

Interrupted Trajectory: The Experiences of Disability and Homeschooling in Post-Soviet Russia

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School years represent a trajectory of educational, personal, and social development for any child. This trajectory is influenced by a variety of factors, but there are expectations as to when a child will start and finish school and what milestones will be reached by a certain grade. In addition to learning trajectory, school years are associated with the time to undergo socialization that consists of peer and teacher interactions. What happens to that trajectory when it is interrupted by a student's disability? How does the reality of disability shape and how is it shaped by the context of school life? How does disability transform the dynamics of schooling, and how do the societal discourses around disability get internalized and impact the practices of schooling?

Through the concept of transition, I will interrogate the complexities of the post-socialist school experiences of a teenager set against and within Russia's transition period. I compare transition—a phase adolescents go through—to the framework of geopolitical and socioeconomic transition in the countries of Eastern Europe and Russia following the collapse of the USSR. Transition imparts a sense of linear and smooth development from

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one stage to another. It also suggests that the changes underlying it are neoliberal in nature (Markovich, 2006) and that any signs of the socialist past can be easily erased and forgotten (see Silova, 2010 for a critique). However, Burawoy and Verdery (1999) suggest that transition is much less certain than it is perceived to be. They argue that transition as it is applied to post-socialist spaces and times represents complex relations of socialist and post-socialist life, emphasizing unintended consequences and the way the past enters the present not as a legacy but as a novel adaptation. To a large extent, transition is a concept that is ironically manifested in rather abrupt measures of the neoliberal reforms that suggest its complex and problematic nature. Contrary to the implied metaphorical meaning of transition as an unproblematic replacement of one ideology (socialist) by another (capitalist/neoliberal), its manifestation was nothing short of multiplicity of coexisting viewpoints and anxieties about location, globalization, ideology, and nation (Koobak & Marling, 2014).

Similar to the ambivalent nature of the macro-level transition is the transformational aspect of moving into adolescence with a recently acquired disability. To ground the macro- and the micro-level experiences within the same conceptual framework is not to say that the processes that characterized Russia after the collapse of the Soviet Union can be used as a metaphor for discussing personal experiences, nor is it an attempt to resort to disability as a metaphorical means to discuss what is known to be as transition. Rather, through my personal experiences of illness and disability, I will interrogate their impact on schooling and identity against the backdrop of a country that was undergoing drastic socioeconomic and political transformations. By interweaving my experiences of schooling with a disability, I interrogate how personal experiences caused by an illness create a sense of discontinuity in the subject's identity (Rimmon-Kenan, 2002) and how the post-socialist context plays an important role in the construction of these experiences.

School has certainly become an indispensable part of my experience of disability. Changes in my health occurred while I was in school, and I went through adjustments that my impairment required in the context of being a student. Even though my school experiences were different from the conventional trajectory, school played a pivotal role in my identity formation. My school was located on the outskirts of Omsk, a city with a population over one million people. During the Soviet period, the city was well known for its military industry. Like many cities in Russia in the 1990s, Omsk experienced years of socioeconomic instability exacerbated by the

political conflicts between the provincial and the municipal authorities (Melvin, 1998). The city was very different from the place where I was born—a relatively small town in Uzbekistan with hot summers and very mild winters. My family moved to Russia to reunite with most of my father's relatives in the wave of the Russian emigration from Central Asia and other former Soviet republics in 1992. As Tatars, though, we were rather strongly aligned with the Russians rather than the local ethnic identity of Uzbeks, and my family was habitually included in the Russian-speaking category (Kolstø, 2011). The reasons for this are manifold and require a separate discussion.¹

