Bioacoustic correction is a similar method, it can be called a cultural variation of Tomatis, developed and popular mostly in Russia, Ukraine, Belarus and other post-soviet countries. The description of this method states that the electroencephalogram activity of human brain can be transformed into sound, and thus during the procedure a patient is made to listen to "the music of her own brain", which leads to the "involuntary self-regulation" of the central nervous system⁷. As we see, the rhetoric, explaining how the procedure works is very close to the description of the nootropics' effect. It is presented and described by its proponents as a "scientific" method, while the "evidence-based" research claim such methods are unreliable. One of our experts, a representative of official public psychiatry, comments:

"What about Tomatis? It's very popular in our region. It's intoxicating the whole country! The problem is that we can't control private services. There are now laws that would allow us to enter these organizations with check-ups. The laws must be changed, the very therapeutic approaches must be changed. People suffer!"

Thus the official psychiatry tries not only to establish control over the "unreliable" methods and organizations, but to retain and bring back the patients it has lost as a result of low level of trust towards the institution. Centres offering such services, have recently started to offer special education classes, speech therapy, and massage to avoid criticism and attract more clients with more "verified" methods. Parents, however, tend not to claim they "suffered from" or felt disappointed after bioacoustic correction, Tomatis or similar procedures.

7 See for instance: <http://www.logopedprofi.ru/bak> (accessed 20.06.2019) in Russian, <https://impulss.eu/en/methods/bac> in English (accessed 20.06.2019).

Even if simultaneously with Tomatis and bioacoustic correction a child attends numerous other institutions and specialists, their progress would be attributed to the effect of these new and fashionable procedures, rather than to the efforts of special education teacher or to naturally occurring development. According to popular belief, one the best devices for procedures like these are located in St. Petersburg, the second largest and second most important city in Russia. Usually parents have to invest a lot of money and overcome a substantial distance to visit St. Petersburg, so that their child could attend a month-long course of therapy. The perceived effects of the procedures are maximized when one has to invest more money or effort to obtain the service, or when it is offered by a prestigious institution.

Animal-assisted therapies are said to boost a child's physical and intellectual development because they involve physical exercise and trigger positive emotions. The dolphin therapy, however, stands out in this category, because on top of these elements that it is claimed to have a healing effect due to the "natural ultrasound" the dolphins produce. This is a typical dialogue recorded during a focus-group with mothers of children with Down syndrome:

- [Vera:] We musn't take anything but dolphins now, doctors say!
 [Sofia:] Dolphins are no go, I hear, because this therapy...
 [Victoria:] It's the same bioacoustics!
 [Sofia:] I've read somewhere, that hippotherapy or dolphins don't have therapeutic effect...
 [Victoria:] Reading is one thing, but you should see your child citing the Boldly Buzzing Fly Poem⁸ just ten days after the ten days' course! It's not just swimming! Dolphins talk with each other through ultrasound, and this ultrasound heals all organs. Dolphins have biolocation glands, and they are the natural source of ultrasound, not electronic, nothing like that. It's natural stimulation of brain cells".

The "natural" source of ultrasound is of value to parents, and it is often, at least at the level of discourse, preferred to "artificially constructed machines", as another respondent says, like the bioacoustic correction machine. "Natural" automatically means "safe" and "harmless", which makes the procedure especially desired in the eyes of the parents. The best dolphin therapy centre, according to parents' opinion, is located in one of the Russian resorts at the Black Sea coast, and the dolphins there are said to be "former military dolphins", who emit "unique" ultrasound.

The price of a month-long course of dolphin therapy reaches 2000–4000 Euro for one child, which is at least ten times more than an average monthly wage in Russia. The costs of stay at the resort city are also high. However, though some parents doubt the effectiveness of the therapy, as we see in the quotation above, many of them try to save money so that their child could take the course at this Black Sea centre, and any progress, for example, the emergence of speech a month later, is attributed to dolphin therapy.

