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## Russian Focus on The Problem of Disability.

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### **ABSTRACT**

The article is considering the problems of marking disability in Russian society and social policy. Statistical data and the results of authors' research are presented here. The authors try to consider the social changes in the context of problems of disabled people and some aspects of social citizenship of disabled people. At the basis of the empirical sociological data the authors consider the existing social dimensions and accessibility of the environment for the disabled people in the Russian cities.

Keywords: disabled people, accessibility, social distances.

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#### INTRODUCTION

The aim of the article is an insight into the modern Russian realities of perception and solving the problems of disability, assessment of dynamics of changes in view of social policy reforms concerning disabled people. Transformation of social structure of the Russian society lead to considerable changes in the field of social policy concerning disability. That entails interest in theoretical reflexion and empirical measurement of changes which happened in social continuum of disability, in the field of social policy concerning the disabled people. Research in the field of social stratification scarcely touch the problems of limitations in social citizenship on the grounds of disability and experience of disabled people themselves in view of modern sociopolitical changes.

#### Literature Review.

It is necessary to start with considering of officially accepted notion of disability. In Russia disabled person is defined as a person who is disabled and has stable disorder of organism functions as a result of disease or accident, or has defects which lead to limitations in life and make it necessary to provide him with social protection (article 1 of the Russian Federal law 183-FZ of 24.11.1995 "About the social protection of disabled people in the Russian Federation). In 2012 in Russia there was ratified the UN Convention "About the rights of invalids", in which the definition has other accents and induces to reconsider the existing normatives and social measures due to new understanding of disability. According to the definition given in the international document invalids are people having physical, mental, intellectual or sensory defects, which together with different barriers can prevent them from effective participation in the life of the society as well as other people. Comparing the two definitions we see that the second definition demonstrates the accent on barriers, while in the first definition there is no such accent. New discourse about disability in connection with barriers reshapes the approach to solving the social problems of disabled and to understanding of disability as a social phenomenon as a whole. Twenty years ago disability in Russia was perceived as a "medical disorder" of a person, today the accents shift in favor of barriers which prevent people from active participation in the life of the society.

It is also necessary to explain the statistical analysis of disability in the Russian context. The existing data base and record keeping system in Russia are incomparable to the international one due to a certain specificity (the absence of uniform methods, certain ranging of employable age which is incomparable to international, disadvantages of scales for assessment of character and the degree of physical limitations, etc.). The researches fulfilled by Service of the Russian Federation State Statistics and other organizations don't give full picture of disability. During the All-Russian population enumeration the respondents could point out the disability problem mainly in connection with the column concerning the disability pension. Data bases of Pension Foundation, Ministry of Healthcare, Ministry of Social Development have the most complete data about disabled people, but it is very problematic to unite all the data into a whole system due to the absence of integrated formalized methods of data collection and insufficient interdepartmental solidarity.

Medical-social expertise bureau (MSE) contains the most complete information about the character of problems of disabled people according to the nosology, but this data base cannot pretend to be universal and accurately reflecting the situation with disability as a whole. Disability in Russia is declarative in character, the situation gets under observation and into the official statistics only if a person goes to a medical examination in MSE agencies. According to other researches carried out with the help of qualitative methods of sociological research (including deep interviews, biographies analysis, focus groups) a considerable amount of families with high income prefer not to acquire a disability status if the child has developmental disorder. A considerable part of grown-up people refuse to go to medical expertise because of the complexity of the procedure which demands from a person to be mobile and be able to make efforts to collect necessary documents and analysis. Speaking about the level of registered disability we base on the data of the Pension Foundation of Russia (PFR) as having the most complete and reliable information notwithstanding that the Foundation keeps count of pensions paid to the disabled people but not disabled people themselves. According to the data there are 10.9% of disabled people in the structure of population in Russia. In Russia high level of disability is among women in pension age. Gender models of behavior explain the peculiarities of disability among men and women of pension age. Women visit doctors more often and do medical examination, men are more often exposed to risk factors such as accidents, vicious habits.



The structure of reasons of primary disability among children has its peculiarities. In 2012 there prevailed three almost equal reasons of infant disability: congenial anomaly, nervous system disease, psychological disorders. In 2012 percentage of nervous system diseases became higher in comparison to 2003. Number of accidents became twice less, 1.7 times less respiratory system diseases, almost by half less tuberculosis (Rogosina, Rogosin, 2016). It is necessary to point out that there are leaps in statistical disability measurements. Adult disability level in Russia grew in 2004-2006 because there came into effect the law FZ-122 "About the monetization of allowances", which motivated some part of the population to acquire an official status of disabled in order to get money equivalent of services granted to disabled people.