My experience in school as a new immigrant to Russia and the only non-Slavic eight-year-old child highlights the complexities of the transitory migration processes that transcended the notion of “returning home” and going back to my ethnic roots. Over time, as I realized there were other Tatars living in Omsk, I developed a sense of belonging. My otherness was drawn to my attention at the very beginning of my new school experience by someone who asked me why I had such a strange name. I did not know how to respond because I had grown up in a Soviet household where my national identity was never at the forefront, and I found that I could not communicate what it meant to be a Tatar. By the time I was diagnosed with osteogenic sarcoma at the age of 12 and sent to the children's department of the city's oncology hospital, my disability became the defining aspect of my identity formation. After months of misdiagnoses and referrals, the diagnosis felt like a relief. This is not to say that my family and I were not devastated to hear the news, rather we silently accepted the reality that finally explained what caused so much physical pain. I remember sitting with my mother on the bench in front of the hospital on the day I was diagnosed and crying quietly, confused about the present and terrified of the future. I was admitted into the hospital the day I was diagnosed. Looking back at that day, I remember feeling as if I ended up in a different world—children with clean-shaven heads, skinny bodies, pale faces. I was confused because I could not associate myself with what I saw. It was a world invisible to most of the people not only because the hospital was on the outskirts of the city but also because in the midst of the economic and political upheavals in Russia in 1996, childhood cancer was an outsider to the dominant discourses of political democratization and economic liberalization.

This paper is a personal account of school experiences in Russia from the perspective of a student with a disability. I start by introducing auto-ethnography as a method of a critical self-study contextualized against the

social (Chang, 2016) and explore its importance in research around disability. I then move into a discussion of the education system for children with disabilities in Russia, which provides an important background for understanding the lived experience of disability and homeschooling. What follows is a discussion of the issues around access and its negotiation through engagement with the theoretical constructs of disability studies, such as overcoming, staring, and internalizing ableism. Finally, I unpack the relational nature of disability through the discussion of the role of teachers and peers. This paper seeks to expand our understanding of disability in post-Soviet Russia and explore its liminal and complex nature.

DISABILITY AND AUTOETHNOGRAPHY

Autoethnography is referred to as an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural (Ellis, Adams, & Bochner, 2011). More specifically, I ground my writing in a personal narrative with a purpose to understand the self or some aspect of life as it intersects with a cultural context (Ellis et al., 2011). The studies of self, autoethnographies of illness, and disability autobiographies occupy a special place in disability studies. Couser (2009, pp. 6–7) suggests that the rise of disability memoirs is related to the history of the disability movement as well as the “endeavor to destigmatize various anomalous bodily conditions. Disabled people counter their historical objectification (or even abjection) by occupying the subject position.” They create a space for the narrators to reclaim their experiences and provide an alternative account of self, an account that is not dominated by the medical professionals, whose voices were historically viewed as more authoritative and legitimate. The voices of people with disabilities have become a source of empirical knowledge for social science and humanities (Mintz, 2007). These voices represent a diverse range of experiences that suggest a complexity of the disability experiences. Since disabled people do not share a single condition, they cannot be—nor should they be—represented as a monolithic community (Couser, 2005). Autoethnography uncovers the potential of self-representations of disability by shifting the authority and the voice to the individual with a lived experience.

Disability in self-study is not meant to overshadow the complexity of individual life. In fact, Richards (2008) notes that people who are ill or disabled can succumb to a way of writing that simplifies their experience and objectifies them. It can be argued that contrary to that, disability provides a

perspective that enriches the account by illuminating the dynamics of the political within the personal and vice versa. Through the personal, the political has been expressed first in feminist research and later in research around race, ethnicity, and disability (Collins, 2002; Morris, 1992).

My research stands at the intersection of autoethnographic illness narrative and sociological understanding of the concept of “transition” as it applies to schooling and disability. Autoethnographic writing can help provide a thick and textured description of a state of being and interrogate assumptions about that state of being. In illness and disability autoethnographies (Birk, 2013; Defenbaugh, 2008; Liggins, Kearns, & Adams, 2013; Linton, 2006; Wendell, 1996), the story is particularly intimate, and the telling of it can render the writer vulnerable. The importance of vulnerability serves a goal of exploring the social and political in the personal. By sharing emotional and often-painful stories, the researcher recognizes the sociocultural meanings behind these experiences. In addition, it is not only the self that is at the forefront of these ethnographies but rather the self in relation with the broader contexts.

