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Alfiya Battalova

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Ambivalent subjectivities: experiences of mothers with disabilities in Russia

Alfiya Battalova

Department of Disability and Human Development, University of Illinois at Chicago, Chicago, IL, USA

ABSTRACT

Women with disabilities are still rarely imagined in the role of a mother. Narratives about motherhood that promote traditional gender roles and the primary role of motherhood in women's lives (pronatalism) in countries like Russia emphasize the value of non-disabled and heteronormative bodies and minds. The lived experiences and the lived citizenship of mothers with disabilities disrupt societal assumptions about motherhood. However, the structural environment of pronatalism inevitably influences the ways in which mothers with disabilities understand motherhood and construct their sense of selves (subjectivities). Drawing on the framework of citizenship and the feminist disability studies literature, this article analyzes how the personal and the political are intertwined. The analysis is based on empirical data obtained from qualitative interviews with 14 mothers with disabilities in a provincial city of Russia.

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Points of interest

- The policies on motherhood in Russia have historically been influenced by pronatalism (promotion of motherhood and traditional gender roles on a national level).
- Mothers with disabilities are invisible in conversations about motherhood.
- Through their lived experiences, or lived citizenship, mothers with disabilities challenge the societal assumptions about their ability to mother.
- There are multiple ways in which mothers with disabilities construct their subjectivity (sense of self): sometimes they reproduce the narratives about the central role of motherhood in a woman's life, and

sometimes they have to downplay their disability to avoid scrutiny from the medical and social services.

- The study demonstrates that although mothers with disabilities acknowledge the importance of disability in their lives, the context of pronatalism inevitably has an impact on women's construction of self.

Introduction

People with disabilities historically have experienced exclusion from citizenship status and belonging to the nation, based on the imagined threat they present to the gene pool. Meekosha and Dowse (1997) argue that gender, disability, and the denial of citizenship rights come together most starkly around sexuality, reproductive, and marriage rights. Women with disabilities are viewed as a disruptive force in the construction of race and the nation. Gender norms are enacted through bodies, making it easy to imagine constructing the 'wrong' kind of nation if using the 'wrong bodies' (McQueen 2014). Meekosha and Dowse (1997) argue that a gendered politics of nationalism sees women with disabilities as enemies of the nation who represent potential breeders of inferiority. Thus, the state, in policing the boundaries of citizenship and the nation, also polices the sexual freedom of women with disabilities. However, in certain contexts – specifically, in the cultural contexts of pronatalism – disabled mothers might be unwilling or unable to disrupt the dominant discourses that view motherhood and reproduction as related to and embedded in the woman's biology. Since the mid-2000s, Russia has incentivized a higher birth rate both through such policy initiatives as maternal capital, which provides financial incentives for the birth of a second and consecutive child, and through ideological campaigns valorizing motherhood and its role for the well-being of Russia.

Consequently, women with disabilities live in the space of in-between, where their status as disabled people is continuously devalued and their sexuality is questioned whereas motherhood becomes a desired positionality. Such a dichotomy does not suggest that these two statuses can be easily separated but that we need to pay closer attention to how intersectionalities provide a deeper understanding of the phenomenon and how the invisibility of disability creates potential for creative approaches to analyzing motherhood that push against the dominant narratives.

Reconciliation of motherhood with disability is a challenge when an intersectional self remains invisible in the public discourse and when one subjectivity (motherhood) is valued, whereas the other (disability) is not. I will interrogate this dichotomy and the negotiation of the disabled subjectivity in the context of compulsory able-bodiedness and heteronormativity (McRuer 2006). This research shows that disability is highly relational and is

understood through women's relationship with other people and structures. The range of meanings and contestations is what pushes the boundaries of motherhood and makes it less stable. Drawing on data from a larger study of reproductive citizenship of mothers with disabilities in Russia, this article explores the ways in which mothers with disabilities construct their sense of self and negotiate their positionalities.

Conceptual framework

There is no monolithic understanding of disability in Russia. Even in identifying women with physical disabilities as a target group of my study, I recognize there is no one unifying experience that defines the lives of these women. All of the experiences are contingent, fluid, and relational and should be placed in the broader context of historical, economic, and social realities of a place and a life within that place. Yet, considering the relatively recent interest in disability issues in this region, a general overview of the major discourses is needed to develop a canvass that brings together the individual stories. Although the lives of the women I interviewed bear traces of larger processes and shifts, the relationship between individual stories and these processes is in no way direct or determinative. However, singular stories need to be placed in productive tension with the larger narratives (Raikhel 2016).