Theoretical research of disability problems include discussions about mobility sociology (Urry, 2000), conception of creation of cities environment (Lefebvre, 1991) model of inclusive approach to availability of cities objects (Imrie, Hall, 2001), discussions about citizenship (Ongoing, 1999). In the classical Sociological theory M. Veber (1994), V. Zombart (2003) and O. Shpengler (2007) interpreted evolution of the modern civilization, presenting it as a history of formation of the city way of life. Especially interesting are the works of G. Zimmel (2002) which form the basis for considering the social space as a form of execution of things in the world. One of the qualities of relationships of people in the city space he determines as blase' urbanite, we see it empirically determining social discrimination of disabled people in different spheres of social life. D. Harvey (2008) brought up a question about the right for city, which were later evolved in the works of A. Brown (2008). N. Cass (2005) presented deep research about minorities and segregation in cities. E. Soja (2010) speaking about segregation in cities introduced a notion of fairness of space. Conceptions and thoughts of these authors formed the basis for methodology of empirical research and verification of the achieved results.

#### **METHODS**

Using the method of questionnaire survey among the groups of population with limited mobility in Nizhni Novgorod, Saratov, Kazan there were received data about the social distances concerning disabled people, the extent to which their civil rights are observed, accessibility of the city infrastructure objects, discovered the opinions about progressive and destructive changes. 600 people were questioned, the majority of data was received in 2013, in 2015 the data was finally processed and compared to the results of other Russian researchers. The sampling was purposive, the respondents were disabled people who can move independently, the main reasons which obstruct their movement is a number of diseases (25.0%), defects of locomotorium (19.32%), age-related changes (19.16%). Kazan and Saratov were chosen for research as the cities included into the first pilot project of developing accessible environment at the level of subjects of the Russian Federation, solving the problems of disabled was claimed to be a priority. These cities were the part of a pilot stage of the Federal targeted program "Accessibility", aimed at creation of environment without barriers. In the framework of this program realization Tatarstan and Saratov region received additional financing in 2011-2015 for the reconstruction of infrastructure, also there was organized training of state employees, non-governmental organizations got priority support. Intensity of measures for realization of "Accessibility" program in Nizhni Novgorod region was not so high as in other two regions, but it has a status of a million citizens city and a cultural center, so it attract additional financing. Nizhni Novgorod is presented in the sampling to compare accessibility in the cities which took part in the pilot projects and those who didn't. Another important criteria for the choice of pilot regions became an experience of effective cooperation with a number of regional representatives and public organizations. The article cites the data of the All-Russian poll of 2011, in the framework of which the authors of the article carried out the questionnaires of Saratov citizens (200 people, general sampling of the research is 1600 people). The work was supported by 2016 Grant of the Institute for Advanced Study at MSPU (Institute for Advanced Study at Moscow State Pedagogical University, 1/1, M. Pirogovskaya St. Moscow 119991 Russian Federation).

## RESULTS

All-Russian poll of invalids' quality of life in 2011 shows that discrimination of disabled takes place mainly in the sphere of receiving allowances, the most of the problems concern medical care and medication support. There's a high extent of social intolerance: 64.4 % of respondents among disabled people claimed that they sometimes hear offensive notes, encounter with intolerance in the public transport and indifference of bureaucrats; 54.2 % of disabled people encountered with refusal to enter the higher school; 53.4 % were



infringed in labor payment; 51.0 % of respondents were refused to be accepted to work (Naberushkina, 2012). The main spheres where the rights of invalids are infringed:

- refusal to secure well warranted allowances 30.1 %;
- refusal to grant the deserved disability status 17.0 %;
- refusal to be accepted to work without reason 14. 3%;
- infringement in labor payment 5.7 %;
- refusal to enter the higher school 3.2 %;
- offensive notes 23.1 %;
- bureaucracy in receiving allowances 49.5 %;
- other 9.7 %;
- difficult to answer 9.4 % respondents.

Earlier research executed in 2007 with the help of qualitative methodology helped to reveal not only the scope and spheres of violation of invalids' rights, but also to estimate the situation deeper including gender aspect. In the framework of the project "Women and disability: experience of discrimination and alleviation" the histories which the respondents told showed dual discrimination of disabled women. Disability together with gender puts under question their reproductive and economic functions (Yarskaya-Smironova, 2007). On the one hand there dominate the public acknowledgement of equal rights and declaration of anti-discriminational statements; on the other hand listening to the stories of people we see the exclusion and social pressure. The situation with accessibility of the environment for the disabled demands special attention. There are various urban projects, the disability problems are researched well, but research of social exclusion of disabled people is presented poorly. Disabled people are sometimes feel themselves as the "outsiders", their social world is to a great extent presupposed by the ability to move.