I engage with the categories of ableism, difference, exclusion, and inclusion to foreground my own experience of being a part of the education system as a student with a disability in post-Soviet Russia. None of these categories are static—they acquire meaning through stories and experiences and through interplay with other factors. Disability is experienced in and through these relationships and connections (Kafer, 2013). For example, exclusion can be defined as a dynamic and complex social process that entails the negation of fundamental economic, social, political, and educational rights, among others (Morina Díez, 2010). It is this multifaceted and multilayered nature of disability and disability experiences that require a relational approach to examining them. The following description of the context of schooling and disability in post-Soviet Russia contributes to a more nuanced understanding of my experience as it intertwines with the history of social developments in Russia in the 1990s.

EDUCATION SYSTEM FOR CHILDREN WITH DISABILITIES IN POST-SOCIALIST RUSSIA

The education system for children with disabilities in Russia is heavily influenced by the structures and practices that developed during Soviet rule. Iarskaia-Smirnova and Romanov (2007) identify several phases in the development of assistance to people with disabilities in Russian history:

acknowledgment of the necessity of social care and discovery of learning capabilities of deaf and blind children (eighteenth century); individual teaching and first special education settings (early nineteenth century); acknowledgment of the educational rights of the so-called “abnormal” children and the establishment of special education institutions (late nineteenth century). During Soviet rule, the state was responsible for special education. Soviet psychologist Lev Vygotsky played a major role in the development of special education in the Soviet Union. He argued that development of a “defective” child is conditioned by (a) the feeling of low social value of oneself, and (b) the requirement of social adjustment to the conditions of the environment. He concluded that a disabled child has special needs which must be met. In the 1920s, Vygotsky introduced the concept of the “deficient child,” and the discipline of “*defektologija*,” or defectology, was established. A wide network of special residential schools was created in the 1950–1960s. The social relations inside the school represent a compound dichotomy between close and familial relations and strong social control, lack of privacy, and deficient parental involvement in children’s education (Korkunov, Nigayev, Reynolds, & Lerner, 1998).

The underlying principle of defectology was that children with disabilities are capable of full psychological and intellectual development through manipulation of their sensory systems. It was believed that, with adequate training, any child could become a valuable and active participant in society. Sandomirskaja (2008) examined *surdotiflopedagogika*, which sought to compensate for the loss of speech, hearing, and sight and was used as a technology for the manufacturing of socially useful human beings. The construction of the deaf-blind language was related not only to the academic discourse of sociolinguists but also to the Soviet official doctrine in general. In an effort to construct a holistic new individual, deaf-blindness was treated as an experiment. The medicalized approach to educating children with disabilities and the centralization of medical and educational services brought cost effectiveness for the state. This system was notable for the high degree of differentiation, categorization, and stratification (Phillips, 2009).

A positivist approach to education of children with disabilities was a technique of normalization. The idea was not to change the environment per se to make it accessible for children, but to compensate for children’s “defects” by engaging their unimpaired sense organs to make up for the “defect.” Children did not live in their communities but were separated from their families in order to be treated by the specialists. They were

considered as special citizens, who would become a living demonstration and a symbol of the Soviet glory. The right to become such a symbol was applied selectively and channeled through the category of the “educable” rather than the “uneducable.” The latter category mostly included children with intellectual disabilities. Submission to normality permeated all spheres of life during Stalinist Russia, and otherness was positioned in opposition to the ideal and conceptualized as almost-the-same or as not-yet-the-same. Citizenship was contingent on the achievement of this sameness.

The transition from socialism to market economy worsened the conditions of the special education system due to a significant decrease in the public funding for boarding schools (*shkoly-internaty*) and the process of decentralization that transferred responsibilities from the central to the regional authorities (Kulagina, 2014). The situation was further aggravated by the growing lack of specialists entering special education after graduation due to the unattractive salary and alternative possibilities of employment in the private sector (Thomson, 2002). These factors distorted the structure and ideology of defectology that survived through the transition period in the environment of retrenchment of public funds and a wave of education reforms. First, similar to the Soviet practice of differentiation, the categorization of children according to the clinical and pathological understanding of learning differences persisted (Thomson, 2002). Second, children with significant disabilities could hardly be accommodated. The division into “educable” and “uneducable” children continued running along diagnostic lines. Severe disabilities that combine motor and learning were viewed as “too” disabled and were not responded to adequately (UNICEF, 2005). Once deemed “uneducable,” children were placed in institutions rather than special schools, with little chance to get any education.