Citizenship serves as an entry point for understanding subjectivity produced by both discursive and experiential dimensions of citizenship (Canning and Rose 2001). The article aims to emphasize the complexity of being a mother with disability in the context that reduces an individual experience to an essentialist category that does not imagine motherhood in its multiplicity. Instead of viewing the lived citizenship squarely in the realm of the private, I argue that boundaries between the discursive (the macro-level) and the lived (the micro-level) are much more permeable. In fact, the links between the self and society are reflective of the relational nature of citizenship, such that it helps to assess the ways in which people with disabilities see their lives in complex relationship with hegemonic (state) discourses (Phillips 2014). As a relational concept, citizenship emphasizes the links between the self and society. Ideas of citizenship help to assess the ways in which people with disabilities see their lives changing after socialism and to understand how these perceptions conflict or square with hegemonic (state) discourses of invalidity (Phillips 2014). By enacting their agency and claiming their right to be a mother, mothers with disabilities become objects of discursive practices. Understanding citizenship through the lens of agency helps avoid the construction of women and other marginalized groups as passive victims. At the same time, agency is embedded in and shaped by

social structures, making it important to remember that the expression of agency can be constructed by discriminatory and oppressive practices (Lister 1998).

The context of motherhood in Russia

When Russian narratives of traditional values and pronatalism – the policy or practice of encouraging the bearing of children, especially government support of a higher birthrate (Dictionary.com, n.d.) – gained momentum in the early and mid-2000s, it was not clear how the lived experiences of mothers with a disability might align with these narratives. Today in Russia, a woman with a disability who decides to become a mother against cultural stereotypes that position her as unfit and incapable of motherhood must work through multiple barriers to do so. For example, social policies of Russia's Department of Child Protection list disability as a criterion for excluding people from becoming adoptive parents (Adoption in Russia 2016), associating disability with incompetence and a state of perpetual infancy. When maternity and disability register visibly in the same body, they sometimes create a visual and cognitive dissonance, as if one can be either a mother or a disabled person – not both at once (Lindgren 2011).

Gapova (2016), who coined the term public patriarchy (*obschestvenny patriarkhat*) to denote that discussions around reproduction reveal values around gender, argues that social policies focusing on biological difference as a foundation of citizenship are aimed at legitimizing specific national agendas. This then raises the question of what social policies in Russia say about the national agenda concerning women, motherhood, and disability. Researching this question, it is clear that the ways in which disability and motherhood operate against the backdrop of Russian nationalist policies have not been sufficiently explored. The pronatalist agenda has helped shape a horizon of imaginative possibilities regarding state power and gendered citizenship (Rivkin-Fish 2010) by bringing into the spotlight the voices of those who are barely visible in the conversations around what it means to enact motherhood and disability in Russia.

In the early 2000s, gender played a key role in the call for a more paternalist state to take control over a society that was thought to be lacking in direction and ideology. The development of a pronatalist discourse was shaped by the rise of an etacratic (i.e., state-centered) gender order that sees the state as the main agent shaping and monitoring gender relations. The shift toward pronatalist discourses has had a significant influence over the gender order in Russia. Indeed, Kay (2000) sees this shift as logical in the context of Soviet approaches to motherhood that defined women as worker-mothers who had a duty to work, to produce future generations of workers,

as well as to oversee the running of the household (Ashwin 2000). Some researchers describe Russia's move toward authoritarianism over the past decade as a 'gender regime change' (Johnson and Saarinen 2013). Sperling (2014) associates the pronatalist agenda with the emergence of discourses about patriotism and its revival. She argues that support for military service and pronatalism reflect two sides of the same coin. The former signals hyper-masculinization of society, whereas the latter reflects its heteronormativity and femininity. Chernova (2012), meanwhile, analyzes the change of the position of the state in relation to the family common for this period and describes how the state gave families more independence and stopped filling the role of the patriarch, expecting that the man of the family would take over traditional male responsibilities. According to Rotkirch, 'in a society with a changing gender landscape, with increasing uneasiness over gender relations, gender conventionalism stood for a search after unquestioned, solid ground' (as quoted in Pietilä and Rytönen 2008).

Broader trends in society also contributed to the potency of the patriarchal model. According to Rivkin-Fish (2010), by making an explicit connection between the problems facing women and the broader problems facing Russian society, such as the demographic crisis, the new gender order, epitomized by the maternity capital program, signaled shifting symbolic and material relationships between women and families, on the one hand, and the state on the other. The state's demographic crisis necessitated the improvement of women's role as mothers. The new 'maternity capital' entitlement for mothers who give birth to a second and consecutive child went into effect on 1 January 2007. It provides mothers with a payment of \$10,000 (at the time, 250,000 rubles), adjusted for inflation, when the child turns three years old. The money is not given in cash but as a voucher to be used for any of three purposes – improvement of housing conditions, the mother's pension savings, or the child's education.

