

**ACCESSING POSSIBILITY: DISABILITY, PARENT-ACTIVISTS AND  
CITIZENSHIP IN CONTEMPORARY RUSSIA**

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## **ABSTRACT**

**CASSANDRA HARTBLAY: Accessing Possibility: Disability, Parent-Activists and Citizenship in Contemporary Russia**  
(Under the direction of Michele Rivkin-Fish)

This paper highlights ethnographic case studies of two mothers caring for special needs children in Petrozavodsk, Russia (a city of 300,000 near the Finnish border). The still-prevalent institutionalization of children with disabilities in Russia means that there are few options for parents who choose to keep special needs children at home. Parent-activists in Petrozavodsk have staged two civil legal suits to enforce the right to public education guaranteed in the Constitution of the Russian Federation, resulting in a new inclusive education program in local schools. Examining these two case studies, I find that binary axes of autonomy/dependency and public/private that dominate teleologies of the postsoviet transition are upset by the hybrid strategies that the case studies illuminate. I propose that these refractions echo calls from anthropologists to find space for alterity within neoliberalism, and may offer new openings for a politics of disability justice and ethnography of the postsoviet both.

## EPIGRAPH

*as if change were not  
something that just happens  
at certain stages  
but a private test failed  
moment by moment*

-Kay Ryan, *the old cosmologists*

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# MAPS



**map 1**  
*a. Petrozavodsk*



**map 2**  
*a. Petrozavodsk city train station*  
*b. Round Square*  
*c. Key Electronics Store*  
*d. Hotel Severnaya*  
*e. Lake Onego*

## INTRODUCTION

In the spring of 2006, disability justice activists in Russia reported a new victory. In the city of Petrozavodsk, capital of the Northwestern region of Karelia, the success of the first civil legal suit to enforce the federal constitutional right to public education for all citizens<sup>1</sup> was announced. New measures to make public preschools accessible to all children in the region were subsequently instituted by the regional government in cooperation with parent lobbyists. Local press outlets in Karelia, as well as judicial system websites, hailed the decision as evidence of changing policy toward disability, and of progress toward a more Western standard of governance marked by active civil society and rule of law. By October of 2010, a subsequent ruling had upheld integration for public elementary and high school education on the same grounds, designating two primary-secondary schools in the region as target test cases. Local papers ran human interest stories about teenagers with disabilities, who for the first time were attending school with their broader peer group (Tsygankova 2010).

In the context of postsoviet Russia, these lawsuits were indeed victories for disability inclusion. Given that the Soviet Union, through 1991, maintained a policy of institutionalization, or at best separatist rehabilitation, for children with disabilities, the lawsuit marked a new set of possibilities for children and families in the region. At the

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<sup>1</sup>The Constitution of the Russian Federation, adopted in 1993, guarantees "the accessibility and gratuity of pre-school, general secondary and vocational secondary education in public and municipal educational institutions" to all citizens (Chapter 2, Article 43.2).

same time, it demonstrated a major commitment from regional authorities to devote resources to developing new educational infrastructure: public schools had no history of accessibility either in terms of built environment or curriculum, and teachers had no special education training. Negotiations were made to use a combination of public and private funds to hire aides to facilitate the education of the newly integrated students.

Popular consensus, reflected in the news reports, held that the work of raising a child with disabilities fell almost entirely to the mother (although doctors would urge her to institutionalize children unable to pass as normal in school); and, it was primarily mothers who were speaking up for their children's rights in the public sphere (Pravosudiye 2007). In a 1999 article for anglophone audiences, Russian sociologist Elena Iarskaia-Smirnova described what she termed "the complex crisis" facing mothers of children with disabilities in Russia. Iarskaia-Smirnova's article considered interviews with a subset of these women conducted between 1995 and 1997<sup>2</sup>, finding that as a rule they were differentiated from their peers and excluded by stigma – as well as embedded in the shared despondency that many Russian citizens faced during those years of political and economic uncertainty. The crisis of political organization and the crisis of economic uncertainty on household, regional, and societal levels that characterized life in the 1990s in Russia were compounded for these mothers by the demands of their children's special needs. And their lives were further ruptured by the work of reimagining the self to reconcile the knowledge that their experiences of motherhood would never be "normal" (for more on the crisis of self-identity for mothers parenting a

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<sup>2</sup> Iarskaia-Smirnova analyzed interviews that were conducted by a research assistant.



special needs child, see: Hartblay 2006; Landsman 2005; Valle 2009; Ryan and Runswick-Cole 2008; Kittay 1995 and 2002).

With this framework in mind, we might ask, what does parent activism look like in Russia in 2010? What strategies deployed by parent-activists have engendered the successes reported in Petrozavodsk? What insights might this case provide as to the state of civil society and social movements in contemporary Russia? How do the stories of parent-activists require a revision of assumed profiles of the new Russian citizen?

This thesis draws on ethnographic fieldwork conducted during the summer of 2010 in Petrozavodsk with these questions in mind. In many ways, Petrozavodsk, a city of roughly 300,000, is a unique case [see Map 1]. An overnight train ride from Saint Petersburg, and a half day's travel from Finland, Petrozavodsk and its citizens are more closely tied to Europe in sensibility, space, and trade than more Eastern regions of Russia. As a result, residents are quick to identify a progressive and westward-looking character that defines the region and might separate the experience and outcome of disability activism here from that in other Russian regions. However, even in identifying this departure, my collaborators in Petrozavodsk also described a complex of circumstances in which the day-to-day hurdles of deinstitutionalization of people with disabilities continues to rely on the will and hard work of family members and activists with disabilities (rather than on some top-down or in-the-water solution).

I focus this thesis on parent-activists out of an interest in the particular questions that their struggles raise, and refer to broader activism only tangentially. My intention is not to collapse the experience of parenting a disabled child with that of living with a disability oneself, nor to ignore the agentic voices of Russians with disabilities

themselves. More research is needed to explore the charged relationship between parent activism and adults with disabilities, a subject that I will not take up here. Rather, I simply postulate that a politics of accessibility and inclusion is sought by both groups, although the means and ends of this pursuit of disability justice are continually the subject of negotiation from all sides.

My ethnographic research in Petrozavodsk led to me to interrogate a particular question that circulates through conversations about the political in contemporary Russia, as well as through disability studies: what counts as political? Who counts as an activist? To help to tease out this question in the case of Petrozavodsk, I highlight the narratives of two women. Katya and Nina<sup>3</sup>, whom I have selected out of a group of fourteen local research collaborators, since their narratives occupy seemingly opposite positions on a spectrum of activism/non-activism.

Both Katya and Nina are mothers to daughters with DTsP (*Detskii Tserebral'nyi Paralich*), a diagnosis that is relatively equivalent to the spectrum of cerebral palsy in American medicine. Nina, like the women represented in Iarskaia-Smirnova's article, was a parent to her daughter (now in her early twenties) during the 1990s. She participates in no parent groups and relies on social workers and the lobbying of others to maintain the best standard of living available to herself and her daughter. In contrast, Katya is in her early thirties and has a disabled daughter who was eight years old in 2010. Katya is a key organizer for a group of parents that has achieved significant success in

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<sup>3</sup> The names "Nina" and "Katya" are pseudonyms deployed to ensure confidentiality for interlocutors. Both women are ethnically Russian in a province that is majority Russian. Significant minority groups in the region include Finnish and Tartar ethnicities. Tartar Muslim identity seems to carry little racialized stigma; however, many local residents conceal partial or full Jewish heritage and pass as ethnically Russian, as antisemitism is diffuse and internalized. I do not know if this is the case with either Nina or Katya.

using the civil legal system to enforce constitutional rights to education in the region. Her activism has resulted in a new program to engage in the experimental mainstreaming of two local kindergartens and primary-secondary schools, where previously these schools had no special education programs and children with disabilities were either sent to a separate school or allowed no formal education aside from rehabilitative social services. With these successes under her belt, Katya is working on enforcing accessibility in public buildings: having won a court decision that a local theater must, in the course of renovations, update entrance/exits, bathrooms, and audience seating to accommodate wheelchair users, she is now moving on to calling for a more accessible city train station.

The divergent experiences of Katya and Nina propose two obvious explanations. First, that their different positionality represents a sort of temporal progress toward democratization: we might presume that as the political-economic circumstances of the 1990s have stabilized, the potential to engage in civil activism has simply increased since the time that Nina's daughter was school-aged. Second, familial economic resources. Nina is a single mother who relies on a meager teachers' salary and the domestic assistance of her own, aging, retired mother. Katya, in contrast, is married and was able to stop her work as an accountant to pursue activism activities full time, enabled by the fact that her husband's salary is sufficient to support the whole family. Both of these explanations are consistent with the discursive possibilities available in what Alaina Lemon calls "transition discourses", a short-hand for the development processes that have unfolded in the so-called transition from the Soviet Union to the Russian Federation as a neoliberal market democracy.

However, in this thesis, I seek to move conversations beyond these available explanations. Given ethnographic examination, I find that that neither explanation fully captures the complexity of circumstance and strategies that make up the personal narratives of these two women. **The tendency to read events in postsoviet Russia through the ideological prism of successful or failed postsoviet transition obscures moral and cultural valences of meaning present in the agentive actions and self-narrations of these two mothers.** Where discourses deployed by some Westerners and Russians imagine that the Russian Federation is or ought to be engaged in a transitional trajectory from socialism to capitalism, autocracy to democracy, and dependent Soviet subjectivities to autonomous Russian citizenships, neither Katya nor Nina's narratives fit wholesale into such heuristic constructions. Moreover, such binaries obscure the complexity of strategies that these women deploy that make being "out" publicly as a parent of a disabled child a possibility and a sustainable life practice<sup>4</sup>. The discursive realm of transition discourses rely on a combination of logics derived from neoliberal economics and liberal democratic paradigms to assess a positivist progress. In this view, Katya is an enlightened, self-sufficient subject while Nina is a dependent, surviving

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<sup>4</sup> I use the concept of "outing" self-consciously here, in a play on two very rich potential meanings. First, a productive intersection between disability studies and queer studies has worked to examine the ways that publicly performing particular kinds of embodiment (transgender, gay, hidden and unhidden disabilities) requires a self-conscious transgression of implicit social norms of what counts as normal; this moment of transgression, referred to as "outing" has entered public discourse most famously in the terms of the assimilationist gay and lesbian project of "coming out of the closet"; however, the term also circulates (since, at least, Judith Butler's *Gender Trouble*) as pertinent to these more diverse moments of defying social constructions of embodiment (see: Sandahl and Auslander 2005:3). Second, the Russian context is literally one in which during the Soviet era many children and family members with disabilities were literally kept inside and not allowed to enter public space; this entailed both a conscious effort on the part of the state to keep people with disabilities out of the public eye, an incidental after effect of the extremely derogatory and stigmatizing manner in which the medical-social complex referred to people with disabilities, and a layperson belief that disability indicates a profound and deserved misfortune due to some familial shortcoming or sin (which led parents to keep children with disabilities 'secret' to protect the futures of their siblings (Phillips 2010; McCagg and Siegelbaum 1989).

subject, or, that Katya is an activist, while Nina is not. In examining their stories more closely, I find that this reading is incomplete.

