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Perception of disability and of people with disabilities depends on the historical and cultural context and social differences in a particular society. In the past, in Russia, until the mid-20<sup>th</sup> century a traditional, mainly peasant society, a person with serious diseases or defects preventing him or her from performing daily household functions was viewed as an “extra mouth” to feed (Frolova 2019; Shlyakhtina 2019) with the possible exception of those whose skills could be of use (for example, deaf or retarded persons sometimes became shepherds, blind persons wove baskets. Another exception was the attitude to the so-called fools-for-Christ and silly-hearts who were considered a kind of local saints). In addition to that, such perception is in line with Judeo-Christian ideas of punishment for one’s sin or the sin of one’s ancestors. Russian culture was a local version of the “culture of guilt” (described by R. Benedict back in 1989 (Benedict 1989)), which also had a significant impact on how disabled people perceived their disability.

In the USSR, perception of disability and disabled people was ambivalent. On the one hand, a person with disability who was unable to work was inevitably perceived as a “burden to society”. (Fieseler 2014), a perception still largely shared today. On the other hand, Soviet literature glorified persons who overcame a severe disability and became socially “useful” (Nosenko-Stein 2021). In its early years, the USSR pursued a social policy aimed at involving people with disabilities in community work - in the 1920s, workshops for visually and hearing impaired people, also people with some other categories of disability, were set up where simple manual labor was practiced (making brushes, mending clothes, etc.). At the same time - and it became especially obvious after World War 2 - the policy was to “clear” the streets of Soviet cities of disabled people sending them away to remote special-purpose institutions. In the 1960s-1970s, based on organizations for disabled people (the All-Union Society of the Blind, the All-Union Society of the Deaf), specialized enterprises were created where people with disabilities worked. Work there was also generally fairly simple (assembly of electrical plugs and sockets, work in forge-and-press shops, etc.). Those enterprises enjoyed a serious government support (e.g. they were partially or fully exempt from taxes) and could provide welfare payments and benefits to their employees (Nosenko-Stein 2018).

This kind of policy inevitably led to people with disabilities becoming locked in an environment of people of their kind. The situation was even more exacerbated by the perceived Other body. Not infrequently, Other corporeality was an object of all sorts of negative cliches and stereotypes,

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including fear, disgust, desire to distance oneself from it (Bolt 2014; Nosenko-Stein 2017). Such stereotypes manifest themselves especially strongly in respect of mentally and psychically impaired persons as Other corporeality in those cases is often accompanied by secretions, odors, sounds that a person is unable to control (Klepikova 2018). People with physical defects may also cause such emotions - this is evidenced both by autobiographical texts written by people with disabilities and by fiction, especially by mass fiction books reflecting mass stereotypes and fears (Garland Thompson 1997; Bolt 2014; Nosenko-Stein 2021).

This paper is a brief essay on how what I call a “disability ghetto”, a kind of closed sociocultural environment in which part of people with disabilities exist, has occurred. An attempt is also made to describe the attitude of people with disabilities to this phenomenon.

### **Sources and methodology**

In my research I use various sources. One of them is my field materials - the texts of in-depth interviews that I took of persons with disabilities and heads of organizations for disabled people in 2014-2021 in different Russian cities (Moscow, Nizhniy Novgorod, Smolensk, Kislovodsk, and Archangelsk). Those cities in the European part of Russia were selected as they represent mega cities (Moscow, Nizhniy Novgorod), medium-size regional centers (Archangelsk and Smolensk) and relatively small cities (Kislovodsk). Chosen as informants were people with congenital and late-life disability - people with sensory disorders (vision, hearing), musculoskeletal system disorders (these are often disorders caused by various injuries), and also neurological diseases (cerebral palsy). I found informants in various organizations for disabled people and also using the “snowball” principle. I have selected 12 biographical interviews for this paper reflecting the experience of other life, a life in a closed community or outside it, and one expert interview touching upon the issue under investigation. Interviews lasted from one to two and half hours and were voice recorded (in certain instances interviews were recorded via Skype or, in case of hearing impairment, for example, via e-mail). These are also texts of several autobiographies written by persons with disabilities in the post-Soviet period and reflecting life experience and life styles of people with different categories of disability.

