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Strategies of Disability Activism in Soviet and Post-Soviet Russia

SVETLANA BORODINA

Despite the common stereotype of people with disabilities living completely immobilized and segregated lives in Soviet and post-Soviet Russia, they have actively participated in shaping their conditions. Depending on the historical and political moment, their tactics have varied. Through independent and institutional activism, petitioning the state, running mutual aid organizations, building networks, and making art, people with a variety of disabilities have shifted, adapted, and challenged the status quo. They have not followed the familiar model of taking their protests to the streets or confronting lawmakers. But Russian disability activism has a rich history and has taken many forms.

Disability and Equality

Second in a series

A unified movement based on the idea of disability rights as universal human rights did not emerge during the Soviet era, though such activism was beginning in the West at that time. Nor did communities driven by disability pride materialize. Instead, several different groups—the blind, the deaf, war veterans, and people with mobility impairments—developed their own forms of activism through which they engaged with society and challenged the conditions in which they lived.

Due to the differences in their social standing and resources, the forms of community available to them, and their varied capabilities and needs, these groups did not have much contact with each other. They focused on fighting for the well-being of people like themselves, rather than offering a political critique of the Soviet system—or, later, of capitalist Russia. They all worked to improve

living conditions and access to resources within the political system they inhabited.

WILLING SOVIET WORKERS

For blind and deaf people, the revolutionary years provided an opportunity to free themselves from the tutelage and charity that were their usual lot in tsarist Russia. After the February 1917 revolution ended tsarist rule, pioneering organizers in two independent associations, the Union of the Blind and the Union of the Deaf-Mute, fought for legal equality and freedom from guardianships, which were granted in July 1918.

Both activist groups soon backed merging with the state apparatus to ensure systemic support. The All-Russia Society of the Blind (VOS) was founded in 1923 and the All-Russia Society of the Deaf (VOG) in 1926, both functioning under the Commissariat of Social Assistance. This became one of the USSR's first cases of institutional activism in the form of state-run societies. But as historians Claire Show and Maria Cristina Galmarini-Kabala argue, this close connection with the state did not discredit activists' work.

Throughout the Soviet era, VOS and VOG activists refused to equate blindness and deafness with helplessness. They claimed agency by demanding job access and educational opportunities. Aiming to demonstrate that their members' capabilities were no less than those of sighted and hearing citizens, they advocated for the right to live independently and engage in useful work.

Against commonplace depictions of disabled Russians dependent on alms, they counterposed images of capable blind and deaf people. They proclaimed their readiness and desire to transform “uncultured” and “illiterate” disabled people into conventionally productive Soviet subjects. In

SVETLANA BORODINA is a postdoctoral research scholar at the Harriman Institute at Columbia University.

this way, the activists appealed for state support by promising to normalize disabled populations for a future of usefulness to the collective. They argued that people with disabilities could become full-fledged Soviet citizens if they received the necessary help and access.

Yet such productivist rhetoric solidified harmful stereotypes about blind and deaf (and other disabled) people, affirming that in order to be considered “whole,” they needed to change themselves to fit into the labor force. As Galmarini-Kabala says of the Soviet system of disability support, it “combined humanitarian impulses and invasive forms of discipline and control.”

The shortcomings of Soviet industry and educational and housing infrastructure hindered the the activists’ work. Schools for children with disabilities lacked equipment and were in poor condition; urban environments were inaccessible; plants lacked the equipment and diversification to employ disabled workers successfully. Many employers held prejudices against hiring blind and deaf workers, fearing that they would be slower and less productive than their able peers. This inadequacy of material infrastructures was a considerable barrier even for those with disabilities that did not preclude them from joining the labor force.

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VETERANS IN THE VANGUARD

During World War II, much of the Russian population experienced physical and mental trauma. Widespread sectors of the economy and infrastructure were damaged or ruined; the health care system was overwhelmed. The war also resulted in a dramatic increase in the number of disabled people. Among them were veterans disabled by war who claimed the right to special treatment earned by their service.