Despite the law being presented as a choice, the desirability of motherhood is shaped by the socioeconomic conditions many women find themselves in. Career possibilities for young women are located within traditional gendered and classed parameters, and the social mobility remains elusive (Walker 2015). Pronatalism as an idea gets embedded in neoliberal values of choice and autonomy. While being called to become active agents, women are paradoxically encouraged to embrace motherhood not only as a duty but also as a choice and a mark of success in the private sphere (Perelmuter 2014; Salmenniemi and Adamson 2015). The significance of this law is not based on its institutional characteristics in the context of the welfare state but rather on the discursive knowledge it generates to make sense of gendered subjects and the symbolic boundaries of citizen rights and responsibilities.

Along with the policies that were introduced, cultural discourses were starting to change as well. The committee on social policy established a new holiday – the Day of Family, Love and Faithfulness. Initiators of the holiday invoked images from ancient Slavic chronicles that recorded the lives of recognized saints, Pyotr and Fevroniya, who were a romantic couple. The creation of the holiday aligned with an overall strategy of promoting ‘healthy moral values’ (Chandler 2013) that were associated with heteronormative marriage, children, and the traditional distribution of gender roles. Similar to the discourse underlying the creation of the holiday, ‘The Sanctity of Motherhood’ program was developed by the fund that promotes religious and moral values as the foundation of the Russian nationhood.

The policies and the cultural discourses embedded in the policies signified changes in other areas of reproduction. Turbine (2015) argues that the shift of focus to maternity care happened at the expense of programs that facilitate women’s reproductive choice and bodily autonomy. By emphasizing women’s role as the reproducers of future citizens, the conservative nature of nationalism relegates women to a secondary role in civil life and masks gender-based inequality (LaFont 2001) through idealization of the domestic domain and portrayal of women’s participation in the labor force as the source of social problems.

Invisibility of disability in motherhood discourses

The beginning of the post-Soviet era was marked by the redefinition of motherhood as a private institution and responsibility. Work and motherhood were no longer defined as duties to the state; the traditional family has been rehabilitated, and the state no longer monopolizes the patriarchal role. Yet mothers with disabilities were still absent in the discourses of decoupling motherhood experiences from the government.

The social policies introduced as part of the pronatalist narratives do not reflect a comprehensive intersectional and non-heteronormative understanding of motherhood. As a result, parents with disabilities remain invisible and face significant physical and attitudinal barriers – from the absence of ramps for children’s carriages, a lack of elevators in subways, and other public transportation problems to prejudice from the medical and social services. Hartblay (2017) discusses the so-called inaccessible accessibility when building codes serve as centralized attempts to standardize across time and space, and through chains of command resulting, ultimately, in lack of accessibility. They physical barriers serve as a reminder of the importance of intersectional perspectives in the discussion of motherhood and pronatalism.

Parents with disabilities in Russia bring this awareness through their advocacy efforts. Recent years have seen a rise in the number of organizations

initiated by people with disabilities. One such organization is Katyusha, which advocates for the rights of parents with disabilities. Katyusha organizes events for parents with disabilities, provides assistance to families, and engages in advocacy.

Policies that support motherhood coexist with policies that categorize a family with three or more children as 'unfortunate families'. The definition of the latter is quite arbitrary and was shaped in the process of the social service provision (Iarskaia-Smirnova and Romanov 2012). In fact, families from low-income groups that need state support more than middle-class families often have fewer actual opportunities to use maternal capital (Borozdina et al. 2016). For example, if a family does not have enough money for the down-payment as part of a mortgage, the maternal capital becomes useless. It is the discord between the government's pronatalist ideology of motherhood that evokes the old Soviet gender contract, in which the woman is seen as the main provider of child care as well as a passive object of paternalistic state support, and the inadequacy of the program that makes it financially challenging to be viable in the sole breadwinner family (Borozdina et al. 2016).

In the absence of experiences of mothers with disabilities in pronatalist narratives, disability is often evoked as a metaphor (Couser 2009; Mitchell and Snyder 2000) that characterizes practices that do not embrace motherhood as a woman's main mission in life as abnormal. Some women in Russia started openly claiming their 'childfree' position, an idea that motherhood is not the destiny of every woman and that any reproductive decisions concerning a woman's body are her choice. The attacks of the pronatalist supporters are filled with disability-related metaphors. In response to one of the participants of the online discussion forums explaining their reasons for not wanting to have children, the respondent referred to all people identifying as childfree as freaks. One of the deputies of the State Duma requested the Ministry of Health to recognize childfree as a mental disability (Avetisyan 2015). In the environment of the dominance of one discourse, anything that might potentially threaten it is perceived as dangerous and abnormal.

