



## “They fear us because we are Other”: attitudes towards disabled people in today’s Russia

“Nos temen porque somos Otro”: actitudes hacia las personas con discapacidad en la Rusia moderna

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**ABSTRACT** Although the number of disabled people in post-Soviet Russia exceeds 13 million, research regarding many processes occurring within this large segment of the society remains scant. The objective of this article was to examine the different notions and stereotypes dealing with impairments. Using the qualitative approach of oral history, in-depth interviews with 11 men and 16 women with disabilities were carried out in three regions of Russia, as were interviews with six experts in Moscow and Nizhny Novgorod. In addition, accounts of disability experience published in online journals were examined. The analysis of these sources shows that the perception of disabled people and disability in general is ambivalent and impacts the perception of disability and self-identification of disabled people who are also a part of Russian society.

**KEY WORDS** People with Disabilities; Social Perception; Qualitative Research; Russia.

**RESUMEN** El número de personas con discapacidad en la Rusia postsoviética supera los 13 millones, pero hasta el momento se han realizado muy pocas investigaciones sobre los procesos que se desarrollan dentro de este gran sector de la sociedad. El objetivo de este artículo es abordar las diferentes nociones y estereotipos relacionados con la discapacidad. Desde el abordaje metodológico de la historia oral se realizaron entrevistas en profundidad a 11 hombres y 16 mujeres con discapacidad en tres regiones de Rusia, además de seis entrevistas a expertos en Moscú y Nizhny Novgorod. También fueron incorporados relatos sobre la experiencia de discapacidad publicados en Internet. El análisis de estas fuentes muestra que la percepción de las personas con discapacidad y de la discapacidad en general es ambivalente e impacta en la percepción de la discapacidad y la autoidentificación que tienen las propias personas discapacitadas que forman parte de la sociedad rusa.

**PALABRAS CLAVES** Personas con Discapacidad; Percepción Social; Investigación Cualitativa; Rusia.

## INTRODUCTION

The study of the problems of “disabled people” and of “disability” as a social phenomenon spread widely in 1960s, especially after the classic works of Goffman and Allport,<sup>(1,2)</sup> as did social movements for the support of different minorities, including people with disabilities. Over the last four decades, Disability Studies has become an interdisciplinary academic field including social sciences, humanities, arts, and medicine, among others.

In the former Union of the Soviet Socialist Republics (USSR), studies of disability were conducted within the framework of the medical model, which considers disability as a medical phenomenon, as a disease or defect that should be handled via medical efforts of social care. In this way, a strong school of Defect Studies (now correctional pedagogy) for teaching disabled children was created. For example, teaching and rehabilitation of blind children (*typhology*), teaching deaf children and adolescents (*surdology*), and rehabilitation of blind and deaf children (*typhlosurdology*) emerged as special trends in disability studies and many interesting research studies have been conducted in these fields. Nonetheless in post-Soviet Russia Disability Studies are still incipient, although some interesting works dealing with social policy, gender aspects of disability and other topics have been published.<sup>(3,4,5)</sup>

As an interdisciplinary field, Disability Studies include approaches and methods which have been applied in other social sciences and humanities, including social and cultural anthropology, sociology, psychology, history, folkloristics, ethnography, and literary studies. However, in contemporary Russia these disciplines rarely – if at all – touch upon disability as a cultural phenomenon, or as a set of problems of people with different impairments, handicaps or defects that involve notions as varied as: illness/health; abled/disabled body; empathy/aggression; stereotypes and labels associated with different kinds of disability (blindness,

mental diseases); and the representation and self-representation of people with disabilities in folk culture, literature, mass-media, oral narratives, and so on.

### Some statistics and definitions

According to the data of the World Health Organization (WHO), people with disabilities make up about one-tenth of the world population, that is, about 650 million people.<sup>(6)</sup> Moreover, the WHO states that in 2011 about 1-1.5 billion people had some type of disability globally.<sup>(7)</sup> These statistics depend upon the health care system, the criteria for recording different kinds of impairments, and the political situation (wars, conflicts, famine, and so on) in each region. Moreover, there are different approaches towards the definition of disability, impairment or defects. In addition, the high level medicine has reached in Western countries also results in impairments, as people (including babies) who several decades ago would have died as a result of disease or trauma now survive and are often disabled.

According to the official Russian statistics, there are about 12.9 million disabled people registered as having group 1 and group 2 disabilities<sup>(8)</sup>; since the Soviet period, the groups of disability in Russia have been defined according to the degree of possibility of working and not according to the disease or defect. There are therefore three categories of disability in general: *Group 1* (people who cannot work or can work in very limited spheres, such as blind people who can sometimes work as masseurs/masseuses and musicians); *Group 2* (people who can only work in special conditions, such as at special factories for disabled people, or who cannot work at all; those in this group receive a lower pension and allowance than those in Group 1); and *Group 3* (people who can work; in many cases this group is defined as temporary, for example after a trauma, a disabled person can in a year or several years restore his or her health and become “able-bodied”). In this way, Russian statistics do not take into

account people with Group 3 disability, the relatively "minor" disabilities. In addition, people who are not registered as disabled by special medical and social expertise are not included in statistical data – some people do not want the status of disabled people as they do not want to lose a good job, others do not want to spend the time the procedure takes only to receive a very low pension. Some experts believe that there are 14 or even 15 million disabled people in Russia, despite the social policy of increasing restrictions which makes it difficult to receive disability status.