The law that marks the formal recognition of people with disabilities as a group at the national level was the 1995 Federal Law “On social protection of people with disabilities in the Russian Federation” (State Duma, 1995). The legislation was a watershed in that it guaranteed the right to education to all children with disabilities. Yet, the law did not discuss whether such education would be provided in segregated or inclusive settings. Even though the officials and administrators supported inclusion in principle, they insisted on the need for boarding schools for children with more significant disabilities (State Duma, 1995). Inclusion, then, became a selective practice, rather than a universal principle. The extent to which defectology was ingrained in the education system and the massive organizational structure of the Soviet differentiated system can

explain the reluctance to move towards inclusion. Thus, the system of special (correctional) schools for children with disabilities remained in place after the collapse of the Soviet Union.²

Rather than being disrupted by the social turbulence of the early 1990s, it appeared that schools were acting as a set of microsystems in which long-term continuity and stability of educational practice offered a degree of respite from external pressures at the macro level (Elliott & Tudge, 2007). The idea of inclusive education, which can be defined as a commitment to educate each child irrespective of the disability in the school and classroom with their peers, has become the focus of advocacy organizations by the early 2000s and mid-2000s (Oreshkina, 2009). Although inclusion is an essential part of the current debates on education for children with disabilities in Russia, I will not focus on the institutional aspects of the reforms. Instead, I am interested in less visible, negotiated, and lived aspects of inclusion.

HOMESCHOOLING

The right to be homeschooled was stipulated in the 1995 law “On social protection of people with disabilities in the Russian Federation” (State Duma, 1995). The law guarantees that if it is not possible to provide education to children with disabilities within regular schools, the option of homeschooling will be offered, followed by the formal request from the parents. I view homeschooling as a state of in-betweenness that carried characteristics of both inclusion and exclusion, belonging and separation.

After being discharged from the hospital, there were no doubts about whether homeschooling would be the option best suited for my condition. There was no discussion about it because I could not have even imagined myself outside a home setting as home was my refuge, my tower, the place where I could escape my own disability. Homeschooling was as much about education as it was about my sense of self at the time. Looking back, the fact that I treated home as a safe space where I would not have to encounter the physical (stairs) and the psychological (stares) barriers made this option so close to my heart. This way, I could postpone facing the world; I could press the “stop” button. Homeschooling provided me with a much-needed hiding place.

Children educated at home are formally registered with the school, but instead of students attending the school, the teachers visit students at home on a weekly basis. It is mostly intended for children with physical

disabilities who are less likely to require a differentiated approach in teaching or expertise of a special educator.

Most of the students with motor impairments who are officially recognized as disabled by the medical-social commissions are guaranteed the right to home-based schooling. Compared to mainstream school, the student-staff ratio seems to open more possibilities for individualized teacher-student interactions. However, a limited number of hours allocated per student often results in low academic expectations. Social interactions are limited to contacts among the disabled children and their teachers; friendships with non-disabled peers are very rare (Iarskaia-Smirnova & Romanov, 2007). In the meantime, homeschooling represents an element of the general education system in the context of reduced funding for special education on the one hand and insufficient resources for inclusive education on the other.

NEGOTIATING ACCESS

Homeschooling was not as much my only recourse, a mechanism that I depended on as the school system could not accommodate my condition, but it was also my right, paradoxically, subjecting me to a more secluded lifestyle as a teenager. It created a space for a much-needed process of reconciling with a new me and with the idea that things will be different. Constantly worrying how visible my prosthetic was, making sure to wear clothes that would hide what I thought was my very visible difference, and feeling terrified of being exposed to the gaze of my classmates made my decision to receive instruction at home easier. For a recent amputee, navigation of inaccessible environments, such as my school, was certainly also a major reason for opting for homeschooling. Attending school presented quite real challenges due to the risk of falling down the icy marble stairs during winter or being knocked down by the elementary-school children who usually occupied the same building with the students of older ages.