Instead, **I propose that “dependency” and “autonomy”<sup>5</sup> are not mutually exclusive**: both women, because of their decision to keep disabled children at home in spite of latent social pressure to institutionalize them, are themselves thrust into unanticipated roles and modes of citizenship that routinely force them to ask more of their government, their community, their families and peers. At the same time, both provide care for their children and unpaid labor that ultimately contributes to and benefits the state (either in the sense that they are not compensated for their caretaking work, which, otherwise, would be an economic cost absorbed by the state<sup>6</sup>, or in the sense that the demands that they make lead to desirable outcomes, such as an increase in the quality of accessible education, or an increased public awareness of civil legal process). As agents, they occupy strange positions: they are on the one hand willful – going against doctors' recommendations and refusing to institutionalize their kids, enacting rights-based discourse, demanding access to public spaces; and weak – asking for public benefits, in need of accommodations, thrust into the role of self-advocate without prior political impulse. While it is tempting to parse parents into categories of activist and non-activist, their agentic self-positioning, though varied, requires each to make strategic decisions

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5 As these terms are frequently understood in political philosophy.

6 The proposition that the caretaking work for children with special needs performed by Nina, Katya, and their peers indicates an economic freebie for the Russia state is underlined by the fact that the majority of children with disabilities in the Russian Federation continue to be abandoned to state care, and make up a disproportionate percentage of the already large population of “orphans”. For more information on the problem of institutionalization, see [www.everychild.org.uk/russia](http://www.everychild.org.uk/russia) or [www.mdac.org](http://www.mdac.org).

about a particular combination of willfulness and weakness, independence and dependence, assertion of rights and requests for benefits.

In addressing these questions, I intend not only to intervene in popular readings of the postsoviet, but also to contribute to on-going conversations in disabilities studies about constellations of disablement in diverse cultural and transcultural (global) settings, family coping skills, and activist strategies. On a theoretical level, I am examining the ways that feminist and anthropological critiques of neoliberalism can be illuminated by the cases of disability and of the postsoviet. This can most cogently be read as an effort to develop a framework with which to analyze ethnographic data, such as the short case studies presented here, on disability in contemporary Russia.

In order to do so, I (1) review the methods deployed in the course of research; (2) briefly review the ways that contemporary ethnographers have challenged dominant understandings of the postsoviet context; (3) situate this perspective vis-à-vis anthropological critiques of development and neoliberalism; (4) discuss the manner in which I understand disability in contemporary Russia; (5) present case studies of Nina and Katya; (6) engage a discussion of how the proposed framework may illuminate these cases and indicate new questions; and (7) draw conclusions.

### ***Methods***

The case studies related in detail in this paper represent a subset of more substantial ethnographic data gathered both during the summer 2010 in Petrozavodsk and Saint Petersburg, and earlier fieldwork examining the constellation of meanings around disability and the challenges facing mothers of children with disabilities in various sites

across Russia (see: Hartblay 2006). In this paper, I have highlighted the stories of two mothers; I selected these case studies out of a broader data set in order to highlight the thesis herein. The ethnographic data presented here relies on open-ended, but topic-centered, life history interviews. In meeting with these mothers, I identified myself as an ally and activist from the United States interested in learning about the types of challenges and solutions that parents and activists in their city were engaging. I likewise identified myself as such to a broad network of acquaintances, research contacts, and friends, whose observations from both formal interviews and informal interactions provide contextual data about the specificities of life in contemporary Petrozavodsk.

This research was conducted with the goal of eliciting first-person perspectives on workable and failed strategies of building support networks and working toward goals of inclusive education in local communities. Research collaborators included parents and relatives of children with disabilities, teachers of children with disabilities, young adults with disabilities, advocates and non-profit workers serving this population, and legal and social service professionals, and local scholars. During the summer of 2010, I conducted fourteen formal interviews and numerous informal interviews. Data include taped interviews and transcribed interviews, notes from informal interviews, notes from observation, outreach materials produced by my interlocutors, and recent scholarly and popular press articles on the topic of special education in Russia.

My own background as a peer-advocate and organizer of disability awareness campaigns throughout my secondary and tertiary education in the United States has also buttressed my investigation of similar topics in Russia. Having worked as a peer tutor and paraprofessional in special needs classrooms in US public schools, I approach this work

with a certain degree of familiarity with the kinds of challenges, questions, and struggles that arise in educational settings. And having worked as a paralegal for adults seeking disability benefits through the Social Security Administration in Queens County, New York, I have seen and participated in the despondency of bureaucracies of disabilities in the United States leaving me highly critical of tendencies to pathologize corresponding postsoviet bureaucracies (for ethnographic discussions of the social security process for American citizens with disabilities, see: Melhorn et al 2005; Morgen 2002; Estroff et al 1997).



## **DETRANSITIONING RUSSIA: BEYOND THE BINARIES**

Since 1991, the United States government has gone to great lengths to contribute to “building” what experts imagine to be conditions necessary for liberal democracy in Russia and Eastern Europe; along with a state oriented toward the private accumulation of capital (whereas the Soviet Union angled productivity toward a state accumulation of capital), this has meant a drive to establish a citizenship built on a rights-based model of justice (Opalski 2001: 298). A key tenet here is “the persisting weakness of civil society in Russia” (312). Civil Society,<sup>7</sup> as a theoretical sphere of public exchange in which plurality is protected by a neutral state, is regarded as the necessary grounds both for successful establishment of a system of business conducive to capital accumulation and for rights-based justice. This project of navigating the Russian Federation out of Soviet institutions read as primarily autocratic and repressive, and toward a political economy that looks more like those in Western Europe, was colloquially referred to by neoliberals and in the popular press as the “transition”. Subsequently, critical scholars of Russia

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<sup>7</sup> The concept of civil society has occupied a special centrality to conversations about liberal democracy since the fall of the Soviet Union, principally based on the proposition that as an authoritarian state, the Soviet Union fundamentally lacked a civil society, or, a meaningful space of mediation between the private citizen and the state. Beyond the postsoviet transition, the concept of civil society has been taken up and travelled in diverse ways as a universal type in political philosophy that has been central to theories of governance (see: Foucault 1984) and publics (see: Warner 2002), theorized as an arena for brokering a balance between personal liberty and the good of the collective. Adam Seligman has written extensively about the way that the concept has moved through scholarly conversations since Habermas. Moreover, the term has historically been intimately entwined with the development of a concept of neoliberalism, especially considering Adam Smith’s ‘invisible hand’ concept, which posited the free market as governing the public good. For a further discussion of an anthropological concept of civil society in a postsoviet context, see Hartblay (2011), and Phillips (2005).

(Hemment 2007, Yurchak 2006, Collier 2005, Rivkin-Fish 2005a and 2005b) have investigated where these “transition discourses” (Lemon 2008:238) come up short to describe what is happening on the ground in the Russian Federation.

These critical scholars take targeted approaches to dismantling dominant narratives about the postsoviet. Alaina Lemon argues that the socialism-to-market-economy transition tends to overdetermine interpretations of social phenomena in the postsoviet – even of spheres ostensibly removed from the economic, specifically the highly “personal” arena of love. She writes that “it is tempting, for both foreigners and postsoviets, to read [contemporary texts] in terms of “Transition,” dividing the world into “socialism before” and “markets after” 1991. We have learned a great deal from scholarship about changes in the region. Still, the primarily economic frame provided by “Transition discourse” prevents us from conveying forces that motivate persons to aspire to “change” or “continuity,” or to label them as such in the first place” (238). While the “transition” refers to a targeted implementation of a radically different set of economic values, in fact, when we speak about the postsoviet, we often deploy this transition as the primary frame of analysis, and, as a result, may be guilty of using descriptions of economic phenomena to explain non-economic transactions, events, relationships, and narratives; additionally, we may be guilty of assuming that the “transition” is an explanation for an array of social realities or ways of being in the world that have developed on trajectories more complicated than before and after, or are in fact indicative of continuity.

Meanwhile, Alexei Yurchak has argued that American Cold War narratives about Russia – which continue to color perceptions of the postsoviet – failed to capture the

nuance of individual relationships to state power. While popular discourse of Soviet life imagines that citizens were captured in a life circumstance defined by autocratic authority, illustrated by Vaclav Havel's notion of a masked self in public and a true self in private (Yurchak 2006:17), in fact, the performative relationality unfolding in all spheres was much more nuanced, layered, and multiple. He writes,

...late socialism became marked by an explosion of various styles of living that were simultaneously inside and outside the system and can be characterized as 'being *vnye*'. These styles of living generated multiple new temporalities, spatialities, social relations, and meanings that were not necessarily anticipated or controlled by the state, although they were fully made possible by it. ... being *vnye* was not an exception to the dominant style of living in late socialism but, on the contrary, a central and widespread principle of living in that system. It created a major *detritorialization* of late Soviet culture, which was not a form of opposition to the system. It was enabled by the Soviet state itself, without being determined by or even visible to it. [Yurchak 2006:128]

That is, in enacting a variety of behaviors that appear “official” postsoviets may be simultaneously enacting the constitutive, obvious meaning, and gesturing to a subversive, ironic invocation of the same act (2006:20-21).

