

Social Well-Being Of Disabled People In Conditions Of The Modern Russian City

By

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Abstract

The article is devoted to the study of the urban context of disability. The research methodology is built within the interdisciplinary field of "disability studies" by involving urban studies. The research was conducted by the focus group method. Young people with disabilities were selected from disabled students who receive higher education at the capital's inclusive university from small and medium-sized provincial towns. The objective of the study was to diagnose social well-being of the disabled in the format of assessing the inclusive properties of urban design. The results of the study allowed to clarify the way of creating the reality of disability in urban conditions taking into account groups of citizens, things, procedures and urban flows. Sociological analysis showed new contexts of attitudes towards people with disabilities on the part of typical townspeople. Positive changes due to the creation of infrastructure, trends of infantilization of disabled people and increased attention to them are being recorded today. But it does not allow us to talk about significant achievements on the path of normalization of their lives. Urban spaces are sensitive to the presence of people with disabilities. The way how non-disabled people treat the disabled in cities and towns have similarities and differences, but it is worth speaking of a difference in the reasons that trigger a negative attitude towards people with disabilities in the stratification context of the cities.

Key words: people with disabilities, urban studies, stigmatization, infantilization, well-being in the urban environment, architectonics.

Introduction

At the end of the seventies of the twentieth century, the formation of a new research direction - Disability studies – came into being in academic science [1,2,3]. Trying to take the problem of disability away from the field of medicine and physiology, scientists have directed their efforts to the analysis of legal, sociocultural, socio-anthropological, gender and other aspects of disability [4,5,6,7]. D. Goodley [8, p.11] characterizes disability studies as a matrix of theories, pedagogy and practices that can potentially involve many paradigms and break down disciplinary barriers to studying disability issues. At the same time, the analysis of

scientific publications on disability issues shows that the interdisciplinarity of Disability studies is most often provided by the contact between sociology, psychology, social work, social anthropology, political science, medicine and law [9,10,11,12,13,14].

Important methodological principle in the study of disability was formulated at the end of the last century in the context of a social model of disability that criticizes the normative (medical) format. Sociologists, social anthropologists, and social workers began to emphasize two approaches to researching and describing the life practices of people with disabilities [15,16]. The Dutch researcher A. Mol [17] investigates how, in what conditions, in the presence of what people, things, procedures and other external structures the reality of atherosclerosis is produced. Various situations of everyday urban reality associated with shopping in a store, traveling by transport, being in public places and interacting with other people in the city can either activate the disability status, making a person feel incapacitated and inferior, or, on the contrary, neutralize and compensate for existing deviations of health [18,19].

Expanding the field of interdisciplinary analysis of disability by including urban discourse, we will build reasoning in line with the indicated approaches, showing how certain cities define the everyday life of a person with disabilities, forcing him or her to forget or, on the contrary, to experience his disability again and again. How does a city with its architectonics in various manifestations and everyday practices include disability, that is, it literally makes a person remember that he is not like everyone else? How do the communicative strategies of typical citizens contribute to this in various situations of meeting people with disabilities and how does the real physical immersion of a disabled person in all processes and public communications change social and infrastructural orders in the city? We use the discourse of illness to assess how the surrounding citizens in cities and towns react to disability and visible anatomical features of a person.

To analyze the urban reality of atypical citizens and to clarify the specifics of the well-being or disadvantage of people with disabilities in the contexts of small provincial town and the capital, we have undertaken a study among university students implementing an inclusive educational strategy.

Methods

A focus group study was conducted in May 2018 among students of an inclusive Moscow university. For the purpose of sociological analysis, eleven participants were selected from among students with disabilities who came to study in Moscow from provincial towns. The use of the focus group method allowed us to find out how the processes of activation of disability look like, as well as to understand how and under what external circumstances the so-called inclusion of disability occurs, how the impossibility of urban citizenship of people with disabilities arises, depending on the specifics of the situation in which they find themselves. The application of this method made it possible to detect the peculiarities of perception of stigma pressure, as well as urban everyday patterns of stigma reproduction, and to determine the existing differences between cities in this parameter. When processing the data, at the first stage, transcription was carried out, then the main idea was derived. At the second stage, an axis of key categories was built and a search was made for topics that clarified the basic research logic (types of perception of disability, attitudes towards people with disabilities in the capital and provinces, discriminatory and atypical manifestations of citizens in a situation of meeting people with disabilities). In the course of the study, special attention was paid to the self-awareness of young people with disabilities, depending

on their location in a particular city or in certain urban spaces.

Results And Discussion

The situation of a cosmopolitan city (Moscow) with a developed accessible infrastructure normalizes the life of a person with a disability to a greater extent and allows us to talk about the development of conditions for equal urban citizenship of disabled people in the format of an interdisciplinary model of Disability studies. In this sense, a cosmopolitan city with an actively formed accessible environment and a variety of services makes it possible to analyze the realities of disability outside the body.