Not only are the statistics vague, but there is also no general definition of disability used in international organizations or in academic research. According to the United Nations Convention on the Rights of Persons with Disabilities, disability is a consequence of physiological or functional defects resulting from disease, accidents, and the like.<sup>(9)</sup> The WHO differentiates "impairment" (the lack of an apparatus, physiological or mental dysfunction or abnormality), "handicap" (difficulties in normal functions or activities resulting from impairments) and "disability" (limitations in human activities resulting from innate or acquired defects).<sup>(10)</sup> As a result of this lack of uniformity in the definition, various organizations at both the national and international level present different statistics.

### Some approaches and models

Since ancient times there have been many different notions, labels, stereotypes and even fears dealing with various impairments and disabled people in various cultures; these include the notion of the threat and even contagiousness of blindness<sup>(11)</sup> and the perception of people with mental disability as dangerous and socially unacceptable.<sup>(12)</sup> In the so-called "primitive cultures" (peoples who lived or still live in conditions of appropriate economics), some physiological and especially mental defects were often considered as resulting from some negative features of the person. Over the last fifty years, the problem of the perception of disabilities

and the notions of disabled people in different cultures and epochs has been widely explored.<sup>(11,13,14,15,16,17)</sup>

Terminology and definitions of disability depend upon the approaches taken towards this phenomenon. In the 19<sup>th</sup> and first half of 20<sup>th</sup> centuries, the medical model of disability was the most widespread. According to this approach, disability is a medical problem (diseases or functional disorder, results of trauma, and so on) that should be handled by medical means. Disability is always a tragedy, a personal trauma and a deviant personal experience. Indeed, this medical model resulted in an interest in trauma in various cultures. Moreover, within the framework of this model, a disabled person is an individual who deserves pity and who should be taken care of (by his or her family and by society, especially philanthropic organizations). This and other approaches have been described in detail in the literature.<sup>(16,18,19)</sup> In this way, an opposition "disability-health" typical to this approach and in Russian society in general can be observed.<sup>(19)</sup>

During the last 50 years a social model of disability has come to prevail. Within the framework of this model, disability is a social construct; social institutions and social surroundings create this construct and invent numerous restrictions for people with disability.<sup>(16)</sup> According to this approach, disabled people are the most discriminated part of the society that is responsible for their discrimination. Russian sociologist Iarskaia-Smirnova stresses that disability is the result of social agreement and the meaning of this construct depends on traditions, social differences, statuses and others.<sup>(20)</sup> In recent years this approach has sometimes been criticized, as it does not take into account the cultural context and even some physiological and psychological realities, such as pain and physical and emotional discomfort.<sup>(18)</sup>

There are also other approaches to disability, although they are not always mentioned in related works. Among them the affirmative (positive) approach is of note. It emerged as a result of the creative activities of disabled people, concentrating on the value

of their cultural experience, not on the tragedy and trauma. According to this approach, disability is a unique experience which is of great importance for a society. Other treatments of disability come from a legislative (human rights) approach, a corporeal approach and similar approaches focused on the human rights of disabled people and the representations of their bodies.<sup>(15,16,17,21)</sup> However, the sociocultural approach seems to be the most complex and promising, combining advantages of other approaches. According to this approach, a society is a social and cultural system that includes people with disability as an integral part. Their experience and possibilities are determined by a cultural context in a given society.<sup>(16,19)</sup>

Some notions and stereotypes of people with different impairments are widespread in modern societies, including Russia. Among them are found the labels of “useless” “defective,” “burdens to society and their families,” with such phrases as “just let them stay at home” directed to disabled people. These stereotypes are often spread by the post-Soviet mass media.<sup>(1,22,23)</sup> Therefore, this article will concentrate on representation of disability as well as self-representations of disabled people in their oral histories.

## SOURCES AND METHODS

This article is the result of the first stage of a research study dealing with representation of disability and disabled people among non-disabled persons and self-representation of these phenomena by persons with disabilities themselves in contemporary Russia. This stage was conducted from February 2014 to December 2016 in Moscow, Nizhny Novgorod and Yekaterinburg – the latter two are large urban centers located in the Volga and Ural regions. The main sources for this research were field materials: the results of participant observation (mainly in centers and organizations for disabled people in Moscow, the Moscow region and Nizhny Novgorod), the texts of several interviews with experts

(heads and activists of these organizations), and 27 in-depth interviews with disabled people. Interviews were carried out in person (they were recorded and then transcribed), via Skype and via e-mail. Informants in the centers for disabled people were located using the “snowball” technique in which friends and colleagues recommended their friends with disabilities, who in turn also recommended their friends. An additional but very important source was the Internet: social media (mainly Live Journal) and websites in which people with disabilities write their life stories or episodes of their lives dealing with the disability experience. People with different impairments and with various periods of disability emergence – innate disability, sudden disability (at over the age of 18 years) and with step-by-step disability (when disability develops as a result of disease or remote consequences of a trauma) – were chosen, with the understanding that although all these cases have their specifics, in all exist the potential for the people with disabilities to feel Other.