### **Life in a “parallel world”<sup>2</sup>**

People with congenital diseases or diseases acquired early in their childhood leading to disability, often at a pre-school and then school age experience the feeling of loneliness. Ruben Gallego (the **225** grandson of the General Secretary of the Spanish Communist Party who was born in the USSR in

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<sup>2</sup> The phrase “parallel worlds” is taken from the title of a paper referenced here (*Phillips 2018*).

1963 with a severe form of cerebral palsy and put to a special home for children) felt it very early in his life. He wrote about it in his autobiographical notes: "At eight years of age I realized one very simple idea. I am alone and not wanted by anyone <. > I envied Quasimodo. People looked at him with pity and disgust as they looked at me, but he had arms and legs" (Gallego 2004).

The feeling of loneliness and their own otherness is experienced even by those children who grew up in families; with them, the feeling of loneliness paradoxically combines with the feeling of being overprotected. Hyper-protection has been frequently mentioned to me by heads of various organizations for disabled people who said that parents often raise their children in a way that they do not develop any independent-living skills and are incapable of performing simplest actions towards that. The head of a "cell" in the All-Union Society of the Blind said:

I have recently talked to this kind of a mum. Just imagine, her boy is 18 and she laces his boots for him! - "Oh, but he doesn't see!" - "And what of it? - I tell her. "He needs to be able to do everything he needs. You won't be around all his life". But it's no use saying it to such people. (Nizhniy Novgorod 2015)

Such hyper-protection increases the child's isolation from "normal" peers, which, in turn, exacerbates the feeling of loneliness and even of being an outcast that will be there for a long time or forever. Yulia V., 28, life-long disabled (cerebral palsy), studied in a special school for children with musculo-skeletal system (MSS) diseases:

I remember once taking a look in the direction of children who sailed toy boats in a puddle and got besmeared all over doing that. My mum noticed it, smacked me on the backside and shouted something like 'the pigs are frolicking here unattended, you will never ever have anything to do with them!' - "Why never ever?" - I askedю Mum said they had other life and other interests. I felt hurt about having some other way of I life. (Moscow 2018)

Victor V., 42, life-long disabled, MSS disease, does not work, lives with his mother:

My mum told me that in my early childhood she simply had not dared to let me play with other children. As a result, I never attended a kindergarten. I didn't have friends in the neighborhood, when I went out for a walk, it was always with my mum holding me by the hand. Later, I felt all my life that I was an outcast." (Nizhniy Novgorod, 2017)

Such children develop a feeling of their 'otherness', isolation and impossibility to belong to the world of normal people and it stays with them for many years. Those who went to special schools gradually develop a circle of Own people who they mainly communicate with, make friends with and pass their leisure time with outside of school. Yulia V. mentioned above: "I could certainly study only at a special school; how could I be at a regular one? I'd have been henpecked there. Approach to children at my school was normal." (Moscow, 2018).

In the latter case, as Yulia mentioned on several occasions, the situation was exacerbated by Other corporeality (involuntary limb contractions, peculiar speech causing children's and adults' unfriendly curiosity). Other corporeality is a cultural marker differentiating Other ones from normal ones. Isolation from the world of normal ones is much driven by going to special boarding schools which existed and continue to exist in mega cities (when it is difficult for parents to take their disabled child to a school located far from home and pick him/her up from there after classes). After finishing boarding schools, many former school children join organizations for disabled people where they spend their leisure time (excursions, concerts, festive events), which deepens "ghettoisation", sometimes voluntary, of such people.

Vladimir Z., 63, life-long disabled (impaired vision), a history teacher at a school, was very enthusiastic: "Our All-Russia Society of the Blind is really great! There are so many interesting things there and people are so warm. ...A place to rest my mind" (Moscow, 2015). Currently those organizations, no longer enjoying government support, have lost their former attractiveness for people with disabilities and turned mainly into leisure centers (Nikonova 2018).

Later, some people with disabilities continue to study trying to get vocational or higher education, which in the past two to three decades has become more complicated (Voronin 2018). In Russia there still exist special secondary education institutions where people with different disability categories are trained (visually impaired masseurs, deaf librarians, etc.) (Bolshakov 2017). Being in such educational institutions also deepens the trend towards separation of people with disabilities.