The absence of experiences of mothers with disabilities and their lived citizenship necessitates the understanding of how they negotiate their daily lives in the environment dominated by the ableist definition of motherhood. Lived citizenship elucidates what it means to exist within shifting subjectivities, destabilized care structures, and discursive prescriptions. It allows us to contextualize this experience. Phillips (2011) demonstrates how by centering or de-centering one's 'loss of health' or 'extent of bodily defects' to claim official status as a citizen and assert one's rights to benefits and entitlements – and by variously playing up or playing down *invalidnost* (disability status) as a more or less central aspect of personal and social identity – people with

disabilities develop strategies to assert claims to full citizenship (mobile citizenship). Similarly, when analyzing how scientific knowledge and Chernobyl-related suffering were tooled to access social equity in a harsh market transition, Petryna (2003) points out that where suffering becomes a bureaucratized admission ticket to the 'entitlement' of life itself, the disabled subject becomes a form of common sense and is enacted by people to gain protection in the form of biological citizenship. The intersectional experiences of motherhood and disability opens up ways of understanding how mothers with disabilities make meanings of their lives and what shapes them.

Data and method

This article is based on in-depth semi-structured interviews that were part of a project to explore citizenship of mothers with disabilities in the context of the pronatalist state. The questions posed by the study are informed by feminist disability studies and a methodology that make ambiguity central to experiences of disability, thus unsettling the binaries of disabled/abled (Simplican 2017). The sample consists of 14 mothers with physical disabilities in a provincial city of Russia recruited through social media and local contacts of the researcher. Due to a very low presence of social services and advocacy-oriented non-governmental organizations in Russia, most people with disabilities build connections with other disabled people in virtual spaces. What Hartblay (2015) calls pixelization (a particular pattern of social segregation that people with disabilities inhabit and make livable – physically isolated in a family apartment, but digitally networked) is a phenomenon that requires study, but it also becomes a channel for connecting with people who otherwise cannot be reached. Hartblay (2015) draws a parallel between pixels on a screen and people isolated in the physical 'cells' of their apartments. Despite this isolation in the physical spaces, a lot of people with disabilities are embedded and enlivened in networks that produce meaning-making interactions. This embeddedness facilitated the recruitment process. One of the obvious shortcomings of this approach is the focus on individuals with digital access, who tend to live in urban settings and be of a younger age. However, the relatively low involvement of people with disabilities in non-profit organizations and an overall difficulty of identifying potential participants made recruitment through the Russian social media website V Kontakte most feasible. The eligibility criteria included ages 18–60 years and self-identification as a mother with a physical disability. The participants' impairments included spinal cord injuries, multiple sclerosis, other mobility impairments, hearing loss, and vision impairment (see Table 1).

Table 1. Research participants.

Participant		Age (years)	Disability	Number of children
1	Olga	35	Amputation	1
2	Evgeniya	31	Spinal cord injury	1
3	Maria	42	Visual impairment	2
4	Svetlana	39	Spinal cord injury	2
5	Nadezhda	33	Spinal cord injury	3
6	Lyudmila	59	Hearing impairment	2
7	Lidia	32	Epilepsy	1
8	Irina	39	Multiple sclerosis	6
9	Oxana	32	Amputation	1
10	Alina	26	Multiple sclerosis and ichthyosis	1
11	Marina	36	Encephalitis	1
12	Natalya	40	Spinal cord injury	3
13	Kseniya	Unknown	Hearing impairment	1
14	Olesya	28	Spinal cord injury	1

The data analysis was driven by thematic analysis (Braun and Clarke 2006). One of the features of this method is that it is contextual in nature. In other words, this method acknowledges the ways in which individuals make meaning of their experience (in accordance with a feminist methodology) but also recognizes the ways in which the broader social context impinges on those meanings (in accordance with a critical discourse analysis). All of the interviews were transcribed verbatim. The coding was conducted in Russian to capture the contextual and cultural nuances of the participants' narratives in their native language.

Results

Constructing the mother

The process of understanding one's role as a mother with disability is shaped by the process of becoming 'known' and recognized as a mother. Baraitser (2009) suggests that maternal subjectivity is premised not on the capacities to nurture, care, preserve, or contain but to think about what is generative about motherhood for mothers and the material self. Such subjectivity emerges as a result of interruptions, a psychoanalytic concept that refers to the process of child-rearing itself. In that moment in which mothers are interrupted by the child's cry or a tantrum, something happens to unbalance the mothers and open up a new set of possibilities. In the context of disability, interruptions can refer to barriers that a mother with disability has to encounter. By virtue of these non-normative embodiments and experiences, mothers with disabilities contribute specific ways of knowing to the world. Robertson (2015) draws a parallel between a maternal subject continually pulled into the present by the interruptions of the child and a disabled subject who disrupts ideal linear development and fails to 'fit' within normative time and space.