8 A famous Russian poem for children.

The majority of professionals, who support the evidence-based paradigm, deny the possibility that the dolphins' ultrasound can have an effect on speech development. Some, however, take on a more holistic and agnostic approach, saying that the emotions and sensations a child experiences during the therapy might serve as a developmental trigger, because, according to the words of one of our experts, a psychologist, "even if we're all for evidence-based methods, we can't be sure what finally worked, when a parents do this and that and that".

Another popular type of alternative therapy, that also exploits the rhetoric of natural-ity and toxicity, is based on various dietary theories. These alternative methods include, for instance, "chelation" and "biocorrection" methods that are meant to remove heavy metals like arsenic, mercury or lead from the organism, other detoxifying diets, gluten-free and casein-free diets, and naturopathy.

The idea behind these methods is that certain toxic substances have penetrated into a child's organism with contaminated food or vaccines, and poison their brain. The wide-spread notion underpinning this idea is that the functioning of the bowels directly influences the functioning of the brain, as one of our respondents, a mother of a boy with autism, formulated: "Bowels are the leading edge of the brain".

The normalisation of the digestive system and the elimination of poisonous substances are often seen as a prerequisite for restoring the brain cells, which in turn will lead to recovery. These notions spread partly due to the efforts of various centres and organisations of alternative medicine that sell detoxifying medication or offer expensive courses of treatment, sometimes online. For instance, the idea that autism was a disorder caused by external toxins and certain foods in combination with low immune response was once popularized by the "Defeat Autism Now" project launched by the Autism Research Institute in the USA. The project has been closed down, but there are still numerous web-sites, claiming that they adhere to this movement and advertising medication for chelation and detox. As one of such website states:

"The central nervous system is not an isolated system. Its activity is based on three other systems: immune system, digestion system and detox system. It is in the bowels that food, and all necessary vitamins and minerals are absorbed, it is in the bowels that the hormones regulating the central nervous system, are produced"⁹.

This kind of body image or body / psyche interaction model is also sometimes disseminated by the representatives of official biomedicine:

"Our gastroenterologist said that his bowels are in a very bad state. And the bowels are directly connected with the brain, so it would pay to take diet. [...] The bowels, the gut flora are underdeveloped, and the gluten absorption is upset. The ferments are insufficient, and gluten poisons the brain" (Natalia, mother of a child with autism).

9 <http://www.autmedic.com/> (accessed 20.06.2019).

Similar arguments can be easily found in numerous tabloid articles on the Internet, and parents eagerly adopt them and disseminate them to various forums and discussions in social network communities. Sometimes parents themselves are involved in the marketing of dietary, detoxifying or naturopathic medication. At their personal web-pages they usually advertise certain drugs through telling the story of their child's "miracle recovery". An outsider might not notice the traces of recovery, like in the case of one of our respondents, who advertises the bee product medication "Tentorium" through the story of treating her daughter¹⁰. Her adolescent daughter remains completely socially and physically maladapted, spending all of her time at home, in an outdated wheel-chair by her mother's side. For the parents themselves, however, the effects of taking the drugs are obvious. The marketing strategies usually use the rhetoric of eschatology narratives and conspiracy theories, manipulating people's fears of environmental pollution and ecological catastrophe or risks of protein over-eating.

Some commercial centres, or clinics as they call themselves, specialise in conducting tests on detecting casein (milk protein) and gluten (protein found in grains) intolerance, as due to the causal theories described above, gluten and casein intolerance is not just a sensitivity for certain foods, but a trigger for autism or other developmental disabilities:

"At first, we had taken the gluten and casein intolerance test here, in Russian, in In-vitro labs, and they didn't show anything bad, both were within the norm. And then we found a woman, from a Defeat Autism Now clinic, we chatted on Skype with her. She said we'd rather send Mike's pee to France, to the Phillip Augustus clinic, and it would show with a hundred percent accuracy if there was gluten or casein intolerance. We sent his pee, and the tests proved Mike had both gluten and casein intolerance" (Anastasia, mother of a child with autism).