Answers to the polls In Kazan, Saratov and Nizhni Novgorod, which tried to clear up if the interests of the disabled people are taken into account in the architecture of the city, showed that in Saratov the negative attitude is 6 times higher than the positive, in Kazan - 1.5 times, in Nizhni Novgorod this number was inconspicuous. Respondents regardless of categories and character of disability, age, material status seldom estimated the extent of amenities of the city for invalids more than for 3 points. So we can make a conclusion that the situation didn't improve though the state program "Accessibility" was implemented. Low estimates of accessibility of the city always correlated with opinions about social intolerance in the sphere of social communication. That proves the opinion that city full of architectural barriers - is a factor of reproduction and deepening of social deprivation which is created inside and with the help of city environment. The positive moment of changes in the field of citizenship of invalids is the fact of realization of Federal targeted program "Accessibility", the logic of which is that disability is a result of destructive relationships of a person with the environment because of its barriers. Among the respondents there prevail those who think that cities became more convenient for life during the last 20 years, though there are people who think that nothing has changed. Answers to the polls - did your city became more favorable for life in the course of 20 years - are: it became much better and more convenient - 6.5 %; it became a little bit better - 37.3 %; almost nothing has changed -27.3 %; it became worse – 11.2 %; it became much worse than before – 5.0 %; it is difficult to answer – 12,7%. Among those who tend to estimate changes positively there are more citizens of Nizhni Novgorod, citizens of Saratov chose the negative variant. Saratov citizens noted that for the last years the situation with roads and transportation became worse. More than half of the disabled citizens of Saratov (64.4%) consider unsatisfactory the situation with safety in the city. So it is too early to make a conclusion that realization of targeted measures to create accessibility turned out to be effective, though the city was one of the first among the participants of the state program "Accessibility". In the framework of this program realization there appeared rampants and local accessibility, but it didn't influence on accessibility of the city as a whole. The section of positive answers about the extent of accessibility of offices was analyzed more thoroughly. The statement "absolutely accessible" was analyzed, and different offices got various estimates, 71 respondents of 616 chose the estimate "absolutely accessible". There are: shopping centers - 31.0 %; life offices - 7.0 %; cultural institutions – 9.0 %; religious institutions – 15.0 %; social protection institutions – 13.0 %; government agencies – 7.0 %; educational institutions – 8.0 %; medical institutions – 10.0 %.

It turned out that trade centers took the leading position. As a rule, modern trade centers are being built from the ground up and foresee the broad range of accessibility including international norms of universal design stipulated by the construction rules. Social services and religious organizations are



comparatively accessible, and the state, medical and educational organizations remained as the outsiders. Thinking about the possibilities of their citizenship and independence in using the city infrastructure, the respondents in these three cities spoke more often about the necessity of acquiring modern rehabilitation facilities (including personal transport), about the importance of improving the work of public transport, about the necessity of serious changes in cities' environment. Because in realization of the right for mobility the character of the environment plays an essential role. Almost all the respondents connect the improvement of their condition and the quality of their life with disappearance of barriers in cities infrastructure: 45.2 % of respondents said that they would become more mobile and would move around the city more often, 30.0 % of respondents would be able to find new spheres of activity and would become more independent.

Together with local research criteria of Russian cities' accessibility for disabled people in 2015 there appeared an independent rating of accessibility of cities which was created together with the Union of volunteers of Russia, which listed the best and the worst regions according to the quality of life of invalids. Only in 18 regions of Russia the needs of disabled people are being realized in the city infrastructure. There are 5 leading regions: Moscow, Krasnodarsky krai, Tatarstan, Chechen republic, Belgorod region (in Russia there appeared National rating..., 2016).

The tendency of stagnation and of growing social distances in respect of disabled people rise anxiety. As far as 10 years ago the ideas of integration and inclusion were accepted more friendly, today our sociological poll shows that it's too early to make conclusion about reduction of social distances towards the invalids, because the most popular answer to the question about the place of residence of invalids was -dwelling in special houses for invalids (77.6 % in Nizhni Novgorod, 84.1 % in Kazan). Soviet practice of state care about invalids had examples that enterprises system of the All-Union (today – All-Russian) Blind Association, created in the USSR presupposed not only employment of blind people but a lot of other things. The Association built dwelling houses and clubs, nursery schools and sport halls.

## **SUMMARY AND CONCLUSION**

Comparison of the research results of different years make it possible to suppose that there is progress in social policy concerning invalids, but this process is not steady and not as quick as necessary. The situation with marking the invalids' problems turned for the better, the methods of gathering of the information about the disabled people are being corrected, the focus of disability understanding is shifting to barriers, discrimination of invalids is being terminated. The society is ready to change which is more evident in development of legislative base, in the aspect of formation of accessibility of infrastructure. Social distances concerning disabled people remain, but discourse of discrimination calls up great social protest. Positive changes in disability discourse occur due to the accessibility of scientific results of social research in disability problems. Big Russian scientific institutions initiate these researches, which continue to influence the society in its recognition of the rights of invalids.

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