Access to the seemingly mundane aspects of life, such as washrooms, is rarely questioned in the context of the wider exclusionary practices, mostly because of the very private nature of the need. Following the feminist idea of the artificial nature of the divide between the “private” and the “public,” disability advocates bring embodiment into the realm of the public debate (Garland-Thomson, 2005).

In her article, Titchkosky (2008) considers access as an invitation to discuss how public spaces negotiate difference in society. She argues that

for most people, the taken-for-granted washrooms are essential for gaining an understanding of how everyday embodied experiences are managed by discourses of competition for scarce resources, hetero-normative expectations, colonizing powers, and neoliberal demands. All too common for schools at the time were the extremely inaccessible squat toilets, a vestige of the Soviet past. In the environment of limited budgets, when teachers' pay was delayed for several months and when schools had to rely on parental monetary and physical support for classrooms' maintenance and basic renovation, there was no discussion of how the school could be made accessible. After years of providing education to children with disabilities in specialized or home settings, the need to address some of the infrastructural barriers that were indispensable for moving toward a more inclusive system was not on the radar. Exclusion can be discussed on a systemic level, but according to Titchkosky (2008), such discussions can often be referred to as "the say-able," or sensible justifications of exclusion, such as "*When restrooms were built, they were not built with people with disabilities in mind.*" As much as this explanation might seem reasonable, it does not justify the actuality of me not being able to attend school for this reason. When I started selectively attending some classes toward my graduation requirements, my presence at school and interaction with peers were conditioned by issues of accessibility and the say-able justifications of exclusion.

The solution to participate in the exclusionary spaces of school was negotiated through a tacit agreement with the teachers that I would not stay in school for the whole day. It was certainly a patchy approach to the systemic problem of invisibility and exclusion of people with disabilities in Russia. Such an individualized solution to the problem was certainly a privilege. It hinged on the understanding of the school's administration and teachers, my type of impairment that can be minimized through the use of prosthetic device, and my status of being a "good," straight "A" student. In other words, my ability to pass, that is, hide my impairment and blend in, compared to people with other mobility impairment, as well as my ability to "overcome" my disability (i.e., compensate for the perceived lack associated with disability), can be attributed to my access to education.

OVERCOMING DISABILITY

Disability studies has extensively explored the concept of overcoming disability, of being a "supercrip"—a stereotype of a disabled person who garners media attention for accomplishing some feat considered too difficult

for disabled people no matter how mundane or banal it may be (Kafer, 2013). Looking back, I recognize the messages that circulated around me and my disability were part of the same rhetoric. I became convinced that my overcoming will emanate from my academic achievement. I came to be seen as a girl who overcame her disability. One of the critiques that suggests the broad sociopolitical ramifications of this approach to disability is provided by Simi Linton (1998), who points out that if we place the onus on individuals with disabilities to work harder to “compensate” for their disabilities or to “overcome” their condition or the barriers in the environment, we have no need for civil rights legislation. The Soviet literary tradition provides examples of overcoming as well. After my surgery, I was regularly reminded of the story of Alexei Meresyev, immortalized in the novel *A Story About a Real Man*. It was based on a true story of the Soviet fighter pilot, whose plane was shot down during the Great Patriotic War (1941–1945). He survived but lost his legs. He is described as someone who overcame his disability—learning to walk again to return to piloting (Iarskaia-Smirnova & Romanov, 2013). The story was meant to reassure me and suggest that being a double amputee was a much worse plight leaving me with no choice but to overcome.

Similarly, the discourses around the post-Soviet “transition” were built around the notions of “overcoming” and neoliberal transformation (Collier, 2011). In her analysis of post-socialist Czechoslovakia, Kolářová (2014) unpacks how dependence upon ideologies of cure and recuperation were not only closely attached to the discourses around disability but also around visions of the social, or rather post-socialist, world. The ideas of abnormality, constraint, and failure of the planned economy are juxtaposed to the ideas of development, normality, and future of the market economy.