Therefore, in this stage the qualitative approach and Oral History method were applied, which are the most fruitful for studying cultural identities, problems of behavior, representation and spread of different notions and labels. The Oral History method is a kind of in-depth interview during which an informant tells his/her story, dealing with the concrete aspects of problems of his/her experience. In the study this was the perception of disability in general and one’s own disability, including attitudes of “abled” people.<sup>(24,25,26)</sup>

Among the informants were people with sensory disabilities (blindness, vision impairment and hearing impairment) and physical disabilities (spine disorders, diseases of the human musculoskeletal system). Twelve had innate disabilities or became disabled in their childhood, while fifteen experienced sudden disability over the age of 18 (as a result of a disease, accident or similar). The informants were between the ages of 19 and 66 and all were working, looking for a job at the time of interview, or were students. There were 11 men and 16 women. Additionally, six expert interviews were carried out in Moscow and

Nizhny Novgorod. Some fragments of life stories analyzed were also taken from the Internet.<sup>(27,28,29)</sup> Participants were informed that their interviews would be used anonymously (all names below are changed); they could stop an interview or not to respond any question according to a confidentiality policy of research. There is no representative sampling in qualitative research so no special distribution among the regions as well as among age and sex of informants was indicated, but the principle of "theoretical fulfillment"<sup>(24,26)</sup> was followed, according to which a scholar collects sufficient material for his or her research, until the point that new material does not add new information to the object of study.

## RESULTS

### Others forever

Many disabled people share negative stereotypes dealing with disabilities. Often they try to distance themselves from disability and people with impairments. For example, Larissa G. is 54 years old, has low vision and innate visual impairment, and is a former shop worker who was jobless at the moment of the interview. She said:

*I never thought I was defective. You see, in my family nobody said that I was a disabled person, a defective one. My mother raised me in such a way that I would never be defective. [Larissa G., Moscow, 2015]*

This opinion is common among disabled people in Russia. It differs from the approach widespread in Western countries, according to which disabled people have equal rights and possibilities which should be used by the society for its best development.

In research on disability it is necessary to differentiate not only among various impairments or defects (sensory, physical or mental) but also among groups of disabled people. As was mentioned above, disability in the USSR

and in post-Soviet countries was and is tightly connected to the possibility of working, and there are therefore three categories of disabled people in contemporary Russia. It is very important to differentiate between people with innate disability or those who became disabled in childhood and people who become suddenly disabled over the age of 18. These categories of disabled people imply different personal, social and cultural experiences and notions both of disability in general and their impairment in particular. Based on the study sources, several aspects of personal experience perceived by persons with disabilities can be defined.

In all groups and categories we can observe the feeling of Alterity, that is, people considering themselves quite different from other, so-called "normal" people. Natalia B. is 28 years old, has innate disability (Ménière syndrome, a disease of the human musculoskeletal system), chose not to have disability status, is unmarried, has graduated from secondary school, lives with her mother in Yekaterinburg, and is a musician. Her nickname in social media is Djimbo Di, the name that will be used in the remainder of this manuscript. She writes in her online diary: *"I always understood that I was a white raven and blue lamb. Always – in my childhood, in school, everywhere."*<sup>(27)</sup> This unusual expression, "white raven and blue lamb," similar to that of a black sheep, expresses the strength of her feelings of Otherness.

### Care and oppression

People with innate disabilities or those who became disabled in their childhood very often tell of the "hypercare" provided by their relatives, especially parents who often do not believe the disabled children can do even simple housework ("he'll hurt himself with the knife," "she'll break the glass").

Olga S. is 48 years old, became visually impaired in her childhood, has group 1 disability status, is married, has no children, works as a masseuse, and lives in Moscow. She remembered:

*When I was a schoolgirl, not even that little, my mother would say: "Don't touch the oven" or "Don't grab the knife, I'll do everything myself." When I got married I couldn't cook, clean the apartment, nothing. And when I started to do all that my relatives were shocked: "You are blind, how can you do these things?" [Olga S., Moscow, 2014]*

Djimbo Di also wrote in her *Live Journal*: *"in my childhood I constantly and permanently suffered from hypercare."*<sup>(27)</sup>

Olga G. is 42 years old with low hearing. She has been disabled since the age of 9, has group 3 disability status, is unmarried and lives alone in Moscow, where she works as a web-designer. She recalled:

*My father was not so nervous about me but my mother and grand-mother were just crazy – what I would do when I was alone. They often repeated: "You can't call an electrician, you can't do this, you can't do that." [Olga G., Moscow, 2014]*

This problem is reflected in most oral narratives of people with innate disabilities. Many leaders or activists of organizations for disabled people also often stressed that many children with disabilities (especially with severe disabilities such as blindness, blindness and deafness, spinal defects, and so on) cannot do elementary housework and sometimes cannot take care of their own hygiene.