In his ethnographic monograph on tropes of loss and mourning in contemporary Russia, Serguei Oushakine has framed his description of postsoviet subjectivity by describing the geographic expression of public space in Barnaul (the capital city of the Altai administrative region) as a palimpsest of layered symbolic orders: dilapidated celebrations of Soviet glory coexist with advertisements for Baskin Robbins (2009:15). Like the public space that they move through, Oushakine observes, postsoviets themselves try on, discard, and take up various frameworks, explanatory systems, and political imaginaries that refuse to conform to the commonsense teleologies of overcoming socialist state oppression through the freedoms of liberal democracy that continue to circulate in global media and state rhetoric.

Building on Balibar and Foucault, Oushakine writes that “it is by realizing his or her own location within a larger symbolic order that the subject could address and be addressed by others” (38); because the very symbolic orders at hand are quite literally up for grabs in Barnaul, the public sphere that is in turn crafted through discourses addressed to various publics, the arena of exchange and political imaginary remains “up for definition and appropriation” much as Caroline Humphrey has observed that legality was in the 1990s (51). Perhaps, Oushakine suggests, this failure of a dominant public imaginary to emerge can be rooted in the very real sense of postsoviets that “we were duped” (77) – the political imaginary and claims about justice and equality proffered by the Soviet Union were so thoroughly dissolved, regime legitimacy and consent can *only* be considered to be manufactured.

Therefore, scholars agree that ethnographic attempts to interpret meaning, action, and understandings of citizenship in contemporary Russia must take a concerted approach to departing from binary schemas of authority and resistance, economy and politics, socialism and capitalism, and so forth. In fact, scholars have found, these paradigms fail to capture the nuanced, complicated political imaginaries and understandings of selfhood that postsoviets continually negotiate. It is with this critical apparatus in mind that I approach the narratives of parent-activists in Petrozavodsk.

## **DISABLING (NEO)LIBERALISM**

Over the past twenty years, journalists and social scientists have watched and catalogued the so-called “transition” of the Russian Federation toward a new political economic entity – one that ought to embrace liberal democracy, cultivate a vibrant civil society, and balance local, regional, federal, and international influence.

However, as an anthropologist, I want to be careful to avoid neat teleologies of progress. Ethnographers of the global have complicated mid-twentieth century conversations about modernity and development that imagined a global march toward the industrialized state as the most “advanced” model of society (e.g., Ong 1988). Rather, it is important to 1) question the validity of teleologies that posit a universal progress and endpoint, 2) attend to local intentionalities and goals that may or may not align with models of progress, even when the actions they produce can quickly be assessed by a development rubric (e.g. Rivkin-Fish 2005), and 3) make room for a robust globalism that allows for different models of political economy not on a global scale of progress, but embedded in local histories and communities, moving through time on unique trajectories (e.g. Escobar and Osterweil 2010). In conversations about globalization, anthropologists have most often enlisted this set of critiques in reorienting how Anglophone scholarly audiences read the claims and subjectivities of people and communities in the global south or “developing world.” In relation to the former Soviet arena, a similar stance has been taken in relation to the deployment of democracy as a

model of governance (e.g., Kymlicka and Opalski 2001). Others have criticized “transition discourses” in which the postsoviet arena can always be explained by positive and negative movement along a teleological axis of transition from dysfunctional socialism toward structurally stable market-driven democracy (Lemon 2008:219).

Critical scholars interested in undoing these teleologies and cracking open the assumptions about progress in development rubrics have sought to explicate the intellectual genealogy that has led popular wisdom to argue for democracy and free markets. They do so out of a concern for the ways that such unidirectional models of progress act as ideological steamrollers, flattening conceptual understandings of what is taking place in the lives and lifeworlds of people in diverse locales, and limiting perception of global conversations to a west/rest schema in which modernity, power, progress, and knowledge moves from Western Europe outward. Instead, critical scholars (e.g. Chakrabarty 2000, Madison 2012, Tsing 2005) argue for a more complex understanding of how knowledges move, in unfolding dialogic play.

This critical conversation has recently focused especially on ideas of liberalism and neoliberalism<sup>8</sup> as governing philosophies that have become a primary “export” of the

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8 The linguistic territory of neo/liberalism deserves a moment disambiguation. D. Soyini Madison succinctly explains, “*Neoliberalism* is a late-twentieth-century philosophy born out of classical liberalism (that was influenced by neoclassical theories of economics). The central values of neoliberalism are free markets, free trade, privatization of public-sector economies, and deregulation” (2012:66). As Madison highlights, liberalism, as a term that moves in American partisan politics indexes an entirely separate – and often opposing - set of meanings (e.g. public programs, progressive politics of recognition, etc.). Meanwhile, *liberal democracy*, as an ideal type used in political philosophy describes a particular model of democratic governance in a nation state model that emphasizes a balance of the private rights of citizens with the public good, hinging especially on “free and fair elections” (Kymlicka and Opalski). Liberal democracy occupies a special place in modernity and development models as the favored and most just form of government. Meanwhile, neoliberal economics, although also circulating via development schemas, does not necessarily imply democracy, or that democracy is the path to the common good. Madison, citing Jane Lou Collins et al (2008) and David Harvey (2005), writes, “neoliberalism is an ideology that believes human well-being is better served by ‘liberating individual entrepreneurial freedoms and skills’ within in structures and institutions

Euro-American intellectual heritage, and are entwined with popular understandings of what separates the “developed” world from the “undeveloped” world: representative democratic governance and free market economics. This rubric applies equally to Russia as to other global territories.

To this perspective, I add the lens of disability, which offers a deepened critique of productivity and individualism as orienting concepts of personhood and citizenship. Contemporary disability theory observes that by considering possibilities for people with “non-productive bodies” that escape rationalities of economic value and contribution, a space is opened “to create a less exclusionary definition of subjects” (Mitchell and Snyder 2010:183-184). Considering disability urges us to challenge assumptions about ability, dependence, and justice in a liberal democratic framework (Nussbaum 2007). Both neoliberalism and liberalism are troubled by the persistent presence of bodily and cognitive alterity.

While scholars in disability studies have begun examining potential convergences between disability justice and critiques of capitalism, modernity, and liberalism, little scholarly writing has taken up the question of disability justice in relation to Soviet models of productivity. Sarah Phillips, in her ethnography on mobility impairment and citizenship in postsoviet Ukraine (2010) draws on Aihwa Ong's notion of “mobile citizenship” (2006, 2007). Ong has observed that while development narratives imagine a movement from native concepts of self and sovereign toward neoliberalism and rights-based citizenship, in fact, even when subsumed in discourses of neoliberalism, citizenship itself is a “mobile concept” that can be selectively assembled to include changing arrays

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that generate, promote, and sustain strong property rights, free markets, and free trade, all of which take precedence over the interest of labor, social services, and local entrepreneurship” (2012:66).

of practices, ideologies and ways of being. Neoliberalism itself, then, is cast as a technology or tool, selectively deployed to the ends of citizens in embedded realities. Phillips appropriates Ong's phrase to help explain her observations about disability activists in Ukraine. On the one hand, Phillips deploys the phrase as a double entendre: she makes the point that her informants, people with mobility impairment due to spinal injuries, are perceived to be both physically and socially immobile. Thus they are actively seeking ways to become more mobile on both of these counts at the same time that they assemble new citizenships. Phillips argues that her interlocutors made "hybrid claims". That is, depending on context and situation, their articulations of deservedness may have been rights-based or needs-based, market-based or public welfare based. By playing to audience and situation, disability activists wore different hats to stage varied requests.

In particular, this reading of *citizenship* as a node of negotiated relational meanings is an important counterpoint to popular discourses about Russia that imagine the nexus of neoliberal economics and liberal democracy as a normative model of how people might organize themselves politically. Ong writes that neoliberalism must be "conceptualized not as a fixed set of attributes with predetermined outcomes, but as a logic of governing that migrates and is selectively taken up in diverse political contexts" (2007: 3). That is, not as a universal ideal type, but as a moving and contested set of selectively applied logics. Anna Tsing has argued, in conversation with Ong, that ideas and concepts imagined to be human universals actually circulate in in diverse incarnations that move and produce "friction" with one another. Rights, justice, civil society, productivity, and prosperity may masquerade as travelling categories, but the actual way that they are taken up and deployed by actors on the ground are messy,



heterogeneous, and may not match one another; but these mismatches may be mobilized usefully.

It is in this context that Phillips articulates the idea of “hybrid claims.” Disability activists respond as bricoleurs, cobbling together arguments for justice in a unique context. This complexity shadows development language usually used to describe the political realm in the postsoviet world in a way that flattens difference. For the mothers with whom I spoke in Petrozavodsk, neither Soviet notions of “social protections” for the disabled nor Western notions of “civil rights” alone provided an adequate explanation of how they imagined themselves in relation to the state. From the point of view of parents and advocates on the ground, teleologies or hierarchies of citizenship types are beside the point.

One of the challenges posed by critiques of neoliberalism is a problematization of rights-based claims to justice. This has prompted the positing of several alternative frameworks, from the “capabilities” approach embraced by Amartya Sen and Martha Nussbaum in an attempt to reframe human universals (Nussbaum 2006, 77, 114), to reworkings of concepts of identity, consensus, and deservedness (for example: Siebers 2008, Fraser 1997). This type of challenge can help us to complicate the anticipated readings of the case studies presented here by dethroning the primacy of juridical rights (imagined as the culmination of development toward a civil society) as the best path to disability justice. For instance, Tom Shakespeare has observed that civil rights discourses, like transition discourses, place too much stock in markets as arbiters of justice: “the focus on civil rights still implies a liberal solution to the disability problem... seem[ing] to suggest that the market will provide, if only disabled people are enabled to

exercise choices free of unfair discrimination. But market approaches often restrict, rather than increase, choice to disabled people,” (2006: 66-67) and, I would add, their families and caretakers. This insight from critical disability studies troubles assumptions about what civil rights alone can achieve, about the promise of a transition to liberal democracy, and complicates the meaning of redistribution of resources by state institutions not as dependent bureaucracy, but as a pragmatic justice-seeking strategy.