However, the psychoanalytic understanding of mothering cannot be divorced from the contextual environment in which the mothering practices take place. Despite a variety of different models of femininity in post-Soviet Russia ranging from working mother and housewife to sexualized femininity, these models are similar in that they appeal to biologically determinist practices of citizenship (Temkina and Zdravomyslova 2003).

Maria talked about her experience of growing up in a loving family. Her mother had the same kind of vision impairment that Maria has. It was her mother's example that inspired Maria. The special school for the blind that she attended taught her the skills to be independent. Maria, who is a head of the district branch of the organization for the blind, projected confidence during the interview. Motherhood was never a matter of doubt and consideration for her, it was a matter of time:

There was no question whether I can be a mother because of my disability ... To be a mother means everything ... What's life without children? The very feeling of being pregnant ... I was approached by strangers during my pregnancies, and they told me 'You are posing yourself as if you are the only pregnant woman in the world, as if they were no pregnant before you and there will be no pregnant women after you'. (Maria)

By projecting pride in being pregnant, Maria emphasizes how unique it feels. For her, marriage was not just a regular phenomenon, but something that is truly special and something that she can be proud of. The event of becoming a mother and having a child makes it possible for women with disabilities to draw other people's attention away from their disability. In a way, the child makes it possible to 'become known', not as a disabled woman but as a mother (Grue and Laerum 2002). Similarly, Lidia imparted an essentialist meaning into motherhood, associating it with a physical act of giving birth:

I think that every woman should give birth. Unfortunately, doctors don't want me to have a second child, but I am dreaming about it. All women are born to have children.

In thinking about the stakes of motherhood for disabled women, we cannot neglect the histories that deny them not only the right to be a mother but often a basic personhood. In light of the histories that still linger and continue to affect many women with disabilities, especially women with psychosocial and intellectual disabilities, unpacking the meaning of motherhood for the participants of this research cannot be explored solely from the point of view of patriarchal motherhood. Instead, the lived citizenship of mothers with disabilities allows us to recognize the moments of agency-driven fractures in the dominant discourse and fluid positions. Before we start questioning the underlying notions of compulsory heteronormativity that accompany

the dominant discourses of motherhood, we first need to get to the point of incorporating disabled body into that discourse.

Feminine subjectivity

A majority of the participants not only discussed the importance of self-sufficiency when it comes to carrying out most of the tasks, but also brought up femininity either as something they had to discover again through involvement in certain activities (i.e. dancing) or as a way to counter disease and/or impairment. The latter was discussed in terms of an outside influence. One of the participants who has an unapparent disability asserted that her disability never made her question her femininity that she associates with the attention she is getting from men:

I consider myself feminine and attractive. I have a high self-esteem. When I go out with my girlfriends I can't complain of the lack of attention from men. My health condition doesn't make a difference. (Lidia)

Gradskova (2007) argues that regulations of beauty and maternity played a particularly important role in shaping femininity in the Soviet Union. Beauty during that period was performed through the discourses of aesthetics or taste, functionalism, hygiene/health, and modesty. These discourses were institutionalized through the practices of uniforming, centralized distribution of goods, and queuing. Although the enactments of beauty regimes changed with the introduction of free market reforms, the interconnectedness of beauty and motherhood discourses remained. Instead of analyzing femininity as an indicator of oppression, Markowitz (1995) suggests that:

while on one hand the values and practices of femininity (in the early 1990s Russia) may unwittingly serve to perpetuate the status quo and thus women's exploitation, on the other hand, femininity, as women's mandate to bring beauty and light into an otherwise glum and desperate situation, operates as an avenue for women's self-expression (sec. 5, para. 5).

The culture of hyper-femininity in Russia (Rudova 2011) creates fantasies (Porteous 2017) and ideals that are impossible to reach. The fantasies of feminine beauty are deeply engrained in the able-bodied tradition placing disability in opposition. However, by rejecting the fixed and binary theorization of the body and femininity, and by thinking of it in terms of fluid subjectivities (Inahara 2009), we can provide some space for expressing difference and for opening up new possibilities for all embodied subjects. This creative expression of subjectivity enabled mothers with disabilities to find manifestations of femininity that are not reduced to corporeal domains and that transcend the body.

Olga discusses a search for her femininity. She argues that even after her marriage and childbirth, she was still trying to determine whether she is

feminine enough. Olga views femininity as an important component of who she is. After many attempts to reconcile her disability with her pursuit of femininity at the increasingly popular in Russia psychology/self-help trainings, Olga convinced herself that such trainings were not necessary and she simply needed to remember that her biological sex already made her feminine:

I was not looking in the right place (referring to the psychological trainings Olga used to attend), I am a priori feminine, I am a woman, I was born a woman, it is natural. However, it is hard to accept yourself 'How can being without a leg be considered beautiful?' (Olga)

Russians are engaging with popular psychology of self-help as a technology of the self (Salmenniemi and Vorona 2014). Olga feels empowered that her self-realization was the result of the internal work rather than an influence of trainings that focus on fixing one's embodied self as part of the personal project of self-governance. However, this project hardly challenges the very structures that create the standards of femininity (Sothorn 2007).