When I came to North America for the first time at the age of 16, I came across inspirational speakers who highlighted the experiences of individuals who overcame adversities and achieved remarkable goals. Disability was certainly one such adversity. I wonder how my story of overcoming disability was perceived among my Russian teachers and classmates. I regret not asking. Would this “inspirational” story be applied to me? During the graduation ceremony that I attended, I remember one of my classmates approaching me and saying how much he respected me. We barely knew each other.

Because I did not see a multitude of avenues for myself to fit in, studying seemed to be the only realm where I could exist. All the social aspects of schooling were not really available to me. My school was known for its

math-oriented classrooms. As a rule, students who enrolled in these classes did well in the other subjects as well. One hour a week was certainly not enough to bring my math skills to the advanced level, and this severely limited my opportunities to get into technical or business universities. In other words, I satisfied the minimum requirement that allowed me to remain an “A” student, but I was not encouraged to explore my potential. Suggesting a diverse theory of justice for disability, Silvers (2009) argues that by providing only equality of opportunity (i.e., a basic level of education) instead of equality of outcome (future capabilities and accomplishments), we might overlook diversity and talent. I learned about the myths of disability only when I took my first disability studies course at the University of Maine. However, without seeing any other way to make sense of my life at 15 or 16 years old, I followed what was expected and preferred in society.

PASSING IN THE CONTEXT OF INTERNALIZED ABLEISM

As much as it was easy to overcome disability at home, it became an insurmountable task once I was outside. The phenomenon of “staring,” so eloquently captured by Garland-Thomson (2006), finds a special meaning in the context of my experience. Unpacking the multiple layers of staring, Garland-Thomson argues that it registers attraction at the same time as it witnesses confusion. Staring is the materialization in the human bodies of a search for narratives that impose coherence on what appears to be randomness in our experience of the world. We stare at that which perplexes us in an intense effort to make sense of what is at once unfamiliar yet recognizable. Any visual sign of impairment provokes such stare. The non-disabled gaze is driven by curiosity perceived as a right to intrude, inquire, and appropriate impairment as a public spectacle. To stare is to “enfreak” (Garland-Thomson, 1997) and to assert power over. “Curiosity” is an invasion of personal space and may manifest itself in direct personal questions unthinkable in “normal” discourse. Yet disabled people tolerate these ableist interjections.

Staring accompanied my adjustment to life as an amputee outside the hospital. Most of the time, I was aware of the stare but was not willing to engage, and I preferred to look down. In addition to feeling immense anxiety, insecurity, and increased sense of self-consciousness around my own impairment, all I wanted to do was to avoid attracting attention. Lack of positive role models who looked like me and who I could identify with

intensified the feeling of being different and conditioned me to hide my disability. Staring instilled in me a fear of being exposed as an amputee, as someone who failed to hide behind the prosthetic with its jerky movements and a mechanism that could make me lose my balance and fall. Many amputees are concerned with passing to retain a sense of sameness and hide what is missing through prosthetization (Crawford, 2014). It took me several years to start reclaiming that stare and replace my discomfort with being stared at with the starrer's discomfort of being stared back. Trying to pass as able bodied was my goal, an identical replication of my prosthetic to my real leg—a source of joy. The years of school life and spending a lot of time at home made the goal not to be noticed one of the major ones. I clung to my mother's elbow for support to maintain a shaky balance as I made painful and clumsy steps in public. More importantly, I also clung to her with the hope to salvage a sense of normalcy. This physical support from my mother gave me the protection that I did not believe I had from the outside world.

Years of trying to hide what I found difficult to talk about and ultimately accept was rooted in internalized ableism. Campbell (2008) contends that within ableism, the existence of disability is tolerated rather than celebrated as a part of human diversity. Internalized ableism utilizes a two-prong strategy—the distancing of the disabled people from each other and the emulation by the disabled people of the ableist norms. Internalized ableism can mean that the disabled subject is caught “between a rock and a hard place,” that is, in order to attain the benefit of the “disabled identity,” one must constantly participate in the processes of disability disavowal, aspiring towards normativity, a state of near-ablebodiedness, or at the very least to effect a state of “passing.” Passing occurs when there is a perceived danger in disclosure. It represents a form of self-protection that nevertheless usually disables, and sometimes destroys, the self that it is meant to safeguard.