Bairamkis, 48, life-long disabled (impaired vision), masseur, studied at a remedial school, then at the Kislovodsk Medical School for the Visually Impaired People:

After school where all of us were more or less the same, I continued for another two years in Kislovodsk. Everybody was like that there and we kind of stewed in our own juice. <.. .>  
When I got married and moved to the city of Kemerovo, not only did I feel self-conscious, I was awfully inhibited and uncomfortable. For roughly 12 years I had lived in a circle where everybody was blind or partially sighted. And when we left that environment, when we went to work, I felt like a disabled person, I felt bad, I cowered. I felt my disability, my inferiority (Moscow, 2015).

Thus, a "disability ghetto" begins to be formed early in disabled people's lives. If they happen to get outside it, they often feel like Strangers, like people who are "worse" than those who are normal. They feel psychologically comfortable among people of their kind, while from others they feel wariness and sometimes a negative attitude. Lidya N., 38, disabled from cerebral palsy, university **225** background, does not work:

When after school I was enrolled at a university, I immediately felt that I was being looked at in a kind of peculiar way. No, they didn't bully me. Nothing of the kind, I was simply very much unlike all the others, I was a freak to them. ... I felt it when I was a child, too, but at school I was among kids of the same kind, in the street, though, it was different. Sometimes people wouldn't just stare at me, they would point their finger at me. ... I remember literally throwing a tantrum crying: "I want to be like everybody else, like everybody else, like everybody else." (Archangelsk, 2017)

Another reason for ghettoisation of people with disabilities is the fact that such people tend to massively select certain universities for their higher education. For example, many go to the Moscow State University of Psychology and Education to become psychologists, the State University of Culture trains librarians and bibliographers, the Russian State Social University trains social workers, etc. People with disabilities find it much more difficult to find a job as a result of being overtly, and more frequently covertly, discriminated against. Many of them fail to get employment. (Lazoukova, and Seletkova 2018; Nosenko-Stein 2018).

Not infrequently, life-long disabled people eventually stop striving to break away from the "ghetto" and prefer to continue to be with their own kind, including dating them, marrying them, etc. The low status of people with disabilities discourages a considerable part of them from living in such "ghettos" - they do not want to join "disabled" organizations because they do not want to belong in a low-status community.

For example, Larisa G., 54, visually impaired, at the time of the interview was temporarily unemployed: "I have never felt inferior. You see, there has never been any talk of disability in my family. I was brought up not to be inferior" (Moscow, 2017). Larisa was not a member of the All-Russia Society of the Blind and her perception of people with disabilities as "inferior" fairly well characterizes her reluctance to belong with them.

### **Life beyond the watershed<sup>3</sup>**

The "disability ghetto" is also avoided by those who became disabled as adults as a result of an injury, a progressing disease, wrong medical treatment, etc. For them, identifying themselves with the "disability ghetto" does not only mean joining a low-status community, it is a kind of confirmation of their final passage to the netherworld (Nosenko-Stein 2020), a confirmation of their othering, of acquiring the status of Other, "worse" people. In her autobiographical notes, Irina Yassina described the feelings she had after the verdict of a diagnosis had been passed on her (she is the daughter of a well-known Russian economist, Yevgeniy Yassin, in the past worked in the bank

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<sup>3</sup> The title of this section is a paraphrase of the title of a chapter in A. Grafov's autobiographical book "Notes of a Blind Person" (2009).

system, at the age of 35 was diagnosed with multiple sclerosis, a neurological disease leading to a severe disability): “My future seemed more terrible than death to me, it meant helplessness, dependency, and loneliness. I feared waking up” (Yassina 2011).

As has already been said, many organizations for people with disabilities have now turned into leisure centers, therefore people with late-life disability do not see any sense joining them - there is no real possibility of getting help with employment, no chance of making friends or meeting future spouses as horizontal links have already been formed by those life-long disabled people who joined the organizations a long time ago.