Building subjectivity through contestations of disability

In the environment where motherhood itself can be considered a challenge, disability gets enmeshed into an array of other challenges. Disability, then, is always contextualized in relation to life circumstances and disrupts the normative ideas about motherhood.

Oxana spent several months alone when caring for her baby. Her husband held a shift job at the time, working six months a year in a different city in Russia. Oxana lived in a five-story apartment building with no elevator. She was also just fitted for her prosthetic leg and had to learn how to use it. Carrying a stroller up and down the stairs was part of her routine. Learning to use a prosthetic leg required months of rehabilitation in a specialized clinic with a professional psychical and/or occupational therapist. Oxana came back after months of treatment and she had to learn how to use her prosthetic along the way. Her disability was shaping her motherhood experiences, which was not a standalone journey:

I was fitted for a prosthesis. I just started to learn how to walk, it didn't even have a cover yet. So I would go out using stairs twice a day holding a child in my arms along with a stroller. It was very hard. Perhaps that's why I wanted to learn how to walk sooner. Imagine he would start running down the street. He just learned how to walk, and he was eager to run all the time. (Oxana)

Disability shapes people's lives without becoming all-encompassing. Another participant thinks about her disability not as something that can be dismissed but as a starting point for new plans:

I have a goal, I have my son. Moreover, we are planning a second pregnancy. And I'm not thinking, I am trying not to think about the problems. (Alina)

Some participants credit their impairment in giving them opportunities that they otherwise would not have had access to. Women talked about new opportunities as well as an overall motivation that disability gives:

Even though it might sound strange but if I didn't become disabled, I wouldn't have what I have now. I wouldn't have gone on vacation that I have a right to go to as part of my in-kind benefits, I wouldn't have met people that are in my life now. Completely different life. Sometimes, I even tell people who are in a similar situation 'Just imagine you have a new life now in a different body, but you are lucky to remember your previous life. You need to appreciate that, you can live a different life.' (Svetlana)

Such incorporation of disability into a larger scheme of life is different from a widely criticized in disability studies trope of overcoming disability. The participants do not resort to viewing their disability as something that needs to be overcome. Disability studies explains that society expects people with disabilities to work extra hard to 'overcome' or 'compensate' for their disabilities (Vidali 2007). The juxtaposition of disability to something that can nullify and hide it is what disability studies scholars find problematic in this approach that implicitly devalues disability.

The essential nature of motherhood certainly dominates over any self-perception of being disabled. Motherhood is foregrounded in the context of the challenges that mothers with disabilities face. Despite the acknowledgment of the transformative role of disability, it is predominantly associated with a failure to be a mother as a protector of her child and a bureaucratic designation. What is reflective in these accounts is not necessarily the outright refusal of disability, but the refusal to accept it in its current dominant understanding as something associated with a bureaucratic label and weakness. Petryna (2003) provides a poignant image of how the bureaucratic state can become an overarching authority of knowledge about disability through the regimes of biopower. The continuing domination of medical discourses in the domains of disability determination process and welfare perpetuate a negative perception of disability. The participants barely discussed their disability in terms of the official disability categories, weaving it instead into a more complex story of their lives.

Irina discusses the difficulty of accepting her disability. The image of what it means to be disabled does not coincide with how she views her life. She does not feel that her illness, as she refers to it, dominates her life in a way that people around her think:

Disability (*invalidnost*) for me is a bureaucratic word. I don't feel disabled ... People often talk to me about my illness. It feels as if it is happening to someone else. I'm simply refusing to accept. I will not come to terms with it even though I

experience the pain. I'm not being melodramatic. But when I hear 'Become friends with your illness', how can I? (Irina)

The undesirability of disability status to many people with disabilities is theorized by Watson (2002) as a way to confront 'disablist stereotypes' to present a picture of herself as an active, resistant agent. It is a way of recognizing one's bodily difference without ascribing to the characteristics associated with that difference. It pushes us to think beyond the dualism of ability–disability.