CARING SPACE THROUGH INTERACTIONS WITH THE TEACHERS

Caring as it relates to both the physical work of providing support as well as the environment where individual needs are recognized as valid is central to families that have children with disabilities. Care-less spaces that are symptomatic of a lack of care within an educational environment can have a significantly negative impact upon identity formation of a child

transitioning through momentous milestones (Lithari & Rogers, 2016). The caring practices are not necessarily created within a formal framework of the school system. The relational nature of my homeschooling and the way I learned to see myself through the connections with the teachers created the space for nurturing and caring practices. These practices consisted of friendly conversations before or after the lesson, reassurances and stories of teachers' lives outside of school, and the realization that my schooling transcended what was possible within a traditional classroom.

My teachers were the conduits of news from me and to me. They were crucial in the post-treatment stage of my rehabilitation when I needed to redefine myself. In the absence of the actual rehabilitation that left me with no tools to adjust to my new life and no knowledge about the way to address the psychological repercussions of my amputation, my family and school were the defining external factors that witnessed all the challenges I experienced after my illness.

What home education secured was not only a refuge from the traditional school environment that I thought would be unfriendly for someone like me but it also guaranteed companionship and a closer connection to the lives of teachers. Our one-hour long class would usually be followed by an informal conversation about the teachers' families and children. The settings of the home were conducive to sharing and blurring the boundaries between the teacher and the student. I remember that when my new history teacher came to my house for the first time, she ambushed me with a stream of questions that seemed rather personal. I was taken aback and burst into tears after she left. I was not ready for the personal conversations that touched upon the topic that was still very sensitive.

Throughout the years following my illness, I never had a chance to actually articulate what the experience of disability has been like for me, and every time I was asked these questions, I would get very emotional, as if I heard about my own disability for the first time. The lack of similar experiences provided me with no baseline on how to cope and address my insecurities. The concepts of rehabilitation or peer support were non-existent. The year I got sick—1996—was characterized by high unemployment and poverty. The government financing of the prosthetic and mobility aids (traditionally covered by the state) was secondary. My family was left to deal with the repercussions of not only cancer and its treatment but also with the emotional pain of coming to terms with a child who needed to rebuild her identity, who had to face physical consequences of learning to use a fairly outdated prosthetic device, who had no peer support to rely on, and who struggled to make sense of everything that happened.

My last years of school were mostly focused on what university and major I intended to select, what testing requirements it would involve, and what I could ultimately do with my degree. At least three of my teachers insisted on me becoming a doctor. They certainly had high expectations of me and insisted that the medical field was associated with respect, intellectual rigor, and stability. They invoked the examples of their own children, people they knew who followed that path, and they argued that my disability was not a hindrance for me. "They used to call her Dr. Limp," said one of my teachers, who knew a female amputee who became a doctor. Such encouragement suggested my teachers' active interest in my future and their confidence that my disability was in any way a hindrance to pursuing one of the most challenging fields.

INTERACTION WITH PEERS

One of the fondest memories I have from my time in the hospital is the letters I received from my classmates. A teacher had allocated part of her lesson to writing letters to me. I kept them for several years. I wonder how hard it was for them to write these letters. Did they struggle? Were they selective with their words? What had the teachers told them about what happened to me? When I read them, I remember stories about school life and wishes of good health. In the months that followed my discharge from the hospital, several of my classmates visited me at home. I was not fitted for my prosthesis; I was bald, and I was terrified to face them as I was. It was awkward for everyone, yet, it was through this moment of relationality that I tried making sense of myself and my new body. I was still trying to understand how to build relationship with a disability. I did not know how to talk about it and whether I should do it in the first place. It was an uncharted territory with too many unknowns.