Children with relatively "light" impairments, for example with low vision like Larissa G., are sometimes raised as "normal" children and the word "disability" is not even mentioned in their families in order to escape this stigma.

Olga B. is 56 years old, with innate low vision and group 2 disability status, is married with two children, lives in Moscow and is a teacher of English. She explained:

*No, my parents never stressed my impairment; I was raised as a normal person. They always said: "You must do*

*everything, you will do everything, do not behave like a pitiful child, you are normal." [Olga B., Moscow, 2015]*

Sometimes this approach can be even found in families in which there are children with severe impairments. For example, Elena N. is 37 years old, was born with low vision and later became blind, has group 1 disability status, is married and has two children, lives in Moscow, and at the moment of the interview was not working. She said that she had finished high school in the town of Aleksandrov (Vladimir region), then law college in the same town and graduated from the Law Department of Moscow State University. She discussed the attitudes towards her in her family: *"My mother always repeated: 'What will you do when I die? You must do everything yourself'" [Elena N., Moscow, 2014].*

## Isolation and loneliness

Such attitudes and perceptions of a disabled child as a weak and helpless creature deserving pity often result in isolation of the disabled child from abled children and in turn in a feeling of loneliness which lasts for years. These children often think that nobody needs them and even feel like outcasts.

Vladimir V. is 42 years old, has innate disability (disorder of human musculoskeletal system), does not work, and lives with his mother in Nizhny Novgorod. He recalled:

*My mother told me that when I was a little boy she did not dare allow me to play with normal children. So, I did not go to kindergarten. I didn't have friends, I always walked hand in hand with my mother. And all my life I felt like an outcast. [Vladimir V, Nizhny Novgorod, 2015]*

Djimbo Di wrote:

*In my childhood, after the death of my grandmother who kept the house, I became suddenly quite alone. My*

*mother wanted to escape bringing me up and was totally busy with her work. She often went on business trips and left me with my great-grandmother who was 87, who had low hearing but was full of energy. I lived with her two or even three weeks out of the month and felt quite lonely.*<sup>(27)</sup>

## Descending into the Netherworld

People with sudden disability often consider themselves Others and in addition "useless," "defective," "miserable." This feeling is especially deep after the trauma or disease resulting in disability, especially as the level of social and psychological rehabilitation for disabled people in Russia is very low. Some people continue to be labeled in such a way all their lives; others choose active life strategies in order to overcome this stigma.

Maksim V. is 37 years old, became a disabled person at the age of 32 as a result of a car accident, and has group 1 disability status for his spinal paralysis. Before the accident he was a businessman, was married and has a daughter. At the moment of the interview he did not work and lived alone in Nizhny Novgorod. He recalled:

*At first it was very difficult, terrible. I didn't know how to live, whether it was worth living. But my friends then came to support me, my wife hadn't left me yet. And now I am quite alone, I feel that I am in a steel cage and can't break free from it. I don't have anything except the Internet, thank God. It helps me, although I don't know to whom I can send messages. [...] Nobody is interested in my problems. You see, sometimes I write letters and e-mail them to addresses which I invent. Maybe somebody will reply. [Maksim V., Nizhny Novgorod, 2015]*

Vladimir K. is hearing impaired with group 3 disability status, having lost his ability to hear at the age of 44 as the result of the flu. He was a teacher of chemistry at one of

Moscow's universities. Vladimir is married and has a son. At the moment of the interview he did not work and lived mostly in the family cottage in the Moscow region. He was interviewed via e-mail:

*At first I thought I would go mad. Everything – work, family, friends – I was sure all that had come to an end. Nobody needs me, a disabled person. I can't hear anything, even a hearing aid does not help. Everybody has to write everything down for me. Little by little I got used to this situation, but I couldn't teach any more. Now I spend a lot of time alone in our cottage, we have an apple grove there and I like it. [...] This is also life although this life is very lonely, I live apart from everything. [Vladimir K., Moscow, 2014]*

## Schoolmates and schoolteachers

The feeling of Alterity, difference from everyone, from "abled people," often deepens during the school years, especially when children with disabilities attend inclusive schools. This feeling appears frequently in the oral narratives. Disabled people often stress that this feeling was influenced by the attitudes of their schoolmates and – especially – of the schoolteachers. These complex interactions at school have been described with specific reference to children with various disorders including physical and mental ones.<sup>(30,31)</sup> The negative attitudes, including bullying or at least indifference towards disabled children, suggests the necessity of revisiting the rejection of special schools in contemporary Russia in favor of inclusive education.