Disabled veterans introduced a new element to the relationship between the state and citizens with disabilities. They insisted on the symbolic debt that the state and society owed them as soldiers who had sacrificed their bodies for their country and were thus entitled to privileges and benefits. Their demands challenged the extant rehabilitative model, which was focused predominantly on vocational training and called for attention to other aspects of well-being: family, marriage, friendship, affection, and care.

Under Stalin, any form of independent political organization (except those authorized by the state) was prohibited. But veterans managed to establish connections among themselves. They planted the seeds for a movement that would eventually flourish.

After Stalin’s death, organizing became somewhat easier. In 1956, thirty mobility-impaired people on scooters gathered in front of the Moscow headquarters of the Communist Party’s Central Committee to protest the state’s inability to guarantee disabled war veterans the same rights that Western capitalist countries did. Later that year, a new Moscow-based organization was founded—the Soviet Committee of War Veterans (SKVV).

Despite demands to extend the committee’s purview to advocating for disabled veterans and improving their living conditions, its official goal was to produce international and domestic propaganda. During the SKVV’s meetings, activists pushed to make the committee a centralized organization of veterans, analogous to the VOG or VOS.

Although the committee was slow to change its mandate, activists took the initiative to form local mutual aid groups, often flying beneath the party’s radar. As historian Mark Edele notes, in the 1960s such groups existed in military schools, officers’ housing, factories and other enterprises where veterans worked, and local history museums across the country. In 1965, the Central Committee finally granted the SKVV permission to establish local chapters.

In 1976, however, the Central Committee ordered a downsizing of the SKVV. But the veterans’ movement continued lobbying for special rights and status, which it won in 1978. The movement was finally allowed to establish the All-Union Organization of Veterans of War and Labor (VOVVT) in 1986. Edele observes that unlike the SKVV, which had focused more on international propaganda than on promoting veterans’ interests, the VOVVT “combined such interest politics with service to the Soviet state.”

DISSIDENT ACTIONS

Not all self-organized groups of disabled people drew recognition and appreciation from the Soviet state. The anthropologist Sarah Phillips has noted a stream of disability rights activism

that emerged in the 1960s from disability group homes, or *internaty*. Shared experiences and dissatisfaction with their living conditions fueled their activism.

Among the activists cited by Phillips is Gennadii Gus'kov, a polio survivor and an advocate for establishing the All-Union Society of the Disabled. He collaborated with local authorities to push for improved job opportunities, with some positive results. But after associating with dissidents, he lost state support.

Another prominent example of activism that lacked state authorization was the Action Group to Defend the Rights of the Disabled, founded in 1978. The three founding members of this group—Valeriy Fefelov, Yuriy Kiselev, and Faizulla Khusainov—all had mobility impairments. Like Gus'kov, they sought to establish an All-Union Society of the Disabled.

They published information bulletins documenting the living conditions and experiences of people with disabilities in the USSR and appeals to the authorities to defend their rights. They also connected with international disability organizations, mainly in Europe. The Soviet authorities perceived the group as a threat to the regime and harassed its members. Their apartments were searched and they were threatened with arrest and imprisonment.

Fefelov fled to West Germany. In 1986, he published the book *There Are No Invalids in the USSR!* It detailed the problems faced by Soviet citizens with mobility impairments, including universal inaccessibility, inadequate medical care and hospital equipment, poor-quality prosthetics and assistive technologies, long waiting times, bureaucratic indifference, and a lack of job opportunities for wheelchair users.

Disability rights activism in the USSR did not pursue political goals. Yet bureaucrats treated these activities as a threat to disrupt the political system and the socialist project.

While the later Soviet period brought new openings for war veterans, deaf people faced a different situation. Historian Claire Shaw emphasizes that the VOG was initially driven by a revolutionary impulse to “free” deaf people from the presumption of defectiveness and open up opportunities for them to become valued Soviet citizens. With the development of hearing aid technologies and the expansion of welfare over the years, the society’s activist impulse gradually declined. Also, when deaf enterprises became successful,

they were usually taken over by non-hearing-impaired management and bureaucracy. This led to depreciation of the deaf community in the late Soviet years.