That is the reason why people with late-life disability, for whom its appearance is usually very painful (quite often perceived as a personal disaster), try to avoid getting into the “disability ghetto” preferring loneliness and choosing either active life strategies or, on the contrary, the path of self-isolation. Vladimir N., 45, hearing loss (lost his hearing at 42 as a result of a post-flu complication), was a chemistry professor at a university in Moscow, had to quit after the diagnosis, lives with his wife and son:

In the beginning, I thought I’d lose my mind ... My job, my friends, my family - who’d need me crippled like that, - I thought. Not hearing anything, everybody having to write to you. ... Then I began getting used to it. I had to part with my job and now spend a lot of time in our summer house <...> It’s also life, isn’t it, only kind of detached from everybody. Honestly, I thought I’d go off my chump <when I lost my hearing>. I was like in a cotton-wool cocoon, rather like in a sound-proof chamber. <.> How can I work - I can’t give lectures, can I? <.> It was very hard at home, too. <.> Bad thoughts occurred - well, you understand. Even now I try to spend more time in the summer house in the countryside - apple trees don’t need to be spoken to.

- Did you try to turn to the All-Russia Society of the Deaf?
- No. Well, my mother-in-law called them. They say: “Please, join and be our member”. She asks: “What can you help my son-in-law with?” They said they organize parties, hold meetings. What do I need all that for? (Moscow, 2018)”

Maxim V., 37, became disabled at 32 as a result of a car accident, now in a wheelchair; before the accident was a sole trader, was married, has a daughter; currently does not work, lives alone:

At first, it was more than just hard - I didn’t know where I was and what had happened to me. But at that time some of my friends visited me, my wife was still with me, and my daughter. Now I’m like inside a cannon ball, I don’t have anything. Just the internet, my little window <sup>225</sup> into the world. But then who shall I write to. Who could care about my problems? You know, I sometimes simply write letters and email them to fake addresses. (Nizhny Novgorod, 2015)

In other words, those who become disabled as adults perceive their new status as a ruin of their life passing from their former world and status (rather, statuses) to another world and a lower status.

Such people for a long time - sometimes for their whole life - remain in a liminal state much written about by V. Turner, R. Murphy et al (Turner 1983; Murphy et al. 1988): “.they do not have a status, <.>. Their behavior is passive or humble; <.>. It is as though they are being reduced or ground down to a uniform condition to be fashioned anew and endowed with additional powers to enable them to cope with their new station in life” (Turner 1983: 81).

Some people with late-life disabilities join different disabled people’s organizations and communities, but, according to heads of such organizations and informants themselves, they usually remain “passive members” or simply are on their membership lists.

Svetlana M., 36, with serious MSS disorders resulting from a car accident), works from home: I always wanted to do something artistic, something related to beauty. But my parents thought it was unreliable, that there wasn’t much money in it. And I listened to them and went to a sales vocational school. <.. .> And after all that (Svetlana means the accident and subsequent disability) I began making all sorts of trinkets - beads, pendants, earrings. First for myself and friends, then for sale. Well, you know, maybe it’s really true, after all, that every cloud has its silver lining (smiling). And then, one wants to make at least some extra money, pensions in Smolensk are low. <...> - Did you try to turn to the All-Russia Society of Disabled People? - I did. I am even registered with them, or whatever it is called. But they didn’t help me in any way Well, they do hold meetings but I can’t physically get there anyway.” (Smolensk 2016)

### **Walls around the ghetto**

The “disability ghetto” is a construct of normal people. The leitmotif of a great many oral stories is embarrassment and even fear felt by people at large towards people with disabilities (Nosenko-Stein 2017). These emotions may take the form of concern for disabled people’s physical or mental disorders (‘he will fall down’, ‘he will break something,’ ‘he will not manage’). Very often people do not know what is the right way to help a disabled person in this or that situation and whether they should be helped at all. As a result, normal people want to distance themselves from and avoid people with disabilities.