This set of ideas – detransitioning Russia and disabling (neo)liberalism – helps to orient us toward the kinds of theoretical work that this ethnography, which is “about” disability issues, brings to broader conversations about postsoviet Russia, critiques of neoliberalism, development and neocolonial globalization.

The particular way that I approach the idea of disability here is also important and critically situated between several scholarly literatures. First, as a scholar of disability studies, I am concerned with questions of justice, stigma, and equality as they pertain to bodily and intellectual difference (Linton 1998), to normalcy or hegemony of the center (Davis 2006), and continue to present a challenge to the establishment of a fully functioning liberal democracy in the United States as well as in Russia (Nussbaum 2007). Within the field of disability studies, I am most compelled by those scholars who foreground justice in a manner that situates the theoretical potential of bodily and cognitive alterity in conversation with ongoing feminist and queer conversations about the body (Finger 2009; Wu 2008; Kafer 2003; Kudlik 2002; Linton 1998), which intersect inevitably with critical attention to how race and class are performed social categories (Madison 2012; Stubblefield 2010). As such, this research contributes to an overlapping feminist discourse on the politics of care and the category of dependency

(Kittay 2002; Rapp and Ginsberg 2001; Fraser 1997). In addition to ethnographers (Ingstad and Whyte 2007 and 1995; Rogers and Swadener 2001) and social historians (Stiker 1999; Baynton 1996; Stone 1984), this includes the work of disability studies scholars in cultural studies and literary theory, that attends to the ways that narrative deployments of disability do different kinds of cultural work (Quayson 2007; Berube 2005; Mitchell and Snyder 2001).

Second, as an interpretive medical anthropologist, I seek to contribute to a body of work that interrogates categories of diagnosis (Young 1995, Lock 1995, Cohen 1998); by juxtaposing the meaning of *disability* (as a type of difference, and a nexus of economic, medical, and social meanings) in Russia with that in US, I destabilize and defamiliarize both in order to open up new ways of conceptualizing enablement. Similarly, the anthropology of disability considers the ways that “cultural circumstances (such as assumptions about personhood) and social ones (such as the existence of disability institutions) shape the meaning of disability in different local worlds” (Ingstad and Whyte 2007: 1) so that disability becomes a lens through which to view local subjectivities.

## **DISABLING RUSSIA**

Where is disability in Russia? While gendered approaches to a critical engagement with the postsoviet are many, scholarly works that contribute a disability studies perspective on the postsoviet, or that offer a specifically Russian or postsoviet chapter to disability studies, are relatively few. In this section, I attempt to briefly sketch the cultural scene in the city of Petrozavodsk vis-à-vis disability, drawing on ethnographic observations in conversation with existing literature. In doing so, I have several objectives. First, to situate disability soundly as an arena of profound civil rights advancement at the turn of the twenty-first century (Berkeley Law Disability Rights Symposium). Second, to turn the theoretical lens of critical disability studies, engaging disability as what Catherine Kudlik as called “another ‘other’” (2003) on the postsoviet context. And third, to elaborate ethnographic description of some of the ways that the narrative and symbolic potential of accessibility to public resources for people with disabilities as a civil rights issue gets deployed in Petrozavodsk. I bring the concept of narrative metonymy as developed in disability studies (Mitchell and Snyder 2001; Berube 2005) to bear on the Russian context, and, turning this theoretical move back on itself, suggest that in the Russian context, an aesthetic of accessibility becomes a signifier of transition toward liberal democracy.

I first began to consider the question of disability in Russia in 2005, when I studied in Russia for four months with a mind to write about this topic. At that time I

observed a situation in which the burden of the stigma of disability came to rest on the shoulders of the mothers of children with special needs, as Elena Iarskaia-Smirnova has articulated (1999: 69, 71, 77, 81). In many cases they seemed to be the first generation to be raise children with disabilities outside of institutions; if they were not, the lack of infrastructural support effectively rendered them pioneers in addressing the logistics of this task. I began my investigation by literally reading anything I could find about disability in Russia – mostly newspaper articles – and engaging a disability studies perspective to think through representations of disability in Russian literature and film.

Narrative representations of disability in popular culture help to understand popular perceptions of people with disabilities. This is not only because disabled bodies are used to communicate certain messages in literature and other cultural texts (for example, Tiny Tim helps us judge the moral character of the literary personages that copopulate *A Christmas Carol* (Dickens 1843), likewise for Dostoevsky's Lizaveta (1879), but, because othered bodies and minds are read as metaphor and symbol in real life (Mitchell and Snyder 2001). This means that a body in public space (a street corner, a photo on the internet) becomes a text, which others read for meaning, reaching for familiar narrative tropes. Poverty, suffering, and ostracism exist as metonymic totalizations of people with physical and mental differences: someone with a limp and a partially paralyzed face on snap judgment becomes poor, ill, and outcast.

The various media representations of disability circulating in Russian in 2005 roughly corresponded with the rubric that Sarah Phillips (2010) has subsequently

developed in her research on disability in postsoviet Ukraine<sup>9</sup>. Modeled on Rosemarie Garland-Thompson's investigation of photographic representations of disability in the West (2001), Phillips' rubric proposes four tropes of disability that appear, sometimes in combination, in popular press. I relate the rubric here, as a manner of grasping the types of popular attitudes toward disability in contemporary post-Socialism. First, the *symbolic*, uses disability to illustrate the “incredible misfortune”; in this trope, disablement is deployed as a warning, an embodiment of ill fates that can come from immoral behavior, such as a billboard that implied that drug users will give birth to malformed babies (148-149). Second, the *sensational* relates “shocking details” of physical or intellectual disability, or the resulting hardships that family members face, as high-drama entertainment; sample narratives include the shocking mistreatment of a mentally disabled woman by her relatives recounted in gruesome detail, or incredible stories of miraculous total recovery (149). Third, a *critical* register uses disability as a platform to criticize the state's failure to fulfill its responsibilities, that is, to be more like the West by embracing civil rights models of justice and supportive policy (150). Fourth, Phillips identifies a *personalizing* tone that considers the personal narratives of a particular person with a disability, navigating what is frequently represented as an ostensibly out-of-reach parallel world of the normal (151). These discursive categories help us to grasp the epistemological place of disability in postsoviet popular imagination.

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9 Although Phillips writes specifically about the Ukraine, and her ethnographic examples draw from that country, these observations can broadly be understood to apply to the Russian context as well. As Phillips demonstrates in chapter two of her monograph, the contemporary Ukrainian notion of disability is a historically contingent set of perceptions that have been shaped by the Soviet political economy, tropes about work, the body, and citizenship, and the bureaucracy of disability adjudication and social support.

Since 2005, I have observed a growing popular awareness of disability issues, from a more frequent presence of (often poorly installed and questionably functional) rail-ramps in public places, to an increasing use of “politically correct” terminology (usually phrases translated from the English) in the cosmopolitan press. Additionally, as the internet has become increasingly accessible to provincial cities, the growth of a national network of local community-based grassroots organizations has facilitated greater intra-Russian and international communication regarding workable strategies for organizing and lobbying and problem solving<sup>10</sup>. At the same time that my interlocutors in Petrozavodsk have had increased and more fluid communication with mentors in Finland, they have also been able to network with colleagues in Pskov who work with German advocacy groups who have had success working toward community inclusion for young adults with disabilities.

But, overall, in Russia, disability continues to act as an extremely stigmatizing category of identity. The narrative power of *suffering* associated with bodily difference (*symbolic* in Phillips’ schema) dominates the Russian cultural imagination, and therefore the interpretive and meaning-making possibilities. In seeing bodily difference, Russians frequently read “incredible misfortune” such that encountering disablement is sobering and upsetting remains the norm. For example, a close friend in Petrozavodsk, talking with me about my research while looking at pictures on the website of an inclusive summer camp said offhandedly, “I don’t know how you can spend time on such a subject – doesn’t it make you so sad to be around such unfortunate children?” The symbolic misfortune of disability, for my friend, acted to obscure or erase, in her vision, any

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<sup>10</sup> See, for example, <http://eng.perspektiva-inva.ru/>.

individuality or capacity for happiness for the disabled children pictured on the website.

In this context, disabilities, no matter how seemingly minor in their actual effect on the activities of daily life, become symbolically totalizing, erasing further character traits. Phillips (2010) describes the attitude that a man who became paralyzed due to a spinal injury recalled from his days as a “normal.” He told Phillips,

I was eating breakfast, looking out the window. I saw a girl down below [in the courtyard of our apartment complex], and something struck me. She probably had cerebral palsy. I found myself thinking – cynically, and now, I realize, stupidly – Why do people like that live near us? Why can't they all be rounded up, all those old, weak ones who can barely walk. Let them live separately, far away, to keep them out of sight. [Phillips 2010: 23]

This is the attitude that he himself subsequently encountered as he began to negotiate this same neighborhood as a paraplegic. Bodily and mental difference imply an unpleasantness that ought to be regulated. Moreover, bodily and intellectual difference are often conflated and even cast as a moral failure.

Similarly, I recall asking an acquaintance in Irkutsk about *invalidi*<sup>11</sup> in 2005. “Do you know anyone who has a disability or disability status?” I inquired over dinner one

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<sup>11</sup> The Russian word *invalid* is commonly used to refer to anyone with an impairment or disabling condition, much the way that “disability” is currently used in American English, or “handicapped” once was. Like the American term disability, the common adjective aligns with a complex of medico-legal regulations that pertain to disability benefit regulations. That is, like “disability” in the United States, *invalid* describes a category established by the Soviet welfare state that defines those deemed by a medical-legal process to be unable to perform daily work. Unlike the American social security definition of disability, which offers support or compensation only for so-called total disablement, the Russian policy recognizes three degrees or classes of *invalidnost'* (disability), translated as, “100% loss of working capacity and requires constant attendance (Group I); 100% loss of working capacity and does not require constant attendance (Group II); 50% loss of working capacity and does not require constant attendance (Group III)”, all of which carry some assortment of social benefits (ssa.gov) [while in the US veterans benefits and private workers' compensation both do recognize so-called partial disablement. See: Melhorn et al 2005]. The Russian schema was developed during the Soviet era (McCagg and Siegelbaum 1989) and has carried over into the policy of the Russian Federation. In 2010, new regulations came into effect that instituted a disability labor pension for those with a work history (similar to SSDI in the US); previously only a state disability pension existed (see ssa.gov for an overview of current policy in English). The state-funded pension will continue to exist; however it necessary to point out that all federal subsidies in contemporary Russia are extremely meager, and poverty and subsistence living continue to be a reality for many in the general Russian population. A corresponding state pension category exists for children, *deti-invalidi*, with pensions disbursed to guardians. However, the etymology of the word *invalid* and the complex historical genealogy of the term differs rather dramatically from the English disability (see Hartblay 2006 for a full discussion of the differences herein).



evening. “Oh... no,” she replied, seemingly both confused as to why I would ask such a thing, and also considering the category for the first time. A few days later, she mentioned that it had occurred to her that her mother’s friend had a daughter with a harelip. I asked her to tell me more, and again she looked puzzled. “Well,” she replied, “we don't really talk about it... I guess it would be hard for her.” “For the mother, or for the daughter?” I asked. “I don't know,” she replied, hesitantly, “I guess for both.”