For example, Elena N. attended an inclusive school and then a college, but she suffered from the attitudes of teachers:

*Teachers perceived me differently; some of them helped me. Some of them even tried to take care of me in their own way – "Just sit and don't do anything,*

*this is too difficult for you.” Some of them saw me as a burden to them because they had to help me or pay special attention to me. [...] Some teachers in my school would even say: “God punished you for something.” [Elena N., Moscow, 2014]*

Djimbo Di also recalled her school years<sup>(27)</sup>:

*In my school I always was a white raven and blue lamb. I never spoke to anyone without a reason. I just believed in myself and didn't want to be “like everyone else” Schoolteachers wanted me to leave school and study at home. They decided that it was not worth spending their time on me because I wouldn't study or work anywhere.<sup>(27)</sup>*

Some informants, both with innate or sudden disability, feel subject to a kind of “unfair injury” which life/God/society/fate caused them. Sometimes this feeling results in self-hatred.

Olga G. spoke of her “unfair life” during the interview in spite of her good job, apartment and salary:

*I know that I am defective, ugly [Olga is an attractive woman] and I have friends who are like me, they are deaf. You can't imagine their intellectual level, they are idiots. [...] Sometimes I try to prove to them that I am not as idiotic and ugly as them. I want to be like everyone else but in fact I am just as idiotic and ugly as they are.*

Tamara Cheremnova, 58 years old, writes children's books. She has innate disability (cerebral paralysis). When she was six, her parents took her to a special orphanage where doctors defined her disease as “severe mental retardation.” In spite of that Tamara taught herself to read and write; then she – also herself – studied the entire mandatory school curricula and began writing stories for children. The diagnosis of “mental retardation” was revoked. Now her books are translated into many languages. Tamara lives in the special

institution for disabled people No. 2 in the city of Novokuznetsk.<sup>(28)</sup> She writes:

*At first I didn't want to contact anyone. At night I used to bite my pillow, I hated myself, my cerebral paralysis. Because of this terrible disease my arms and legs didn't work well and I also got this unfair, offensive diagnosis – I was accused of being mentally defective!<sup>(28)</sup> [emphasis added]*

## After school

After finishing school many informants continued their education at colleges or universities. In this period self-perception and self-representation of people with innate disabilities usually changes. If we compare attitudes towards them at schools and universities we can see that students with disabilities normally interact with teachers but, at the same time, they often do not have contact with “normal” students. As a result they continue to feel Others and even Aliens.

Vladimir Z. is 54 years old, with visual impairment and disability group 2 status for a disability he acquired at the age of 14 as the result of disease. He first attended an inclusive school, then a special school. Vladimir teaches history at a special school in Moscow, is married and has two children. He recalled:

*At the university I felt more at ease than at the inclusive school. I had no problems with professors – they understood my handicap. Once or twice somebody had trouble understanding that I couldn't read the blackboard or see something else. But I just explained and they understood. [...] As for students, the situation was worse. Nobody said or did anything bad, no. But they were indifferent, did not pay any attention to me and I felt – well, I was quite separate. [Vladimir Z., Moscow, 2014]*

In spite of disabilities and the difficulties resulting from them, many informants



graduated from good universities or achieved good professional careers. Nevertheless, many of them, especially those who finished at special schools, had a feeling of "abnormality" which they equated with disability. Therefore, they continued to feel (and to be) stigmatized.

For example, Bayramkis A., who is 54 years old with innate visual impairment and group 2 disability status, attended a special school for children with visual impairments in Dagestan, then a special medical college for people with visual impairments in Kislovodsk. She is a masseuse and lives in Moscow. Both her husband and her son passed away. Bayramkis said:

*When I was young and had just started working I constantly felt defective, I was embarrassed of my low vision. I think I felt so because we lived in a special college in Kislovodsk and everybody there had visual impairments. Now the students of my school go home for weekends. But we lived there through vacations, sometimes even through summer vacations. We had almost no communication with other people, we lived in a separate world. Then I spent two years at the Kislovodsk College. So, for 12 years I lived in a world where everybody had visual impairments. And when I left that world and started working I always felt disabled, always felt bad, embarrassed. I always understood that I was disabled, defective. [Bayramkis A., Moscow, 2014]*

This attitude towards disability is also typical in informants with sudden disabilities like well-known writer and activist Aleksey Grafov, who became blind during his studies at university. In his work, he describes coming to the sudden understanding that his disability was forever and that he was now disabled person.<sup>(29)</sup>

### Job and attitudes towards disability

Almost all informants stated that when they tried to get a job they suffered from

different forms of discrimination. Sometimes informants even tried to keep their defects secret – they did not wear glasses or hearing aids, did not use lenses during the interview, and so on. They explained that it was very important during the interview and the first weeks at their workplace to behave "like normal people" so that their employers would understand that they could do everything "like normal people" and would get used to their impairments. This behavior reflects the approach to disability Garland Thompson defines as "normate," or the view of "abled" people towards everything regarding disability and disabled people; this "normate" viewpoint is typical of so-called "normal" people who apply their notions, views and politics to people with disabilities.<sup>(32)</sup>

Many informants in addition stressed that during their careers they were discriminated against because of their disabilities – their employees and colleagues did not believe that disabled people could work "like normal ones."