As part of the effort to create specialized classrooms, the classmates I started my school years with were reassigned to other groups. I wonder if I could have nurtured the connections with the classmates that already knew my story instead of facing the task of nurturing new relationships. I was assigned to a different class, which did not seem to matter, considering I mostly stayed at home. In the years that followed, I attended some classes, such as chemistry and biology, that often involved lab-based activities. I was mostly accompanied by my mom, who helped me navigate the slippery marble stairs during winter and the hectic environment of the school that was filled with children of different ages. I did not thrive during those moments. I was desperate to go back to the safety of my home.

I had a couple of friends who would visit me on a regular basis; however, the experiences of navigating the socialization aspects of adolescence were challenging.

When I was 16, my English teacher wanted me to participate in what she thought was a city-wide competition for students to test their knowledge of English. That competition turned out to be the first round of the regional selection for a US initiative meant to promote communication and educational exchange between students of the former Soviet republics and the United States. That trip was the beginning of a different chapter in my life because living so far from my family for a year meant a real test in terms of contextualizing my disability and looking at myself through the eyes of other people from a different culture.

After I returned from the trip, I had to repeat a year in school with all of my classmates graduating. I was placed with the peers a year younger than me, but because I attended school almost every day to prepare for final exams, I managed to make meaningful connections. One particular episode stands out to me. I joined my classmates to celebrate an International Women's Day, an official holiday in Russia marked on March 8, by getting together in the school canteen with our English teacher for tea. I remember feeling relaxed and accepted then. When it was time to go home, I did not have to walk back alone and put myself in danger of walking on icy roads. I remember walking with a group of my classmates; they were gently holding me at my left elbow making sure I did not slip. What is memorable about that moment is how much we laughed during this walk because my classmates were having a hard time keeping stable on the ice, while I managed to keep my balance. The details of the conversations are vague, but the laughs that accompanied that walk transformed what might seem like an act of help with an underlying charity motive into something that friends do; something that is not conditional, something that just happens. I was regretting then that it was my last year of school.

CONCLUSION

To analyze the experience of disability through the prism of homeschooling is not to suggest that such experience is universal. The overview of the education system for children with disabilities discussed earlier in the article conveys the complexity of the system that is built around diagnostic and medicalized approaches to education. This personal narrative is an attempt to add more nuances to our understanding of disability and

schooling. By examining the role of homeschooling, I hope to contribute to a more complex understanding of disability that is as personal (my struggle of coming to terms with it) as it is relational and political. Without diminishing the weaknesses of the system that, ultimately, does not put inclusion as its goal, homeschooling created a safe space and a temporary solution, or a patch, in the otherwise-challenging environment that involved many anxieties about disability.

Disability serves not only as a lens for exploring the lived and embodied experience of growing up but it is also a way to understand the post-socialist context in general. Disability as a topic has been largely neglected in research on Russia (Rasell & Iarskaia-Smirnova, 2013), especially within a realm of intersectional research that explores categories of age, gender, sexuality, and ethnicity. By interrogating the analogies between the interruptions that are the nature of growing up as a child with a disability and the context of the tumultuous changes of the post-socialist transition, I foreground the importance of subjectivities in enriching the understanding of post-socialist Russia and challenge the perception of the linear development that followed the collapse of the USSR. The memories of disability in the context of post-socialist schooling and school memories in the context of disability emphasize the ambivalent nature of the schooling experiences and the entanglements that shake up the assumed monolithic nature of the post-socialist education system.

NOTES

1. For more on the history of Tatars in Russia, the complexities of migration from the former republics, please see Rorlich (1999), Brubaker (1995), and Radnitz (2006).
2. In Russia, eight types of special schools exist: blind, visually impaired, deaf, hearing impaired, motor problems, speech problems, development delay, and mental disabilities (UNICEF, 2005). Children with milder disabilities (usually musculoskeletal disabilities) were a part of a general education system; however, there is not enough research on how schools in the Soviet Union and Russia accommodated these children. It is part of the unknown history of Russian education. I do not know how different my experience would have been if I had to go back to school as a disabled student in the USSR. It would depend on whether I had access to prosthetic or other assistive devices, whether I had a family to take care of me, and if the school wanted to take me back.

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