Here, the register of response was complex. She references in her response both her own lack of awareness, and her awareness that she is missing an awareness expected or desirable to her American acquaintance. She stretches her answer, attempting to mind the gap, as it were, between our divergent perspectives and vocabularies. Not able to give a ‘correct’ answer, in the cultural assessment of her visiting friend, she strives to be as correct as possible, though lacking vocabulary or even details to speak to the original question. Without being socialized into a world in which people with disabilities participate, or are even seen or talked about, she struggled to inflect her usual sensible intelligence in her response.

It is not unusual anywhere to find that the broader public is unfamiliar with the challenges that face people with disabilities and their families. However, the totality of absence of accessibility in Russia has and continues to occupy a plane of severity that either has faded or never managed to exist in the United States. If in the contemporary US, the public is accustomed to encountering people with developmental disabilities bagging groceries, encountering Braille on ATM keys, or bounding up steps to the post office as a fellow citizen in a wheelchair uses a ramp (even if some might feel at a loss when it comes to directly interacting with the bagger, the blind bank customer, or the

wheelchair user, embarrassed to find themselves fumbling and unsure of etiquette), such images are still remarkable in the postsoviet world.

This aesthetics of accessibility marks a particular stage of cultural acceptance of people with disabilities as viable citizens. Simi Linton, in an article about the separate and unequal treatment of citizens with disabilities in the US, and the gross social discrimination that was the norm, cites a pair of letters submitted to an Ann Landers column in the United States in 1987. One of the letter writers claims her “right” of a “normal” person to eat a meal at a restaurant without being made to want to “throw up” by the sight of another patron in a wheelchair. The other letter writer goes so far as to suggest that restaurants provide special seating to hide the unsightly from other patrons (1998:34). Examples like these helped bring about the passing of the Americans with Disabilities Act in 1991, which canonized disability as a civil rights issue in the United States, and has subsequently, based on the continued lobbying of activists, resulted in a dramatic restructuring of American physical public space.

Today, in the US, the implementation of mandated accessibility measures is visible and audible all around us – from the mechanized chirping of crosswalk signals, to curb cuts, to closed captioning symbols. Some of these measures are more successful than others; for instance, Braille may not be useful to a new generation of blind citizens who use it less frequently than screen readers and other technology. These mechanical and material instances of accessibility have, twenty years after the passing of the American with Disabilities Act, become so commonplace as to be taken for granted; meanwhile, still existing structural barriers are further obscured by these visual cues indexing inclusion and accessibility. While the American built environment has become

(ostensibly) more accommodating, evaluations of the state of (in)visibility and (in)accessibility return to one point: the social attitudes that ultimately prevent inclusion have not been the target of the law's impact (Zaleski 2010). In spite of the sobering assessments of the barriers and challenges still facing the disability movement in the US, the situation remains much worse for people with disabilities in Russia, where encountering people with visible disabilities out and about remains rare, and physical space unaccommodating. There, the aesthetics of accessibility are marked by a lack.

The aesthetic of accessibility, therefore, is integrated into the discourse of transition. Evaluations of “progress” in the public sphere of a developing state measure the degree to which a nation has successfully modernized; accessibility has become a component of successful modernization worldwide (Kohrman 2005). A visibly accessible building or public space marks a kind of modernity. In some ways this is largely decontextualized from the political implications, reading only as forward-thinking architecture. At the same time, an aesthetic of accessibility is linked to modernity by indexing the trappings of liberal democracy. Processurally, an accessible public sphere requires the peace and stability to lobby for justice and implement a particular kind of built environment that is often in development rubrics collapsed with liberal democratic governance and rule of law. Symbolically, an agora that welcomes every citizen references a genealogy of democracy in Western thought that stretches back to ancient Greece, indicating an embodied participation of all citizens in civic life. If, in transition discourses, the Soviet Union lacked a public sphere, then accessible public space indeed marks the quintessential reform, both symbolically and materially. In this way, disability comes into play in the register of the *critical* trope described by Phillips.

As I walked through the center of Petrozavodsk with a group of friends one evening in 2010, they suddenly elbowed me and nodded excitedly: across the intersection, two able-bodied young men were pushing a third in a wheelchair, chatting excitedly amongst themselves. “Look, look!” my friends whispered, “we *do* have people with disabilities out and about!!” This attitude was partially one of goodwill, an eagerness to help out an American friend conducting research. It was also connected to a different sentiment: the desire for a new Russia that “catches up with” Europe and America in political and social terms. In contrast to the attitude of rote surprise and revulsion at seeing an *invalid* out and about that Phillips' interlocutor recalled (with embarrassment), these young Russians responded with excitement. They were both performing competency for their American friend and hailing the presence of a wheelchair-user, who was bucking the Soviet tradition of invisibility, as a sign of progress.

This attitude was underlined by the grave and earnest manner in which these young professionals, in scattered side conversations and offhanded moments, confided in me that they felt the topic of my research important. More than idle gestures of goodwill to a new friend from abroad, they explained that they perceived the lack of integration of people with disabilities as a microcosm of a broader failure of the Russian state to accommodate the needs of its citizens. In a sense, there was a certain degree to which these four young people themselves all identified with the notion of *bezbar'ernost'* (accessibility, literally, “without-barriers-ness”). They encountered the concept of *bezbar'ernost'* as a component of more a progressive governance, toward which they hoped to nudge Russia, not only as a marker of more progressive relations toward disability, but as a politics that put people first.

Moreover, it wasn't only the talking points, but the achievements of the local movement – both literal and figurative – that they respected. On a literal plane, one of the group, Oleg, was severely asthmatic as a child and categorized as an *invalid* (that is, he qualified for state disability status and was entitled to a corresponding pension and other benefits). This allows Oleg to invoke charming linguistic constructions when talking about *invalidnost'* (such as, “when I was one – an *invalid* I mean...”), and also it means that the group of friends has a profound sense of the hardship faced by families struggling to obtain sufficient medical care, social support, and financial resources for family members with special needs.

The successes of the local disability movement in affecting change in actual state policy stood out to my young friends as a noteworthy political achievement. They emphasized to me that, for example, no public demonstrations may take place without an official permit, and such permits are nearly impossible to come by, unless the 'protest' in question furthers an agenda of the state. In an environment in which overt political activism is severely policed, they perceived the capacity to devise and carry-off a change in state policy as worthy of attention and respect. Of course, in a more cynical mood, they might just as easily point out that there is a sort of vulgar international pandering taking place, in that a more progressive stance on disability offers a good public face for the Russian state, and in that sense can be considered to be a protest in the state's interest. At the same time that a group of worldly, cosmopolitan twentysomethings in Petrozavodsk expressed these attitudes, many other Russians remain indifferent to or ignorant of disability movements.

## CASE STUDIES

### *“Now you can go up the ramp, and when you've gotten to the top, you'll stop there”: Nina's story*

One summer day, I made my way through the streets of Petrozavodsk, Russia in the midst of a record-breaking heat wave, on a visit to Nina, an English teacher at the city's foreign language high school. Nina's daughter, Sveta, now 21, was born with cerebral palsy, and is unable to walk independently. Over tea and cookies, Nina told me a story that I had heard segments of from numerous mutual acquaintances: the hardships that she and her mother, Sveta's grandmother, had faced during the transitional years of the 1990s, when Sveta was a young, sick child and the institutional structures of Russian society were between collapse and ideological and economic restructuring. Even before arriving in Petrozavodsk that summer, back in the US, my former Russian teacher had related a memory of the days when no one could find nor afford a wheelchair for six year old Sveta, and Nina, a small woman even by Russian standards, had had to carry her up and down stairs and to and from doctors' appointments. This anecdote, prompted by my intention to investigate the experiences of parents of children with disabilities in Petrozavodsk, echoed many similar orations that had peppered Russian language lessons over the years. It fit neatly into an ever-expanding collection of narratives laden with images of hardship and loss, inhabited by women with steely will and perseverance in the face an injustice of fate that delivered them into a life that unfolded in a place of great political and social uncertainty.

Now, with the windows wide open in Nina's fourth floor apartment, Nina herself invoked narrative imagery that intertwined the description of parenting a disabled child with that of enduring the despondency of the immediate postsoviet years. Both events – the birth of disabled child, and the end of the Soviet Union – entailed a radical disjuncture in the way that Nina imagined herself to be a person in the world, and required a renewal of personal strategies and social roles.

The strategy of survival that Nina described to me that summer in day in Petrozavodsk did not sound like the narrative of an activist. In contrast to younger parents who had been making national and international news with the groundbreaking civil court decisions to allow their children to attend public schools, at first, Nina's self-described support system of herself, her daughter, and her aging mother appeared one of minimal commitment. Just as studies of people in chronic pain note an increasing social isolation that comes with a physical suffering, it seemed that Nina's strategy for dealing with her daughter's special needs was one of turning inward. But later, as I reread the transcript from our interview, my assessment of Nina began to change. Perhaps it is best to begin with her story.