Vera Z. is 62 years old, with innate visual and hearing impairments and group 2 disability status. She is married and has a son. She is also a psychologist and works in a Moscow research center as the Head of the Department. She said:

*I always knew that the Director of my Center and others do not believe I can work like a normal person. Of course, they didn't say so. But they never promoted me to be a member of Academic Board, although I have a lot of publications. My career – if it is possible to speak about it as a research career – was not successful. Yes, they promoted me to be a Head of the Department. Why, I was already 60 then, I didn't have enough energy to work as a Head. When I was 50 I had energy, ideas. I wanted to organize the work of this Department. And now I am just tired, I have no energy any more. But they did not promote me to this position before. [Vera Z., Moscow, 2014]*

Olga S. is 58 years old, has visual impairment from her childhood and group 1 disability status, works as a masseuse, is married, has no children, and lives in Moscow. She also said:

*When I was young I was asked to join the medical college – to teach methods of massage, different kinds of massage. You see, I finished the medical college in Kislovodsk – it is a very good college. But something happened then and they did not invite me. Somebody told me that they just did not want to hire a blind person. A year ago my friend asked me whether I wanted to teach. I answered: “No, I am too tired now, I don’t have energy any more, I don’t want this job now.” When I was younger, I wanted to work and I could work very well but nobody believed I could be a teacher. [Olga S., Moscow, 2015]*

Sometimes informants even recalled that their employees or colleagues insulted them when they wanted to advance their careers. Larissa G. wanted to get a better job. She recalled her colleague saying: “You are blind, how can you do that work? You can’t, you have to keep working here” [Larissa G., Moscow, 2015].

Disabled people do not feel these prejudicial attitudes at the special organizations for people with disabilities which have survived since the Soviet era. However, it is very difficult to be a success at these organizations – the salaries are low and personal promotion is difficult. Moreover, the number of jobs available at such organizations is declining.

## Fears and indifference

The general motif of the oral narratives of disabled people deals with the indifference of the world or, more to the point, of people towards the problems of disabled persons. For example, Anton P. is 33 years old, with innate visual impairment and group 1 disability status. He graduated from Moscow

State University and now works as Director of a commercial firm, lives in Moscow and is unmarried. He spoke in relation to attitudes towards blind people in Russia, but it is possible to expand his evaluation to disabled people in general: “You know that in our country everyone just pities a blind person. Sometimes it is also possible to admire such a person” [Anton P., Moscow, 2015].

Anton is referring to shows in the mass media on the “achievements” of disabled people, such as Paralympic athletes, singers and so on. At the same time, public opinion is not interested in the daily life of people with disabilities, people do not know about them, mass media rarely touches upon this subject. Thus, “pity” is often sporadic and in some cases damaging.

Vadim E. is 28 years old, with innate visual impairment and group 1 disability status. He graduated from the Moscow Psychological University, does not work, lives in Moscow and is unmarried. He said:

*Once I was waiting for my friend in the street. I was standing near a metro station and holding a can with sparkling water. Suddenly somebody threw a coin in my can. Can you just imagine – he thought that I was a beggar! Couldn’t he see that I wore good clothes, that I was clean, that I was just standing? He spoiled my water, by the way. [Vadim E., Moscow, 2014]*

These attitudes towards disabled people as poor, beggars, money collectors, helpless and so on is typical in many societies and cultures. For example, the image of a blind person as a beggar is widespread in English culture.<sup>(11)</sup>

In some cases informants talk about the prejudices and fear which “normal” people feel when they come in to contact with people with disabilities. These are not fears of the socially unacceptable behavior associated with people who have mental disorders<sup>(12)</sup> or notions of the contagiousness of the impairment, such as was mentioned earlier regarding blindness.<sup>(11)</sup> Informants

stress that people are often afraid of wasting their time on helping a disabled person and fear that a disabled person will break something, fall down, or something similar and it will take time and energy to help him or her.

Elena N. said:

*It always seems to me that they fear us. People don't know us and they are afraid. They think: "Maybe I'll have to spend my time or something for this disabled person." I have the impression that they are afraid of what I might ask of them. Maybe I'll be a burden and they try to avoid me, I've always felt that.*

[Elena N., Moscow, 2014]

Often people who want to be helpful do not know what to do that and feel embarrassed. Valentina M. is 51 years old, with a sudden disability (skeletal) and group 2 disability status. She was a schoolteacher and now works at home, is married, has a son, and lives in Moscow. She spoke of an incident:

*Once I was going somewhere by tram. You see, I walk with two special canes, and it's very difficult to climb the stairs of the tram. But it's much more difficult to exit. The tram stopped and I tried to get off. It was very difficult, inconvenient and even painful for me. Nobody moved to help me. At last a young lady ran to me and helped. Then she said that she was afraid of hurting me and didn't know what to do. [Valentina M., Moscow, 2016]*

As a result of these fears, a public and personal avoidance of disabled people can be observed.