Maria explains why she did not want to pass her vision impairment to her children. She looks at it as a way to protect her children. She recognizes the challenges she experienced herself and simply wants to minimize them for her children. Maria sees disability as something that makes you vulnerable, unprotected. Thomas (1997) discusses the fear of giving birth to a disabled child in the context of the risk discourse. She suggests that women with disabilities defy these discourses embedded in the ableist rhetoric and suggests that women with disabilities do not necessarily evaluate risks negatively. They 'take that risk' despite the pressure from the outside. Despite that risk, the underlying desire for a non-disabled child does not square neatly within the logic of emancipatory feminist disability studies. Similarly, in her analysis of literary texts, Kim (2016, 57) unpacks the role of 'cure' in reproduction that conditions a mother with a disability 'to ameliorate the social rejection of her aesthetic disability by reproducing beautiful offspring'. By reproducing a non-disabled child, mothers with disabilities have the power to alter how they are perceived. In other words, the underlying logic that devalues disability is deeply entrenched.

Often, this refusal to be associated with disability was justified by the importance of presenting oneself as capable in front of the child. Oxana focuses on the perceptions, not in the sense of how they relate to her but how they will impact her child:

I always thought, well from the moment my leg was amputated that I would do everything, I would manifest something so that my child didn't think of his mother as disabled. Overall, I don't consider myself disabled (*invalidom*). I don't associate myself with this word. (Oxana)

Prilleltensky (2004) suggests that a desire to shield children from the effects of disability can be understood in the context of the institution of motherhood, on the one hand, and the medical model of disability, on the other. The romanticized notions of mothers as all-giving and self-sacrificing have been critiqued; however, mothers continue to be at risk of self-erasure, they are supposed to be on the giving end, not on the receiving end of care. In my interviews with mothers with disabilities it was not so much the perception of being a care receiver that the women were concerned about, but the stigma of having a disability as a mother in the first place. One of

the participants described a general sense of society not being aware, not being able to imagine a life as a mother with a disability. But beyond shielding children from the effects of their own disability, mothers with disabilities are not immune to the discourses that devalue disability and, thus, create a preference for a non-disabled child. Most of the research on disability in Russia focuses on the perception of non-disabled parents who have a child with a disability. How can we make sense of the discrepancies and non-linear narratives without providing a somewhat reductive explanation of internalization of ableism by these women? As Grech (2009) contends, we need to engage with what surrounds disabled people and their families because the possibilities and limitations they confront are largely contingent on the broader sociocultural, economic, and political environment. The fear of raising a disabled child in Russia is born out of the very material conditions that shape these mothers' everyday life.

The participants also claimed the right to be a mother by emphasizing their mental fitness to take care of the child. Thomas (1997) writes that living with a fear of losing the right to care for their children forces some mothers to 'present' themselves as 'normal'. Normalcy has a specific connotation in the Russian context that places it specifically on the mental capacity scale. *Nenormalny* (not normal) can be translated as mentally ill. The history of mental illness in Russia (Phillips 2007) illuminates a less stigmatized view of mental illness there, predicated on the idea that irrespective of one's mental illness, people in Russia face palpable conflicts between their desired and state-compelled roles. However, motherhood as an expression of responsibility for another life changes the stakes. Alcoholism and drug abuse are listed as reasons for the termination of parental rights according to Article 69 of the Russian Family Code (Konsultant Plus 2017). Although a parent's disability, including psychiatric disability, cannot be a sole reason for stripping the parental rights, it can be one of the factors for limiting them. By challenging the doctor's question about her capacity to be a mother, Maria appeals to her mental health to be used for determining her fitness:

As for my first pregnancy, the doctor asked me what I was going to do with the baby, he asked why as a blind woman I intended to give birth. I asked him back whether a drug addict is asked the same questions. The doctor didn't reply. And then I asked why he is asking me these questions, was I not being reasonable, was I not behaving like everybody else?

Svetlana complained about the emotionally draining process of challenging the doctors' assumptions about whether she can be a mother:

The director would be after me and say 'You have a first degree disability,¹ you have no right to give birth'. I said 'Why? Am I intellectually disabled? Or emotionally unstable? Why not?' They are simply scared of taking that responsibility. They emotionally exhausted me, I ended up in the hospital. (Svetlana)

Deal (2003) discusses the phenomenon of disassociation of one impairment group from another impairment group depending on what impairment is more stigmatized. The study finds that some people with physical disability 'may be annoyed at being labelled as having a learning disability' (2003, 898). It is rightly indicated that by distancing themselves from what they perceive as more severe and more stigmatized disabilities, people with physical disabilities perpetuate the notion that there is a hierarchy of disabilities depending on the diagnosis and rely on the mechanisms that have been used by non-disabled individuals to alienate them.

This research shows that mothers with disabilities do not necessarily share a sense of commonality with mothers who might have intellectual or mental disabilities. In the environment that promotes a narrow definition of ideal motherhood and that puts disabled mothers under heightened surveillance by social services and medical professionals (Frederick 2014; Malacrida 2009), such an association becomes a strategy for claiming the right to be a mother.