The medical test offered by the alternative medicine representative and taken in the "Phillip Augustus clinic" in France, whether it exists or not, should look more convincing for parents, then a test in a biomedical lab in Russia, and the aim of it is to sell the service, or later on dietary goods, to parents. In a similar clinic Mike was diagnosed with "candida" disease, and to stop its growth he was prescribed a strict diet and certain medication. According to Anastasia, the doctors claimed that the autism symptoms, like stimming or stereotypical behaviours, would decline with the decline of "candida".

Anastasia set Mike on a casein-free and gluten-free diet, and she noticed improvements in both the functioning of her son's digestion and the normalisation of his behaviour. When Mike managed to steal some prohibited pastry from the kitchen, she found him stimming more and laughing nervously, due to gluten. Many parents see

10 See <http://www.dcp-recovery.ru>, in Russian (accessed 20.06.2019).

connection between the casein- and gluten-free diet or a certain ferment intake with positive behavioural changes and developmental progress as absolute.

Such therapy offered by numerous commercial alternative medicine organizations resonates with parents' hopes for finding the magic pill after investing time and effort into visiting various biomedical specialists. The way the alternative medicine specialists or web-sites elaborately explain how the therapy works, which is usually not the case with the representatives of biomedicine, is also attractive and looks trustworthy.

Anastasia, however, managed to keep Mike on a diet for a year only, though she found the therapy successful. She admitted that soon she felt tired of constantly baking gluten-free bread, and it was impossible to guarantee that Mike would not eat the same products as other family members. It is usually the case that family routines finally fail to be organised in such a way as to incorporate strict dietary schemes. Besides, many parents take their child off the diet because their negative emotional reactions to the restriction of habitual or delicious foods override the positive effect of the diet that parents notice.

In the case of Anastasia and some other parents, the fact that they turn to numerous and diverse specialists, including dubious online services, might be due not so much to their belief that therapy would work. It is rather a result of the desire to fulfil the role of good and responsible parents, who do everything possible to rehabilitate their child, and in this manner to try to make up for the blame they feel for their child's non-normative development.

It should be said that children with developmental disabilities, autism in particular, often have problems with digestion, which is sometimes due to the limited assortment of foods they choose to eat, and problems with digestion, like in any children, may cause mood changes. Children with developmental disabilities might have gluten and casein intolerance or any other food allergies, as often as other people might have them, and keeping casein-, gluten-, lactose-, and-so-on-free diets might be necessary for them. There are also certain diseases that are caused by metabolic problems, where special diet is the only therapy. For instance, in the case of phenylketonuria such problems might lead to central nervous system damage and cause intellectual disability. Our experts, the representatives of biomedical evidence-based science, deny the same scheme in case of autism and other popular developmental disabilities. Families with children with disabilities form a whole market for the manufacturers of dietary products supported by the mythology around certain foods.

Though these cases demonstrate that rehabilitation of a child with disabilities usually blends various approaches and methods belonging to different systems of knowledge, the divergence of the biomedical doctors' and parents' points of view and medical systems they adhere to, sometimes lead to conflicting interpretations of children's behaviour. Thus in our materials there is an illustrative case. Christina, mother of Nina, interprets her unruly behaviour as, in the first place, the side-effects of antipsychotic

drugs, prescribed by a public psychiatrist, and in the second place, a result of violations of gluten- and casein-free diet, that she administered to her daughter herself. The public psychiatrist, who is in charge of Nina's treatment, claims that her psychotic attacks are a direct result of a restrictive diet, imposed by her mother, when Nina became deprived of her favourite food. Christina is also experimenting with the dose regimen of antipsychotic drugs because she does not trust the public psychiatrist's prescriptions and she is critical of the public psychiatry at large. Such cases of self-prescription and self-medication, according to Sylvie Fainzang, are socially meaningful, rooted in certain cultural ideologies and can be interpreted as political acts (Fainzang 2013).