«The story took place at the airport: in Vnukovo, I ordered assistance for people with disabilities, so that they would help me climb the ladder. Everyone addressed me in a very polite way. And when I came home, I immediately felt that they began to address me completely differently. And another bad fact is that they began to perceive me as a child. It was strange. Basically, you can't tell by the face that I'm a child. But upon arrival in a small city from Moscow, I felt that people are becoming rude, grabbing things and treating me humiliatingly» (female, a disabled person of group 2, Robinow syndrome, 19 y.o).

If we accept L.S. Vygotsky's point of view as a basis, who believed that the effect of a defect is not immediate, but secondary, and that the difficulties faced by people with atypical appearance are realized primarily as a decrease in social position, the experience of our informants suggests that provincial, small and medium-sized cities sometimes instantly force a person to become involved into the disability, to turn from an adult and independent person into a small and handicapped one, to remember what he or she is and what he cannot do. Disabled health or an atypical appearance is a certain condition for a person's life, but urban spaces are sensitive to these conditions and needs to varying degrees. Taking disability out of brackets, we come to a stratification analysis of urban realities, the specifics and mentality of urbanism.

«I live in the city where I was born. It is clean, and this is good. But it is inaccessible, which is a huge minus. And sometimes there are many inadequate people» (male, a disabled person of group 2, CP, uses Canadian crutches, 22 y.o.).

«We came to the club to relax, but they did not let us in and could not explain why they did not want to let us in. We were all over 18 years old, we all had our passports with us. But we immediately realized that this was discrimination: supposedly we would scare people. This does not happen in Moscow. It happened in Penza and in Ryazan too» (male, a disabled person of group 2, dysfunction of the upper limbs, 23 y.o.).

Stigmatizing practices are reproduced in the everyday life of the capital as well. The stories of our informants about the encounter with obvious discrimination enables us to conclude that there are no significant differences between the city and the town in the degree of respect or rude attitude towards disabled people. However, it can be assumed that there are differences in the reasons that trigger negative attitudes towards disabled people. If we refer to a provincial town, our participants talked more about the rudeness and bad manners of local citizens, as well as about the infantilization of the disabled in such cities, and in the context of the big city.

«Maybe this is the rhythm of life. In Moscow it is faster than here in a provincial town. And it also depends on, what mood each person has...» (a disabled person of group 1, uses a wheelchair (spinal injury), 19 y.o.)

«The human factor in Moscow sometimes is simply turned off» (male, a disabled person of group 2, dysfunction of the upper limbs, 23 y.o.)

The most revealing cases are when focus group participants talked about how they tried to ask for help to go up or down stairs, but people mechanically reacted to them as to beggars.

« Moscow is a big city. We have asked people for help many times, for example to climb the escalator in the metro, or even the stairs. We were always refused, because people thought us to be beggars and passed by but we just needed someone's help. (male, disabled person of group 1, uses a wheelchair (lack of legs), 22 y.o.)

On the one hand, infrastructural accessibility, variability and populousness of the capital provide significant advantages of mobility, employment, growth of social well-being and opportunities for communication, however, negative attitudes, as well as sensitive empathic ones, are present in all cities.

«In my town (Tchaikovsky), I actively ride a bike and once I came to the service center to replace the brake system, and when this repair had been done and it was time to pay, the seller did not take a charge.». (male, a disabled person of group 2, CP, 22 y.o).

Among the focus group participants, these stories caused a double reaction. One part considered it a manifestation of pity for the disabled. Another part of the group, slightly exceeding the first in number, considered this a manifestation of kindness but not humiliation. Many people are sure that people with disabilities should be able to accept help with gratitude.

All participants in our study agreed that in our cities, in particular, in the metro, on the trains, near the church or on the roads, disabled people are seen in the role of beggars, that is, the agency of disabled people predominantly takes on such forms. Based on this, the majority of ordinary citizens construct stereotypes of perception of disability, which then take the form of clichés and apply to absolutely all people with visible disabilities.

«Well, probably there is an opinion here that disabled people constantly stand near a church or somewhere else and beg for money regardless the fact we are dressed good.» (female, a disabled person of group 1, uses a wheelchair (lack of legs, underdevelopment of the left hand), 25 y.o)

«This, by the way, is a very common thing. My friend and I wanted to go down to the subway so tried to ask passers-by. Only foreigners came to us and offered their help» (male, a disabled person of group 2, dysfunction of the upper limbs, 23 y.o).

Stigmatization is not absolutely correlated with the degree of accessibility of the environment, but the infrastructure that allows a person to do without outside help helps him or her to avoid facing stigmatizing attitudes. All participants in our study talked about special and positive feelings, about the feeling of freedom that they have in places with an accessible environment. Here the disability status goes to the peripheral level. On the contrary, negative feelings, fears and resentments are associated with places that are inaccessible, places where

there is a offending spatial organization.