POST-SOVIET OPENINGS

The dissolution of the Soviet Union and the development of information technologies dramatically diversified the scope of Russian disability activism. Suddenly there were many ways for disabled people to push for social change: participating in NGO-led projects (newly allowed by the state); lobbying through centralized organizations such as the All-Russia Societies of the Disabled, the Deaf, or the Blind; running support groups; channeling corporate responsibility funds toward disability inclusion; pressing for implementation of legally mandated changes in private and public institutions; engaging in art activism; or creating content on social media platforms. Some also went out to the streets to protest—a tactic that has become increasingly unavailable in recent years.

Russia signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2008 and ratified it in 2012, committing to taking steps toward ending disability-based discrimination. In December 2014, President Vladimir Putin signed a range of amendments to existing federal laws to reflect the UNCRPD’s principles and requirements.

In 2011, the federal government launched Accessible Environment, a national program directing unprecedented funds to making spaces, services, and information accessible to people with disabilities. Alternative domestic funding sources, such as presidential grants and substantial support from large corporations, also began flowing to the projects of various socially focused disability organizations.

But this is often not enough. During my ethnographic research in Russia, several NGOs told me that insufficient financial resources, shortages of workers, mind-boggling amounts of red tape, and normalized exclusion of people with disabilities were the most difficult problems they faced. These were more pressing than other factors that have gained international notoriety, such as government surveillance and the “foreign agent law,” which makes it hard for Russian NGOs to receive foreign funding.

Much post-Soviet disability activism has been harbored within NGOs. Their size, goals, and

working methods will vary, but these groups can raise funds domestically and obtain state-authorized status. Currently, it is essential for NGOs to emphasize that their programs are not part of a political critique, but instead are social projects to improve the living conditions of a vulnerable population.

Collaborations with local elites—including members of the ruling party, United Russia—often serve as a prerequisite for the viability of certain NGOs. During my research, I observed that although such collaborations tie NGOs to the political establishment, they also provide access to channels through which NGO workers and their constituencies can promote their interests.

Since the legal changes implemented in 2014, prominent museums and cultural centers have begun to develop accessibility and inclusion programming. They are now holding educational seminars, debating definitions and best practices, and adapting their services to reach more diverse audiences on more equitable terms.

These museums include the Polytech Museum and the Garage Museum of Contemporary Art in Moscow, the Russian Museum in Saint Petersburg, and the Yeltsin Center in Yekaterinburg. They have limited resources and expertise, and not all have employed experts with disabilities to shape their accessibility initiatives. The programs they have launched vary in quality and scope, ranging from critical research labs on forms of inclusion to segregated programming whereby people with different kinds of impairments can access exhibitions only through “special tours.”

Activism on behalf of people with cognitive disabilities who live in institutional care facilities known as *psycho-neurological internats* (PNIs) is also notable. Scholars such as Anna Klepikova and Anna Altukhova, as well as NGO workers and journalists, have revealed that PNIs are in dire need of reform. They are overcrowded, understaffed, and underfunded; they rely on the tools of punitive psychiatry, and they deprive residents of their legal decision-making capacity. As Klepikova observes, once someone enters the system, it is virtually impossible to leave. On social media, the hashtag #stoppni (#стоппни) denotes posts about alternatives (such as supported living homes), as well as reports on problematic aspects

of the current system and opposition to building new PNIs.

In the early months of the COVID-19 pandemic, several Moscow- and Saint Petersburg-based NGOs carried out an “evacuation” campaign. They managed to move more than 30 people out of PNIs and into apartments provided with assisted-living care. This operation was part of the longer history of lobbying for PNI reform by NGOs and prominent activists such as Nyuta Federmesser.

FINDING A VOICE

A sketch of the Russian disability activism scene would be incomplete without considering some individual activists with disabilities. Based on interviews I conducted in June 2021, here are three portraits of activists whose work is not directly realized through established institutions. They may help build a more nuanced understanding of the diverse and sometimes divergent tactics of contemporary disability activism in Russia.