## CONCLUSIONS

These fears, avoidance and prejudicial behavior towards disabled people have roots in ancient times. They are fears of Others who

are unknown and may be even dangerous. However these fears and avoidance are rather typical for modern cultures<sup>(15)</sup>; for example, Bolt has analyzed notes about the contagiousness of blindness which existed in 20<sup>th</sup> century.<sup>(11)</sup> These prejudicial attitudes result from the abovementioned stigmatization of disability and disabled people. Moreover, they are consequences of a "normate" viewpoint in which people with disability are still Others,<sup>(32)</sup> but their problems are resolved by "abled"/"normal" people. In the late Soviet and post-Soviet context such attitudes stemmed from the concept of the social care of disabled people who were very ill and often helpless, especially the mentally disabled.<sup>(23)</sup> Scholars stress that such attitudes resulted not only in negative attitudes towards disabled people but an underestimating of the role of people with disabilities in the society and even to a denial of their existence, formulated in the well-known phrase "there are no invalids [disabled people] in the USSR."<sup>(3)</sup> In the post-Soviet period people with different impairments are still perceived as "useless," "a burden to society," and in this study it was shown that disabled people sometimes share these stereotypes. Such notions are partly rooted in the historical context – attitudes towards disabled people in Russian culture in the past<sup>(23)</sup> saw them as miserable, the result of the sins of their parents. In the Stalin era in the Soviet Union, disabled people were considered "useless" as they could not work like "normal" people.<sup>(33,34)</sup> In spite of all the changes and transformations which took place in Russia in the 20<sup>th</sup> century, some of these notions still exist, such that one can have pity for disabled people but not desire to have contact with them or even see them except for in special cases of their "incredible achievements."

The mass media also promote such attitudes; a head of an organization for disabled people in Nizhny Novgorod stated that for many years he could not recall any TV or radio program dealing with the real problems of disabled people. The organizations for disabled people which survive from the Soviet era do have not enough funding to improve

the situation. Little by little these organizations turn into clubs for disabled people and have very limited resources. They cannot and do not try to struggle for the rights of disabled people with respect to the discrimination they face in various fields such as education and employment, a situation typical in some post-Soviet states.<sup>(35)</sup> Neither do these organizations try to improve the ambivalent or even negative attitudes towards disabled people in Russian society, such as feelings of

fear and indifference. In many cases these organizations simply promote the “admiration of achievements” of such people carrying out different competitions and exhibitions of such “achievements.” As a result, avoidance is a typical reaction to disabled people in post-Soviet Russia. As we can see, these attitudes impact the self-perception and self-representation of disabled people and impede their successful integration.

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## REFERENCES

1. Allport GW. *The nature of prejudice*. London: Addison-Wesley; 1954.
2. Goffman E. *Stigma and Social Identity*. In: *Stigma: Notes on the Management of Spoiled Identity*. New Jersey: Prentice-Hall; 1963.
3. Phillips S. “There are no invalids in the USSR!” A missing Soviet chapter in the new disability history. *Disability Studies Quarterly*. 2009;29(3):936.
4. Naberushkina EK. *Invalidy v bolshom gorode: problemi sitsialnogo grazhdanstva* [Disabled people in the large city: problems of social citizenship]. Moscow: Variant, TsPGI; 2012.
5. Rasell M, Iarskaia-Smirnova E, (ed.). *Disability in Eastern Europe and the former Soviet Union: History, policy and everyday life*. New York: Routledge; 2014.
6. World Health Organization. *Disabilities* [Internet]. 2016 [cited 2016 Jan 26]. Available from: <https://tinyurl.com/n5hycar>.
7. World Health Organization. *New world report shows more than 1 billion people with disabilities face substantial barriers in their daily lives* [Internet]. 2011 [cited 2016 Jan 26]. Available from: <https://tinyurl.com/lqs3bsa>.