Here is what I wrote about our first meeting shortly afterward:

*Nina and I came to be in touch through the exchange program that I participated in during my high school years with one of the Petrozavodsk high schools, where she is an English teacher. Ultimately, if it were not for this connection, and her colleagues' request that she meet with me, I do not think that I would ever have come across her in the course of this research: she is statedly uninvolved in activism projects, and her daughter, Sveta, though part of a cohort that includes other young adults with disabilities that I have become acquainted with, seems to keep mostly to herself. Meeting me at the bus stop that same hot day, Nina brought me back to her apartment for tea. Introducing me to Sveta, and then closing the door to share her story without burdening her daughter further, Nina opened a floodgate. Before she had even served the tea, she found herself telling me about the confusion of giving birth to a preemie in a time when the*

*chances of survival were minimal, the declaration of a miracle from doctors when Sveta did survive, and arriving home with her mother to place the tiny, weak, shaky baby on the sofa and read aloud a long list of unpronounceable, unknown, and unexplained diagnoses.*

*All the doctors told her was, “you will have a hard time with her.” And when she wasn't walking on time, they thought that maybe by age two she would walk; then maybe age four; by the time she was seven and still not walking, they began to give up. The doctors advised that she be put in a home. Nina's mother spent hours in the doctors' office, transcribing by hand the definition of DTsP [equivalent to the spectrum of cerebral palsy diagnoses] from a medical textbook. The one book that Nina managed to find directed at parents told her that as mother to a child with Cerebral Palsy, she would have to be everything at once: therapeutic masseuse, doctor, nurse, nutritionist, teacher, speech therapist, parent. And this is the way she remembers that time, she tells me, that there was absolutely no one to rely on but herself. This is a narrative that is very similar to what I heard from parents of children with disabilities in remote and rural small towns in the Eastern province of Buryatia.*

*As single mother, caring for Sveta took Nina's entire force of will, and more than her financial resources; she rushed from home to her full-time job and home again; helped Sveta up and down the steps to the apartment, and when they were finally able to acquire a wheelchair, lugging it along so that it wouldn't be stolen. Nina's mother, already retired, by default became Sveta's full-time caretaker. Without her, Nina related, she doesn't know what would have happened. The family traveled several times to St. Petersburg, and once to Moscow to visit medical specialists – each time encountering physical barriers and prejudice in traveling by train (the high, steep, narrow stairs that one must mount to board a Russian train coach are familiar for their difficulty to anyone who has attempted this mode of transport with more than a backpack; likewise the often curt tone of train conductors to travelers who inevitably fail to meet expectations of orderliness and efficient boarding).*

*Nina's introduction to activism occurred only through Project Harmony, an exchange program with a group of families with special needs children from Vermont. Looking back she says, the association with other parents was useful for a time, but for her, perhaps because due to her particular disposition, she finds it is difficult to ask for things, it was easier to solve these problems within a family. From her perspective, things are different in the US, and the kind of mutual support that she witnessed when attending a conference in Albuquerque, and through her correspondence with a sister family in Vermont – this simply isn't possible in Russia.*

*Every step has been a struggle. The trips to the sanatorium [a sort of public spa for rehabilitative care; patients receive (and often ask for) prescriptions from their physicians to spend a few weeks or a month at the sanatorium where they receive therapeutic massage and other treatments] ended with the grandmother in the hospital after living for three months at a time in makeshift conditions with no hot water or cooking facilities [although the visit to the sanatorium is covered as health care, conditions are rustic, and patients and*



*their caretakers must provide their own food and standard of living]. The internat [a school/rehabilitative institution for special needs children] was good enough education-wise, and Sveta was assigned a social worker to take her to her classes. Now at the teachers' college studying drawing, she can attend because they have renovated the first floor of the building for accessibility, with a grant from a German foundation. The second and third floors are still not accessible, and the bathrooms are only marginally accessible. Since her social worker is male – the better for lifting and moving her, the thinking goes-- she is too embarrassed to go to the bathroom during the day, so she doesn't drink any tea or water in the morning or during the day to avoid having to pee.*

*Nina got teary thinking about the immense friendliness shown her by the American parents that she had met. She feels like things are utterly different in Russia, and that there will never be the type of activism that there is in the US. Everything has to come from above here, not from below. Or maybe once things happen in Moscow, then they might happen in Petersburg, then maybe start to happen elsewhere. The only reason that some motions toward inclusion are being made now, she says, is that the President has pronounced that this is necessary. But, she said, with the wryness of a Soviet citizen-observer, this is one thing, and real accessibility is otherwise. At the corner store they have added a ramp, so now, Sveta's wheelchair can get up to the stoop; but since the door is too narrow for a chair to enter, that is where she'll stay for now.*

*Nina drifted into contemplation about the meaning of having a special needs daughter, and the need for a mother to adjust her expectations of parenthood and of her own role in life. But, she said, her daughter gives her life meaning, every day. Meaning, which it did not have previously.*

So, on first reading, the impression of Nina is of a woman who views her only child through a lens of struggle. A woman who closed the bedroom door so that her twenty-one year old would not have to be burdened by the weight of her mother's emotion – to risk the implication of guilt for the manner in which her disability had so fundamentally altered her mother's life.

But Nina made sure I knew that though she is burdened by the standard of care available to Sveta in the public realm, she is not burdened by her personally. Rather, Sveta's life has altered Nina's own in much the same way that any child alters any parent's life: unexpected at unanticipated points, and with unpredictable gravity of meaning. Michael Berube, an American literature and disability studies scholar, has eloquently

described this phenomenon in his own experience parenting a son with Down syndrome. He writes, for instance, of his fourth grader, “over eleven years, then, we've come to expect that Jamie will defeat or exceed our expectations when we least expect him to. And from this I draw [the primary observation that] he's a child” (2003). And, as Nina was sure to let me know, Sveta has given her life meaning. She is a receptacle for care, and this position in itself begets a reciprocation of love and meaning (see: Taylor 2008 for a discussion of redefining care).

My understanding of Nina's story began to change further when I looked back over transcripts of our conversation<sup>12</sup> that day. Nuances that had initially sounded like resignation, perhaps because Nina was speaking to me in a low voice (to preserve privacy) and in a confessional tone (to indicate her commitment to telling me her tale thoroughly and soulfully), turned out to obscure an autonomy and self-conscious decision-making. On a second and third reading of transcripts from our interview, I was surprised to find words and grammatical constructions that articulated a *willfulness* and *agency* that I had missed in face to face interaction<sup>13</sup>, when my imperfect Russian and the performance of roles – I as sympathetic listener and she as witness giving testimony – had cast attention elsewhere.

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12 Interviews were tape recorded with the permission of interlocutors. Subsequently, select interviews were transcribed by a native speaker of Russian contracted for this purpose; the real names of the interlocutors were not disclosed to the transcriptionist, who signed a confidentiality agreement regarding the content of the material. All translations are my own.

13 There is no word for “empowerment” in Russian, and while scholars participating in international conversations use a Russianization of the English word “agency” (for example, Chepurnaya 2009), the average well-educated Russian is unfamiliar with the notion of *agentsvo*. Frequently, Russian use the word *volya*, will, or *sila*, strength, to describe moments of personal empowerment. For a further discussion of this issue, see Harblay 2006: 131-139.

In the first place, Nina's narration of why she did not participate in activism was more pointed than I had remembered. She said,

And we decided... and Sveta too, 'No, we won't be going to any kind of organization,' because something was always coming up, some kind of scandal, someone snapped at someone, someone did something, they didn't give something to someone. I am saying that I already had enough stress at work. At the school there is never any peace. And with a kid with our own problems... to end up getting snapped at there too? So in general, we just got away from that.

It is clear in this statement that rather than not having an opportunity to participate in organizing, Nina and her daughter made an active choice that local organizing wasn't enhancing their lives.

Tom Shakespeare notes that the dogmatism of disability activism in Britain has in that context served to alienate many people who are categorized by the state as disabled; overt political action is a rarity.

Despite the visibility of disability rights protest, it has always been a minority activity for disabled people. For example, the Direct Action Network may be very vocal, but it now appears to number less than 100 people, with approximately 30 attending recent demonstrations. Even at the height of disability protest, approximately 2,000 disabled people joined the 1988 Elephant and Castle demonstration. Given that there are more than six million disabled people in Britain, this represents a small proportion of the potential support. [2006: 72]

Similarly, anthropologist Emily Martin (2009) has observed a complex mix of comfort and vulnerability created by social support groups for Americans who carry a diagnosis of bipolar disorder. In this sense, the choice not to participate in political or social action toward greater recognition of disability in the public sphere is hardly unusual; in fact, it is the norm. Though, as Shakespeare is quick to point out, "lack of activism does not necessarily imply lack of affiliation to the values or demands of the disability rights movement" (72). On the one hand, this may seem to be a counterproductive move from the perspective of those who are activists. Perhaps non-activists "wish to assimilate with the mainstream and negate demeaning difference," leading some activists to imagine that they are victims of internalized oppression, isolating themselves and perpetuating the

stereotypes their activist peers seek to break down (74). On the other hand, Shakespeare argues, when non-activists do not identify with a politicized conception with disability, they are “refusing to allow disability to dominate their lives ... this approach may be rather individualist, and may overlook the problems of discrimination and prejudice. But surely it is a legitimate alternative to a minority group approach” (74).

Shakespeare’s assessment of the dynamics of activism fails to capture here three aspects that seem to influence Nina's distaste for disability organizing. In the first place, her personality: she told me, “I am just not the type of person who likes to ask for help.” In the second place, the way of assessing what is valuable in life may not align with politicized movements: Nina's interest in having a peaceful home life in between full time work and Sveta's ongoing transportation fiascoes and healthcare needs, may take precedence over a move to find solidarity. In the third place, the horizon of political possibility: Nina is disdainful and mistrusting of Russian peers and leadership, particularly when she contrasts the Russian parent-movement with that in the United States. She said, for instance,

[In the US] they have these organizations, they can call on each other, pull each other up. Here, it still seems like if you have a problem, you yourself are the [therapeutic masseuse], you yourself are the psychotherapist, you yourself... and if you have a serious diagnosis, then what? So it hasn't gone anywhere... Now you see a little bit they're building ramps here and there, they start a little bit to somehow -- in general the treatment of *invalidi* here is changing, but very slowly.