Jerry Mercury, from Saint Petersburg, identifies as a nonbinary, transgender, neurodivergent self-advocate. He is a poet, musician, artist, filmmaker, and blogger. He uses his own experiences to generate a critical, anti-ableist narrative about neurodivergent people in particular, and people with other disabilities in general. His work in multiple creative forms is informed by critical insights from feminist and civil rights discourses, which is uncommon in Russia.

His first film, *Setting Off with Malcolm*, was made singlehandedly in 2020 and featured Jerry performing a symbolic death of his old, socially conditioned self to regain freedom and dignity. In 2021, he has been working on a sequel, *Saffron March*, about how that initiation ritual changed his life and opened the way to self-advocacy. He now openly identifies as an “invalid,” reclaiming a label often used in Russia in a pejorative sense.

Also in 2021, Jerry started his third project, *The Non-Loneliness Train*, which will include a long-term series of interviews about being neurodivergent, as well as his self-advocacy blog, available on Facebook. By the time of our interview, he had created the first part of a series called *Internal Inclusion*, about his experiences as someone who values his neurodivergence while facing the same environmental and social barriers as other disabled people.

*Many institutions stubbornly resist
prioritizing accessibility.*

Finding and deciding to express one's own voice amid normalized ableism in Russia is not easy. It requires undoing one's own internalized ableism and recognizing the systemic nature of disability-based exclusion and discrimination. It also may involve encountering irritation and misunderstanding in an audience unwilling to hear about its own privileges and complicity.

CLAIMING AGENCY

Alena Levina is a 33-year-old Moscow-based artist and accessibility expert. Although she previously lived without disabilities, she now uses an electric wheelchair and is also hard of hearing. Through performances, feminist critiques, art exhibitions, public talks, professional work on accessibility, and day-to-day negotiations of the terms of inclusion, Alena helps her audience unpack its deep-seated, harmful assumptions about gender, sexuality, disability, and other markers of difference.

Alena is a co-founder of *Women | Disability | Feminism*—a feminist platform unique in Russia for holding critical and open discussions of the intersections of ableism, patriarchy, sexism, heteronormativity, homo- and transphobia, and other forms of systemic oppression. In a country where addressing issues of sexuality has become increasingly tricky and feminist agendas often draw snide remarks, this platform offers a rare outlet. In 2019, it organized a feminist festival and published an open-access zine with stories by disabled women and translations of critical texts. Alena is currently working on *Inva-Protest*, a grassroots project against domestic violence, run by women with disabilities.

Alena also works with organizers of various events across the city—concerts, raves, shows, exhibitions, talks—to make them accessible to people with disabilities. Afterward, she documents her experiences on Facebook, publicizing the barriers to participation by disabled people as well as possible solutions.

Alena also uses performance as a critical tool. As I wrote this essay, I followed her public performance on the in/accessibility of a major art institution in Moscow—Vinzavod—where she was enrolled in an educational program. The performance was broadcast on Instagram. Alena and two other activists (Sasha Kurlenkova and Anna Ustalost') performed Russian *chansons* in Vinzavod's yard and solicited donations. After collecting about 8,000 rubles (nearly \$115), Alena

donated the proceeds to Vinzavod to help it acquire a portable ramp.

To a Russian eye trained to stereotype disabled people as beggars and to regard institutions such as Vinzavod as temples of art, this was a profoundly symbolic performance. It subverted power hierarchies and disclosed the stubborn resistance of many institutions to prioritizing accessibility. An artist with disabilities, collecting donations as if they were alms, drove home the dehumanizing effect of institutional disregard.

CROSSING THE DIVIDE

Mikhail Voytsekhovskiy, a blind professional massage therapist, is also a founder of an NGO that promotes disability inclusion. But his activism transcends the boundaries of any projects organized by the group. For Mikhail, social encounters, relationships, and actual experiences—as opposed to discourses, rights, entitlements, and labels—are what matters. He creates opportunities for people with and without disabilities to collaborate: by learning, traveling, hiking, sailing, freediving, and simply hanging out together.

When I asked him about his approach, he said: “I think that the best strategy is demonstrating your own example and creating a positive personal experience of interaction between participants.” He added, “We can talk about the importance of interaction” between people with and without disabilities, but until someone “actually experiences this interaction,” such persuasion does not work. Without engaging across the divide, inclusion will not materialize—there simply won't be anyone who knows how to enact it.