Elena N., 37, visually impaired, university education, lawyer, at the time of the interview did not work:

It has always seemed to me that it was nothing but fear, people don’t know and they are 225  
scared right away - what if some additional efforts will be required from them with this



person. That's the impression I get -what if I start making claims, what if I want a free ride on their backs. I have always felt that way. (Moscow, 2018)

Those impressions are not groundless. As has already been said, in the USSR before and in many post-Soviet countries now, a person with disabilities has often been perceived as a "burden to society". Alexander Suvorov, a deaf-blind poet and scholar has many a time written about such a perception. In his autobiographical book he cites the words of a teacher from a boarding school for deaf-blind children:

That's just what I wanted to speak about. A lot has been invested in those children, very much indeed. And what can they give back? That's the first thing to think about. The state has been generous to them and will continue to be - they are domiciled in Moscow, they have a degree,

they have been provided with housing. What for? They cannot give anything back to the state, nothing in return, zero return." (Suvorov 1996)

To add to that, people want to distance themselves from those who in a given society are stigmatized due to their low status, and people with disabilities are one of the most stigmatized social groups (Goffman 1963; Iarskaia-Smirnova 2001). The situation is similar to what G.W. Allport wrote about several decades ago describing the mechanism of distancing from and avoiding Jews in Nazi Germany (Allport 1954). That is why people with disabilities (even lifelong disabled persons "integrated" in the life of a disabled community) sometimes want to distance themselves in appearance from the "disabled status."

Anastasia K., 28, loss of eyesight (was gradually losing her eyesight as a result of progressing macular degeneration of retina until final loss happened at the age of 17). Anastasia graduated from a medical vocational school for the blind and works as a masseur in the city of Kislovodsk: "How can we be disabled? We are not disabled, are we? Disabled is someone who cannot attend to oneself, a vegetable. As for me, I work, do everything myself. We are not disabled, we are people with limited abilities, that's what we are" (Kislovodsk, 2017).

Such people, usually those who opted for an active attitude to life, do not want to live in the "disability ghetto" not only because they are reluctant to find themselves among members of a low-status community but also because they do not see any sense in the mere existence of such communities.

Maria, 32, cerebral palsy, a post-graduate degree in pedagogics, works at the Moscow State University of Psychology and Education. When asked if she was a member of the All- Russia Society of Disabled People, she answered: "No, I hadn't joined it before I came to Moscow <Maria used to

live Stavropol>, somehow hadn't got round to it. I don't know what for. <.. .> Neither have I got round to it in Moscow yet. Maybe if I understand that it's necessary, I will" (Moscow, 2021).

## Conclusions

The existence of the "disability ghetto" leads, on the one hand, to normal people lacking objective knowledge about disability and about real problems of people with disabilities. This results in prejudice, negative stereotypes and cliches, stigmatization deepening in mass consciousness. At the day-to-day level, in turn, this leads to distancing from and avoiding those who are bodily Other, hiding - and sometimes not hiding - the feeling of disgust and fear.

In a number of cases people with disabilities, especially with a late-life occurring disability or relatively "easy" disability, also want to distance themselves from those who have completed the "rite of passage" and who are very low on the social ladder. I have already written elsewhere that for people with a late-life disability a medical diagnosis confirming their new status is the beginning of a kind of rite of passage not only from one status to another but also from one world to another (Nosenko-Stein 2020). Stigmatization of people with disabilities, serious difficulties with their psychological, daily-life, and social rehabilitation, almost total lack of professional re-training and discrimination when being hired lead to people with late- life disability finding themselves in a vacuum. Auto-stereotypes of otherness, perceiving themselves as a Stranger among Strangers also contributes to their separation from other people (the price they pay for refusing to "live in a ghetto", in practical terms it often leads to serious difficulties with adaptation and integration in society).

On the other hand, - and that is typical of many types of ghettos (take for example Jewish ghettos where the gate in the wall surrounding them was locked for the night from inside) - some people with disabilities (especially life-long disabled persons and persons with a severe disability) are not at all eager to go out to the "great wide world" feeling psychologically more comfortable among those of their kind, Own people, where they can easier find the necessary information or help without running into situations of being avoided or directly insulted. That is characteristic not only of people with disabilities but also of representatives of many low- status socio-cultural groups. In cases when internal relations and elements of support develop or already exist inside such groups, the situation of a socio-cultural ghetto may arise.

Normal people are happy with the "ghetto" situation as it makes it possible to have social **225** control over people with disabilities and take decisions not caring much about their opinion.

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