At the same time, Nina, along with women in her age cohort (including those represented in Iarskaia-Sminova's survey and my own interlocutors in rural Siberia (2006)) defied the authority of doctors, who urged institutionalization, to keep their special needs children at

home<sup>14</sup>. Certainly some of her peers did not make such a choice (although we have no way of assessing such a trend quantitatively).

Having survived the 1990s, as did the mothers in Iarskaia-Smirnova's article, Nina constructs a narrative in which the state is principally a negligent presence. Even if “the treatment of invalids is changing” in her estimation, change is slow and late to come.

In a lot of cases it's just a check mark. Is there a ramp? [mimes checking it off a check list]. This is like, for example, the store around the corner built a ramp. Sveta says, “Oh, they built a ramp!!” I say, “Sveta, so now you can go up the ramp, and when you've gotten to the top, you'll stop there.” Because she can't even go inside the store! Because the entrance is still the same as [mimes a space too small to fit a wheelchair through]... There's no way to go inside or through the aisles because there isn't enough space... A ramp? A ramp. So something here is equipped. So that's what we've got for now...

In Nina's assessment of accessibility measures, the bottom line remains: her daughter will be unable to access spaces that others take for granted. When she takes note of changes in the environment or the sphere of policy, as in this anecdote, she is concerned only with the actual effects that so-called progress will have for her life and her daughters. And in her estimation, it is not very much. Like the mothers in Iarskaia-Smirnova's article, when it comes to knowing what's in the future, Nina's orientation is one of not-knowing. For instance, Nina is glad that some minimal accessibility measures were taken at the teachers' college where Sveta attends classes. She is vaguely aware that a grant from a German organization made the renovations possible; but, practically, she is still concerned with the relationship that Sveta has with her male attendant, the lack of accessible restrooms, and myriad other problems. As for Sveta's future once she receives

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14 The question of why this generation of mothers in particular became pioneers in the deinstitutionalization of special needs children in Russia is fascinating, and warrants further research. One possible explanation is that the broader climate of *glasnost'* (openness) and *perestroika* (rebuilding) in the late 1980s and 1990s encouraged an attitude of speaking truth to power. Alternatively, perhaps the constant possibility of state collapse during the 1990s made the thought of turning an infant over to state care more sinister, rendering platitudes of special needs children being “with their own kind” mute in comparison in the inevitability of neglect and destitution.

her certificate as a teacher of drawing and fine arts, Nina simply shrugs. Who knows what will happen then.

Similarly, Nina is concerned less with how changes happen than with the circumstances she is facing. If asked to assess the way that change unfolds in regards to improving policies and attitudes toward disability, she immediately articulates a top-down model of power relations. The impetus and incentive for the store owner must, she thinks, have to do with monetary incentives that begin on the national level (which, in turn, are a sort of international PR<sup>15</sup>). However, upon sustained consideration, she ultimately realizes that the organizations and lobbying of her peers and younger mothers, and people with disabilities themselves must contribute to change. She told me,

I don't know [how these changes happen]. Maybe if the president said something, or for that matter if Mayor Luzhkov said that after two or three years 50 or 70 percent of city buildings in Moscow must be accessible. Every now and then on television I hear that these programs – that someone has started to demand that funding be designated for these matters. People with disabilities are already no nonsense... they are demanding things, they are getting educations, even college level educations, and saying, 'We're not going anywhere. And we'll go where ever we like.' ... there are organizations working on these things.

Nina's attitude toward these changes is also wistful. When I told her that my thesis, more or less, is that something is going on in Russia in terms of disability activism, she sighed, and agreed. Yes, something is going on, she concurred. "Now they are allowing kids with disabilities into schools. If only things had been like that when Sveta was young."

Parents these days, she decided, are more savvy. "They are more aware of the choices available to them" she offered. Doctors, she surmised, are probably more used to parents

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15 "PR" (pronounced not in full translation of "public relations," but as *pi-er*, a Russification of the initials) has replaced the word "propaganda" in Russian conversation about how those in power attempt to manipulate public opinion; however, all the implications of propaganda, in effect, remain loaded in this new phrase.

caring for children with disabilities, and information and resources are available than when her own daughter was beginning school.

***And we understood that all of this exists and that we have rights”: Katya's story***

The historical center of Petrozavodsk, the regional capital of the Russian administrative district of Karelia, is Round Square [see Map 2]. With a name that reads like a parody of American perceptions of Soviet kitsch (life-as-paradox), Round Square [*kruglajia ploshad'*] is a grand, oval plaza lined with baroque three-story buildings. The square is rumored to have been constructed at the order of Catherine the Great. It is anchored at its center by a monumental statue of Vladimir Lenin, one arm raised as if to urge the proletariat on to victory, or, in the winking observation of local tricksters, trying to hail a cab. By any official account, Round Square is the point from which the city of Petrozavodsk flows, as if by some anachronistic arrangement, Lenin directed Catherine to build the square for him to stand in, and she, in turn, bid Peter the Great to lay out a city in the Karelian wilderness to host her square.

On my first visit to the city in 2002, Round Square was gray and barren; now, its ring of palace buildings are appropriately painted in icing colors to befit Catherine's vision, and, rich from a federal city improvement grant, boasts beds of purple pansies. But, as if trying to escape the muddle of history and leave it to rest with respect, pedestrians avoid Round Square. Aside from the layers of history, there seems to be nothing else there.

In 2010, any visitor or local will tell you that the real heart of the city is several blocks away – Prospekt Lenina. Named for the Soviet leader like innumerable others in

Russia, Prospekt Lenina in Petrozavodsk originates at the train station, the bustling portal that links the city to St. Petersburg to the South and Finland to the West. From the hub of the station, Prospekt Lenina stretches due east down a sloping hill of bustling businesses past the iconic Hotel Karelia (always harboring a steady stream of Nordic tourists – backpackers come to hike the wilderness, and beergutted men in polo shirts come to find pleasure on the cheap), on down to the granite embankment of Lake Onego, opening outward from the city between shores lined with pine and birch forests.

It was at the top of the hill, by the train station, that I had arranged to meet Katya, or rather, where she had directed me to meet her. By the *Key*, she had told me. The what? I had asked... The store, the shopping complex by the electronics store *Key*<sup>16</sup>, she had briskly explained. The *Best Buy* of Russia, the Petrozavodsk *Key* boasts a towering animated billboard perched on the four-story high freshly constructed complex announcing weekly sale items to passing buses. Half way between the train station at the head of Prospekt Lenina and Round Square, the *Key* is a new construction that geographically transposes the colloquial and official centers of the city. The store occupies a sort of central but uncertain space in the Russian cultural landscape as well.

When I first came to Petrozavodsk in 2002, it was still unusual for a store to have a name – beyond some requisite description of the merchandise offered within, let alone a brand or franchise. The only equivalents of department stores at that time continued to function on the Soviet system: goods were arranged behind glass display cases, and after arranging the intent to purchase an item with a sales woman, she wrote out a purchase

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<sup>16</sup> I have spelled *Key* here so as to agree with the transliteration used on the actual company's web address. According to the Library of Congress system, the word would be transliterated as *kei*, and seems to stand as a shortening of the Russification of the English expression “Okay!”, or, “kay!”.



slip; one proceeded with this slip to a cashier, paid the sum stated on the slip, and then returned to the first clerk, presented the receipt, and claimed the item. The stores didn't advertise, prices were beyond the reach of most salaries, and the selection of goods was poor. Most preferred to make high value purchases on the black market, passing dollars to friends or friends of friends with connections abroad.

Now, in 2010, the *Key* makes the consumer experience that is so familiar to Western Europeans and Americans available to residents of Karelia. College graduates who work in banks purchase iPhones and digital video cameras; young mothers browse with infants in strollers; teenagers from outlying villages enter in pairs or packs to soak in future possibilities.

It was here that I first met Katya, one of the main organizers for a group of parents of children with disabilities that has become known in parent networks around Russia for their success in utilizing civil legal cases to claim the right of their children to inclusive education. She is mother to an eight-year-old daughter who has a degree of cerebral palsy that keeps her in a wheelchair and has thus far arrested her speech so that her vocabulary includes roughly fifteen words. Immediately, Katya impressed me as a fast talker, a sharp and bright woman with a girlish figure and bobbed dark hair. I found her on the plaza in front of the shopping complex, bidding goodbye to a couple, who she later told me are friends through her organizing activities, since they have a child who is deaf. She was younger than I had expected, and immediately easy and friendly, though clearly someone who meant business, and can get things done; she had no intention of departing from the formal *vy* form of address for the more affectionate *ty*.

Striding down the block to a local cafe, we took a table, ordered coffee and *blini*

(crepes, a popular light meal in Russia) with sweetened condensed milk, and she asked me to explain my interests. True to my impression, she was all business, she stuck to the legal activities of the parent organization. It wasn't until the end of the interview that she told me about herself. An accountant by training, Katya had worked two years before stopping to pursue her advocacy work. She met her husband while they were both studying in Petersburg, and they moved to Petrozavodsk, his hometown, rather than hers. “I'm still getting to know the cities in Karelia!” she confessed brightly, citizen of the world.

Katya's narrative revealed an ease of networking, a sense of entitlement, and a depth of resources. Everything was open to her. She was comfortable describing both rights and what is owed to disabled people. She was critical of the state, but also satisfied that she and the parent advocacy group had used it to their ends. She worked not only for her own interest, but was also conscious that her efforts would benefit those families that “came after.”

Katya recalled that the organization of a parent group was far from easy – rather, it was “chaotic”.

When we began to come together it was a little chaotic, because for us... well when it turned out that our children had problems, we didn't know, in general, where to turn. Then we met this young man, an organizer. He worked with blind children. He was already an adult. He says, 'It'll be easier for you, if you work together in a parents' organization and you can work out these issues together.' And so we in general didn't know what we were doing when we started working together [*ob"edinialis'*]. We got everything registered (there is some kind of procedure) with all the authorities [*instantsiakh*], set up a bank account. But in general we didn't know what we were doing.