DISCUSSION AND CONCLUSION

In his blog, targeted, among others, at parents of children with disabilities, Russian child psychiatrist Elisey Osin (Osin 2012) reviews several research papers describing autism placebo trials related to secretin (for English see, for instance, Sandler *et al.* 1999; Sandler, Bodfish 2000; Esch, Carr 2004). At the end of the 1990s there was a big buzz around the new medication that helps to cure autism. Secretin, a hormone that regulates secretion in the digestive system, was noticed to instantly improve a child's behaviour and boost their progress. Clinical trials were organized.

The medical personnel, scientists, and parents were all agitated and nervous, families were sharing their expectations and hopes, and everyone had the feeling that something very extraordinary was going on because the long-hoped treatment for autism was finally about to be discovered. The atmosphere of the experiment was solemn, the drug was slowly injected into children veins, one after another, the liquid with the new magical drug was flowing through the tubes, and for the parents it was more than just a liquid, but a promise that their child would be cured. Consequently, parents were asked several times to assess the children's behaviour and progress, and thirty percent of the families who participated in the experiment noticed positive physical and psychological changes, as well as improvement in mood and communication skills. However, all those changes could not be explained by the effect of secretin, because in fact children were injected with saline solution. The results the parents recorded were due to placebo effect. Their aspirations and belief in the new miracle drug, the expectation of physicians, the atmosphere of the experiment and the buzz around secretin determined the results. Parents started to notice naturally occurring behaviour and progress, and perhaps they began to pay more attention to children, and the children were emotionally responsive to their positive stance. This is also an example of the work of the symbolism of the modern biomedical clinic, which is similar to the effectiveness of shaman's symbols in the famous Levi-Strauss essay.

The results of the therapies described in this paper are in many cases also due to the work of the placebo effect, and the nocebo effect, when parents notice negative changes in child's behaviour, like in examples of breaking the diet. The example of parents and children with disabilities undergoing therapy illustrate that placebo is in the first place a social, and socially distributed, rather than a psychological effect. In a similar way the ritual healing of the cattle is effective because its target is the owner, rather than the animal itself.

The placebo effect is maximised when the therapy is expensive, fashionable, or offered by a prestigious specialist or organisation, especially foreign, or residing far away. The more money or effort the parents invest, the more obstacles they overcome, the more effect they see. The performative elements of the therapy and detailed explanations of how it works might also be relevant. Like with secretin, parents tend to attribute the natural progress in their child's development and positive changes that might have been triggered by pedagogical intervention or other factors, to the work of the therapies, specialists or institutions they trust most, and the trust is to a large extent based on price, status, exclusiveness and popularity.

The existence of the placebo effect is a condition for the existence and proliferation of numerous institutions around disabilities, and popular psychiatric and neurological diagnoses in children, autism among them, seem to create a whole industry of services, resulting in the disability rehabilitation sphere becoming highly commercialized. In the context of the lives of families raising children with disabilities in present-day Russia disability becomes a means of making commercial profit, rather than an object of care and support, as presented in the public social policy and prevailing paternalistic discourse.

The materials presented in this paper also show that in everyday practice the boundaries between biomedicine and alternative medicine are blurred. Thus, a paediatrician might advise a parent that her child should take up the bioacoustic correction procedure, while the typical neurologist would prescribe a nootropic drug to a child with autism or Down syndrome, though there is not enough evidence that it is effective in these cases, and would use the same patterns and metaphors to explain how the drug works, as web-sites selling the bioacoustic correction service. This is not to say that the work of biomedicine and its symbolism are equally bound to the placebo effect.

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Author's address

Anna Klepikova PhD
Department of Anthropology
European University at St. Petersburg
191187, 1 Shpalernaya St., St. Petersburg, RUSSIA
e-mail: aklepikova@eu.spb.ru
ORCID 0000-0003-2703-5417