Mikhail's focus is on individual people and their ability to change the status quo through changing their practices and patterns of engagement with others. He works to normalize connections across the dis/ability divide. In a way, his activism is prefigurative: by forging relationships with abled people, Mikhail demonstrates the possibility of a society in which disability no longer serves as a reason for segregation.

He told me that after he had attended a special high school for blind children, he realized that society lacked a positive model of engagement between people with and without disabilities. “Society was oriented to help me, not to interact or communicate with me as an equal partner,” he said. To change that, he decided to work from the ground up, making each collaboration, encounter, and hangout part of a broader social change.

ISOLATION AND DEBATE

Digital activism has been growing among disabled people in Russia, at least among those who have sufficient resources to access social media platforms. YouTube, Instagram, TikTok, Facebook, VKontakte (a popular Russian social media platform), and Twitter offer opportunities for self-expression and community-making that have long been denied to people with disabilities. Yet increasing state surveillance of citizens' digital content and social media activities, together with ongoing issues concerning privacy and cyber bullying, have created new risks for disabled digital activists.

The COVID-19 pandemic exacerbated many of the preexisting vulnerabilities of people with disabilities, leaving them with fewer opportunities for direct contact and support. Institutional care facilities set stricter visitation policies—during the initial lockdown, volunteers and relatives could not visit PNIS. Some abled people mobilized volunteer brigades or support services. Disabled activists also organized, aiming to use the situation to bring visibility to the isolation that people with disabilities had faced for many years before any lockdowns.

One example of such activism is the digital campaign #амывсегдадома (#butwearealwaysathome), launched by Ivan Bakaidov, an IT specialist with cerebral palsy, and the Polytechnic Museum of Moscow. On March 17, 2020, Bakaidov posted on his Facebook page a call for people with disabilities to share their experiences and creative solutions for staying at home for prolonged periods of time. He identified a few goals for this campaign:

I would like to urge people to sympathize with those who cannot leave their homes due to their physical disabilities. I would like you to document the services that are becoming popular now (like food delivery or free online cinema) for people with disabilities. After all, #butwearealwaysathome. I also want to invite people with disabilities to [share] their life hacks and stories about living within four walls under this hashtag. Now is the moment when we can convey our position to abled people.

In response, on Instagram, Facebook, Twitter, VKontakte, and TikTok, people with disabilities

and parents of disabled children began sharing their stories about isolation that some had endured for many years. This exchange stirred debate by drawing parallels between the immobilization that people with disabilities experience due to an inaccessible environment, which starts in their own apartment buildings, and the temporary isolation imposed on abled people by the pandemic.

Some have applauded the comparison, noting that it has allowed people with disabilities to educate abled readers about their daily lives, revealing years of unjust treatment and the mentally and physically harmful impacts of isolation. But others have rejected the parallel, arguing that for abled people, measures to cope with temporary lockdowns were short-term and did not compare with the struggles of those enduring long-term isolation, often resulting in depression and other mental health problems.

Some also pointed out an ableist aspect of pandemic coping strategies: accommodations that people with disabilities have wanted for years, including remote work and online services, were normalized and became widely available.

Bakaidov's post drew criticism for hardening the dichotomy between us ("people with disabilities") and them ("abled people"). Some criticized the sentiment that the experiences of disabled peers should serve to inspire abled people. Others disagreed, noting that some people in wheelchairs travel the world, and arguing that individual discipline and willpower can help overcome barriers and allow people with disabilities to live richer lives. Some used the occasion to ask for financial donations or other help to purchase expensive equipment or treatment. In a word, this digital campaign created an opportunity for abled and disabled people to meet and debate.

These are just some of the latest examples of the plethora of activist strategies that disabled people have employed throughout the twentieth and twenty-first centuries in Russia. They call for acknowledging the essential role of people with disabilities as active, participating citizens, despite the fact that their participation has long been silenced and rendered invisible. ■

People with disabilities faced isolation long before any lockdowns.