8. Russian Federation, Federal State Statistics Service. The situation of disabled people [Internet]. [cited 2016 Jan 26]. Available from: <https://tinyurl.com/n772hrc>.
9. United Nations, Human Rights Office of the High Commissioner. Convention on the Rights of Persons with Disabilities [Internet]. 2006 [cited 2016 Jan 26]. Available from: <https://tinyurl.com/bs7w8y3>.
10. World Health Organization. World report on disability [Internet]. 2011 [cited 2016 Jan 28]. Available from: <https://tinyurl.com/mxt58la>.
11. Bolt D. The metanarrative of blindness: A re-reading of Twentieth-Century Anglophone writing. Ann Arbor: University of Michigan Press; 2014.
12. Luse A, Kamerade D. Between disabling disorders and mundane nervousness: representations of psychiatric patients and their distress in Soviet and post-Soviet Latvia. In: Rasell M, Iarskaia-Smirnova E, (eds.). Disability in Eastern Europe and the former Soviet Union: History, policy and everyday life. New York: Routledge; 2014.
13. Linton S. Claiming disability: knowledge and identity. New York: NY University Press; 1998.
14. Gerber DF, (ed.). Disabled veterans in history. Ann Arbor: University of Michigan Press; 2000.
15. Corker M, Shakespeare T. Disability / postmodernity: Embodying disability theory. New York: Continuum; 2002.
16. Johnston D. An introduction to disability studies. 2nd ed. Oxford: David Fulton Publishers; 2005.
17. Bolt D. From blindness to visual impairment: Terminological typology and the social model of disability. *Disability and Society*. 2005;20(5):539-552.
18. Siebers T. Disability theory, boldly rethinking of the last thirty years from the vantage point of disability studies. Ann Arbor: University of Michigan Press; 2008.
19. Nosenko-Stein E. Nekotorye problemi izucheniya invalidnosti i sotsiokulturnaia antropologia [Some problems of studying disability in social and cultural anthropology]. In: Materialy mezhdunarodnoi nauchno-prakticheskoi konferentsii 'Sovremennaya antropologia: novye dannye, perspektivy razvitiya i metodologicheskie printsipy [Proceedings of International Conference 'Modern anthropology: new sources, methodological principles and perspectives]. Minsk: Institute of History of the National Academy of Sciences of Belarus; 2015.
20. Romanov P, Iarskaia-Smirnova Ye. Politika invalidnosti: sotsialnoie grazhdanstvo invalidov v sovremennoi Rossii [Disability policy: social citizenship of people with disabilities in contemporary Russia]. Saratov: Nauchnaia kniga; 2006.
21. Watson N, Roulstone A, Carol T, (eds.). Routledge Handbook of Disability Studies. London: Routledge; 2012.
22. Blank HR. Psychoanalysis and blindness. *Psychoanalysis Quarterly*. 1957;26(1):1-24.
23. Muravieva MG. Kaleki, invalidy ili liudi s ogranichennymi vozmozhnostiami; obzor istorii invalidnosti [Crippled people, invalids or people with disabilities: historical review of disability]. *Zhurnal Issledovaniy Sotsialnoi Politiki / The Journal of Social Policy Studies*. 2011;10(2):151-166.
24. Bertaux D. Biography and society: The Life History Approach in the Social Sciences. Beverly Hills: University of California Press; 1981.
25. Grele RL. Envelopes of sound: The art of oral history. New York: Praeger; 1991.
26. Hummersley M. The dilemma of qualitative method: Herbert Blumer and the Chicago Tradition. New York: Routledge; 1989.
27. Dorogu ukazyvaet mechta [A dream shows the right path] [Internet]. 2013 [cited 2016 Jan 26]. Available from: <https://tinyurl.com/mffbxxw>.
28. Zdravsvuyte, dobrye ludi [Hello, good people] [Internet]. 2011 [cited 2016 Jan 26]. Available from: <https://tinyurl.com/lgreh5r>.
29. Grafov VA. Zapiski slepogo [Essays of a blind man]. *Sibirskie ogni [Siberian lights]* [Internet]. 2009 Oct [cited 2016 Jan 26];(10). Available from: <http://www.sibogni.ru/content/zapiski-slepogo>.
30. Butovskaya ML, Loutsenko YK, Tkacheva KL. Buling kak sotsiokulturny fenomen i efo sviaz s chertami lichonosti u mladshikh shkolnikov [Bullying as a sociocultural phenomenon and its relation to personality traits among younger school children]. *Etnograficheskoe obozrenie / Ethnographic review*. 2012;5:139-150.
31. Vishnevskaya VI, Butovskaya ML. Fenomen shkolnoy travli: agressory i zherty v rossiyskoy shkole [Phenomenon of school bullying: aggressors and victims in Russian school]. *Etnograficheskoe obozrenie / Ethnographic review*. 2010;2:55-68.
32. Garland-Thomson R. Extraordinary bodies: Figuring physical disability in American culture and literature. New York: Columbia UP; 1997.

33. Fieseler B. Soviet-style welfare: the disabled soldiers of the 'Great Patriotic War.' In: Rasell M, Iarskaia-Smirnova E, (eds.). *Disability in Eastern Europe and the former Soviet Union: History, policy and everyday life*. New York: Routledge; 2014.

34. Bernstein F. Prosthetic promise and Potemkin limbs in late-Stalinist Russia. In: Rasell M, Iarskaia-Smirnova E, (eds.). *Disability in Eastern Europe and the Former Soviet Union: History, policy and everyday life*. New York: Routledge; 2014.

35. Phillips S. Citizens or 'dead souls'? an anthropological perspective on disability and citizenship in post-Soviet Ukraine. In: Rasell M, Iarskaia-Smirnova E, (eds.). *Disability in Eastern Europe and the former Soviet Union: History, policy and everyday life*. New York: Routledge; 2014.

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