Discussion and conclusion

This article makes a claim that motherhood with a disability is a basis for claims-making that links experiential and discursive dimensions of citizenship. Mothers with disabilities appropriate different subject positions in relation to other subjects and practices for the purpose of challenging and redefining the boundaries of citizenship. By relying on the discursive instruments of reproduction and nation, mothers with disabilities push against the reified notions of motherhood and womanhood.

In theorizing the need to focus on subjectivities, the philosophical and administrative framings of citizenships are important for understanding the formal rights and obligations; however, it is the process, not the status, that helps the marginalized groups challenge the entrenched prescriptions and delineations of citizenship (Canning and Rose 2001). The notion of subjectivity is both individualized and collectively invoked. The experiences of mothers with disabilities demonstrate that citizenship contains the personal and the psychological dimensions. On the other hand, these experiences are always informed by the ways discourses about citizenship collectively embody citizens by gender and ability.

The focus on subjectivity is a recognition of the instabilities and fractures in the ways in which motherhood with a disability is simultaneously produced and delimited. The participants' lived experiences destabilize identity categories, specifically in a context where identification with disability is not desired and is still widely stigmatized. Russia did not have a distinct history of disability rights movement. The dissident movement known for its

opposition to the Soviet government and active in 1970s and 1980s included some activists with disabilities; however, their activity was closely monitored by the state, allowing them to focus on a narrow set of politically safe issues (e.g. disability sports, and facilitation of communication among people with disabilities across the country) (Phillips 2009). Such ‘rumblings of dissent’ (Phillips 2009) had little impact on dominant understandings of disability in Russia, which revolve around bureaucratic categories embedded in the social welfare system. Disabled identity often became a survival strategy rather than a category associated with pride.

My research indicates that being a mother, in the context of the pronatalist state, is a much more desired identity category than being disabled. However, the concept of subjectivity allows us to see beyond rigid lines of identity politics and recognize structural as well as subjective factors that come into play when creating one’s ‘I’. By enacting their agency and claiming their right to be a mother, mothers with disabilities become objects of discursive practices. Understanding citizenship through the lens of agency helps avoid the construction of women and other marginalized groups as passive victims. At the same time, agency is embedded in and shaped by the social structures, making it important to remember that the expression of agency can be constructed by macro-level practices (Lister 1998).

Feminist literature has contested maternity as an essentialized experience that naturalizes what it means to be a mother and a woman. Looking at subjectivity through the prism of disability brings forward the embodied nature of subjectivity. When motherhood is mythologized and reduced to a narrow conceptualization of acceptable motherhood, mothers with disabilities ‘find themselves in an acutely difficult position, striving to be fully acknowledged as persons rather than a set of mythologized, vilified body parts’ (Mintz 2007). As much as motherhood with a disability is a transgression that pushes against an ableist understanding of motherhood role, it can still be conceptualized in essentialist terms by mothers with disabilities.

Pronatalist narratives reflect a particular gender regime that links the physical ‘body’ of the state to a set of meanings and affects making the physical space sociopolitical (Verdery, 1994). The subjectivities are fundamental elements of the nation-state that reflect some of the nation’s interests but also contribute to reshaping and reconceptualizing the gender regime.

The subject positions shift and shape each other. They do not exist in a vacuum. Narratives reveal how people with disabilities are positioned by structures of power. Yet, irrespective of how deeply entrenched the narratives of an essential role of motherhood in a woman’s life are, the experiences at the intersection of motherhood and disability uncover fractures in the seemingly monolithic discourse. The lived experiences of mothers with disabilities are built around multiple subject positions infusing ambiguous

meanings about motherhood – from the discourses of independence that reflect the neoliberal values of self-governance, to the centrality of motherhood in shaping the everyday experiences, to the ways in which disability serves as a tool in making motherhood more meaningful. The intersection of motherhood and disability reveals the complexity of our subjectivities that are differentially constituted.

This article contributes to the research on lived citizenship using the context of motherhood with disability to demonstrate how the practices of everyday are deployed in opposition to hegemonic conceptions of motherhood and nationhood. The construct of subjectivity underscores contradictions and tensions of forming and expressing the self. As the narratives of mothers with disabilities demonstrated, motherhood might exist as a distinct status position; however, more often, women's subjectivities shift depending on the context (their children, husband, barriers), with disability infusing additional and not necessarily negative dimensions of the self. Motherhood destabilizes the category of disability, and vice versa. In an environment where identity-based categorizations cannot be easily transferred from western contexts, intersectional analysis of subjectivities provides researchers with a language to theorize at the level of lived experiences.

Notes

All translations in the article are the author's responsibility.

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Note

1. The most severe according to the Russian classification system.

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