Physical inconvenience, discomfort and limitations on independent action provoke negative feelings, and on the contrary, a barrier-free infrastructure provides psychological comfort and a feeling of complete freedom, activity and productivity. Accessibility directly affects an individual's attitude and mood. But not only the infrastructural accessibility of cities caused active discussions among the focus group participants, but also the types of citizens' responses ("normats") to an atypical person.. The participants of our study consider the absence of unnecessary heightened attention to them as a prerequisite for decent urban citizenship. The unpleasant feelings arising in connection with it were spoken about:

increased attention of people around: «Gazes are very annoying» (male, disabled person of group 2, dysfunction of the upper limbs, 23 y.o.). «We came to a cafe in a small town with a population of 98000 people. I danced in a wheelchair, and after the dance, people began to approach and say nice things: «Well done, that you are active, that you are not shy and came here», «I know that you will stand up!», «Get well soon», «You are so beautiful, just remember this», «Can I just give you a hug?» (female, a disabled person of group 2, uses a wheelchair (spinal injury), 25 y.o.)

infantilization of disabled people: «Sometimes they treat me like a little child...» (male, a disabled person of group 2, Robinow syndrome, 26 y.o.). «My girlfriend and I were sitting in the park on a bench, she is also disabled. We were on a date, not only did the passers-by scrutinize us, but then one woman came up and began to treat us with sweets, as if we were little children» (male, a disabled person of group 2, CP, uses Canadian crutches, 22 y.o.)

Based on the presence of this type of reaction, the capital seems to be more comfortable for young people with disabilities, although sometimes they speak out about the indifference of passers-by. Small towns always mean heightened attention from harmless approving tutelage to incomprehensible or traumatic reactions.

There are also very harsh forms of interaction with disabled people: «When I went to the regional fitness center to swim in the pool, the receptionist said that their pool was not for people like me. When I asked about the reason, she said that people with my disease should lie at home, eat 3 times a day and not worry about anything else» (male, a disabled person of group 2, CP, 22 y.o)

«A friend of mine with her disabled child visited an entertainment center. She had to persuade the administrator for a long time to allow the child to jump on the trampoline, as he believed that this child could harm other children. In the end, they were allowed to go to the playground, but the administrator did not leave them for a minute and after a while hinted that it was time to leave, justifying the imminent start of a children's party in that center. The child really wanted to play and just be with other children. The money for the tickets was returned a week later» (from the story of a student of the focus group)

We asked the participants of the study to give an association to the combination of words «Disabled person in the city» and received the following answers: a wheelchair; some kind of barrier; workers in the subway, services; a person, just a person; ramps; homeless people; active life; money; strength of mind. The combination «Well-being of a disabled

person in the city» caused the following thoughts: the ability to move around without obstacles; full life; accessible ramps; equality; this is when they are assessed by professional skills and not by disability; the kindness of people around; high pension of 50 thousand rubles; when everything is free; a new stroller; drive a car; well-fed, dressed properly.

The study participants spoke about the changes that had occurred over the past five years in the field of attitudes towards people with disabilities: «People were given the opportunity to interact with us and we were given the opportunity to interact with them. Now people have simply ceased to notice these physiological features in people. More interpersonal communication has probably appeared. It takes a little more time, it is becoming a norm...» (male, a disabled person of group 1, uses a wheelchair (lack of legs), 22 y.o)

For all focus group participants, moving to Moscow significantly improved their quality of life, they began to attend various events more often, walk, communicate more, get to know each other, their self-esteem increased, they became more confident, sociable and more open. On a ten-point scale, students rated the comfort of the capital by ten points, the comfort of their small towns mainly by 1-2, less often the scores reached five points.

Summary

Disability studies today are mainly conducted in interdisciplinary fields, but if sociology, medicine, law, social work and social anthropology have already become traditional for the analysis of disability, then urban studies are just beginning to be involved in a range of disciplines for studying indicators of the quality and lifestyle of people with disabilities. Adding urbanism to the research field let us examine how and in what urban conditions, in the presence of which groups of citizens, things, procedures and city flows the reality of disability is produced. This approach allows us to view the extra-clinical everyday contexts of urbanism, where the disability is turned on and the drama of the relationship of an atypical person with the city is played.

Urban spaces to a certain extent are sensitive to disabilities and the needs of people with disabilities. The capital-province dichotomous field reveals both similarities and differences in disability response. There was a difference in the reasons that trigger negative attitudes towards people with disabilities. In a provincial town, it is the rudeness and bad manners of the citizens as well as the infantilization of people with disabilities. Metropolitan architectonics is filled with features of insensitivity, haste and stereotyped response.

Conclusions

The results of the study suggest that stigma does not have an absolute correlation with the degree of accessibility of urban infrastructure, but it is the barrier-free environment that helps a person with disabilities avoid facing stigmata. In addition to discrimination and stigmatization, two strategies for the reaction of passers-by (mainly in provincial towns) have been identified that contradict the ethics of inclusion: increased attention and infantilization of people with disabilities. In this context and in terms of infrastructural architectonics, the capital is more comfortable with young people with disabilities, who noted an increase in their subjective sense of well-being and rated the comfort of the capital at a maximum of ten points, while the assessment of the comfort of their small hometowns rarely reached five points. The positive dynamics of the urban context largely depends on the agency of people with disabilities

(on their real presence in the city), which normalizes the urban context, and the citizens, coming into contact with people with disabilities in everyday flows, learn to interact correctly and adequately and get rid of stereotypical attitudes, and also form new ideas about situations associated with the atypical behaviour of some people.

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