Katya's emphasis, in relating the origin of the parent-activist group that she now spearheads in Petrozavodsk, is on the amateur status of its members. It is important to her to underline that, far from being a group made up of professional activists, or people with political backgrounds, the organization is simply made up of family members seeking to

improve the lot of their loved ones. Between the roughly forty families represented in the group, she told me, “we have children, parents, grandmothers, and grandfathers – not only moms and dads,” and these people make up the heart of the organization. What they all have in common is a familial responsibility to children who require a different sort of care than others. She said,

We all started to work together, an organization for children in kindergartens, in schools, and then this lawsuit, because in our organization... [pause] We all have the kind of children that can't care for themselves. They can't walk on their own, the majority don't even speak, intelligence levels are totally varied, but they aren't able to care for themselves [*sami sebia obsluzhivat' ne mogu*].

Of course, Katya points out, at every turn they have worked with outsiders and experts: parent-groups in Saint Petersburg and Pskov with longer institutional histories, the organization Perspektiva in Moscow that works to connect local activist organizations to one another, Finnish disability rights activists, the regional ombudsman for the protection of children (a highly professional and devoted woman in a post funded by the regional government), and civil law specialists.

Katya, like the mothers in Iarskaia-Smirnova's article and like Nina, considers the future to be a murky affair. In her own life, and in the activities of the group, she goes by the philosophy that you must tackle one problem at a time. “Otherwise you will be overwhelmed, and just sit in the dark with your head in your hands,” she told me.

The first problem that the parents faced was the problem of lack of adequate educational facilities for their children who were offered only rehabilitative services. Marina, Katya's daughter, was always delighted to get to spend three months at the rehabilitative center. The director of the center is also a mother of a disabled daughter, and her staff members are devoted, professional, and work hard to integrate the newest methodologies for physical, occupational, and speech therapy for young children (the

center treats children from age 18 months through 12 years). However, Katya observed, after two months, Marina was just getting settled into a new routine of taking a van to the center on weekdays, being around other children and adults from outside of her family. Her vocabulary would start to increase, her muscular contractions would show the benefits of daily therapies, and she would be visibly more social. And then, the rehabilitative period would end, and Katya would be stuck at home in the family apartment for another few months, during which she would lose much of the progress she had made. An older group of parent-activists, along with some local teachers had instituted a weekend school, where children with disabilities and their families were invited on Sundays for socializing, outings, and activities.

For Katya and the other parents, this not-quite-education was a problem. She said,

In the first place they would provide a 2-4 month stay, and then the child would go home for two to three months, and then again... this was difficult, for example: the child would spend a long time getting used to being housebound [lit: “a house child”, *domashnii rebenok*] – and then he would for a long time get used to people that were around him, to children. Then 2 or 3 months go by and he would again have to leave, along these lines, all over again. Then again some time would pass and again he would have to adjust. This period of adjustment took up practically all the productive energy (*plodotvornoe*) he could come up with. But in a school or a kindergarten – the child starts attending and as a result is already a part of one and the same peer group (*kollektiv*).

The parents began to talk amongst themselves about this problem. Some parents of children with Down Syndrome convinced a local preschool (*detskii sad*) to allow their children to attend along with the “regular” (*obychnye*) children.

Katya recalled,

[one mother of a boy with Down Syndrome] went to the regular preschool [*sadik*] without an attendant [paraprofessional]. Her son goes to the regular preschool, and gets along well. In the preschool, they have also come to realize that these kids, they could have been going to the regular preschool all along... these are kids that... from the very beginning he has interacted really well with other children, although maybe it will get harder for him as they get older. But in preschool, primary school, middle school – they [kids with Down Syndrome] can do the regular lessons. Of course [the parents] were really worried that it wouldn't be worth it [to send them to] the regular preschool. ... No, absolutely not.

Hearing about these experiences, Katya and others realized that it might even be worth it

to send their own children to such a school, although most were less socially adept than this young man (and Marina's mobility limitations meant that she would need more assistance).

After mulling over the idea, they eventually consulted a lawyer.

And so we ended up in court. The most interesting part is that... we all got together, not all of the parents ended up working with us, because in the first place for us, I don't know how the procedure works in America, but for us it's pretty expensive [*dorogostiashaia*]. But we have a Constitution, where according to the law all, according to the constitution of the Russian Federation, everyone has the right to education. But of course a constitution is a constitution and laws... because when we say even in court that according to the constitution... this was sort of only by appearance... there is such a law and according to it you, we are not able to create the conditions and attend to our children, but the constitution came out of somewhere. And we understood that all of this exists and that we have rights. We lost the first lawsuit, they heard the case at the first level, city court. We ended up in high court. We lost the high court case. We went through all kinds of commissions, that were necessary, that were required... The argument for the other side was, that there were no conditions and that our kids would be worse off in the circumstances available [in the schools].

Perhaps the most important turning point in the struggle came at the point when the group lost the first level. Shortly before the appeal, the parents decided that they had nothing left to lose – and that higher visibility would help their cause. They deployed the “critical” trope that Phillips (2010) described (as described above) in order to demonstrate that the regional administration was failing to aspire to the highest level of international governance by ignoring the educational rights of children with disabilities.

Getting a group of families and children together in a room at a local school, they announced a press conference to local media, including television and print.

we got all the kids together and they sat with us in a room, and we didn't hide them, so as to show here are the kind of kids that we have. We collected all the journalists and told them our story, presented all the documents. And thanks to that, the next day it was on all the channels that Karelia is such and such, and the right to education for children doesn't exist here. In the newspapers there were a lot of different articles. And in general, the court case for us even began to go in our favor. They started to reconsider our issue. In the long process of reconsideration we won in the end.

Thus began the process of the regional government allocating funds to integrate preschools in the region. The funds paid for attendants (paraprofessionals) to aid children

with severe disabilities who need greater degrees of care in becoming integrated into mainstream classrooms. But, for Katya and Marina, although the victory was a highpoint, it was also moot: Marina had already turned five, and was too old to attend preschool. So, Katya recalled, they took a deep breath and decided to start all over again – this time to call for inclusion in primary and secondary schools.

By 2006, the parents had repeated the administrative civil process, and with the help of their attorney and the regional ombudsman. Two primary/secondary schools in Karelia, one in Petrozavodsk and one in another city, were designated as charter institutions to test the new “experiment” in inclusive education<sup>17</sup>. In Petrozavodsk, children with special needs, including Katya's Marina, began attending the schools, rather than one of the specialty schools (*internati*) for intellectual and physical disabilities, accompanied by paraprofessionals paid for by the designated funds. The decision to attend one school or another remained with the parents.

The integration of schools in Petrozavodsk was local, national and international news. In local newspapers, reports tended to focus on a sort of personalizing discourse. For instance, one article related the decision of one teenager with learning disabilities to attend the “experimental” school (Tsygankova 2011). Pictured smiling with her mother, who expressed worry, but excitement for her daughter, the young woman's story was patently one of an “other” who had received a special pass to enter the world of “us”. On

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17 The attempt to integrate these two schools is described as an “experiment” by some teachers and older activists in the community who are skeptical of the educational experience; Katya and her cohort, however, do not use this word – for them, this is not an experiment, but a won, lived reality. Meanwhile, in Saint Petersburg, the focus has largely shifted from “inclusive” education, meaning integrated into mainstream classrooms, to “education-for-all,” following pilot projects that brought out some of the challenges of inclusion (for example: to whom does inclusion extend? What counts as meaningful inclusion in the classroom?).

a national and international level, it is hard to underestimate the groundbreaking nature of this story. In 2008, a disability advocacy group called “Invak Info” conducted a national survey, which found that one-third of school children do not want to have children with disabilities in the classroom; Iarskaia-Smirnova (1999) includes charts that demonstrate even higher levels of prejudice in sociological surveying of the Russian population.

Meanwhile, those international disability organizations took up the news of the first time that a public school had been integrated using legislative processes on an argument of civil rights as a banner. The news was announced via international listserves (MDAC 2006), reported on websites that were beginning to appear on the Russian internet to lobby for disability rights, and in general press, where it was deployed as evidence of democratic change (Pravosudiye 2007).

## DISCUSSION

With these case studies in mind, we can attend to the ways that the framework proposed in the first half of this paper may offer new openings.

While popular representations of Russia continue to be dominated by images of autocratic repression (the “iron fist”)<sup>18</sup>, new anthropology of Russia allows for a relational (rather than sovereign) notion of power and the possibility for multiplicity and alterity in (post-) Soviet experience and struggle. Such a recognition demonstrates that the transition narrative presents a reductionist understanding of dominance and oppression, and suggests that in fact, the Russian political situation may be one characterized by a radical diversity of political imaginaries, rather than a monopoly of consent (or singular form of resistance). What does such a perspective offer? Binary

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18 For example, during the week that this paper was completed the following four articles (along with revelations about US-Russia relations in the wake of the Wikileaks scandal) appeared in the New York Times, and were more or less indicative of a general trend in popular press reporting on Russia. (1) “Russia Approves Road That Will Run Through Forest” underlines the fabled failure of civil society in Russia via a story of a final decision that a long-awaited highway would be built through an otherwise undeveloped forest region, in spite of organized lobbying by environmental groups and citizens against the proposal. The article does not mention that similar failures of environmental groups to stop industrial projects in the United States might, if viewed from the same logical rubric, indicate a lack of civil society at home. (2) “A Beating on my Beat” (Kashin), in which a Moscow reporter relates being beat up, and speculates that the gang that attacked him might have belonged to the Kremlin-backed “Nashi” consortium of radical conservative youth, and could have been responding to his (self-declared) progressive reporting. (3) “Medvedev Warns Against Ethnic Attacks” addresses a flare-up of gang violence along ethnic lines in Moscow. The interpretation of a Hobbsian Russia is underlined by the fact that not mention is made of similar gang violence occurring in the United States capital. Russian exceptionalism and lack of liberalist tolerance and diversity in the public sphere ignores a release of census data that resulted in a map in the same paper of the weighty ethnic and racial segregation in New York City (Gawker). (4) “A Massacre Shows Power of Gangs in Rural Russia” relates the story of a violent massacre that occurred ostensibly at the hand of a gang run by corrupt officials in a rural town several hours south of Moscow, and takes this as indicative of high corruption and an absence of working civil society in contemporary Russia, particularly in the provinces. No mention is made of similar incidences of violence and corruption in the rural United States; the same week, a gunman accusing a Florida school board of corruption staged a violent shooting at a public meeting (O'Connor and Mackey).



schemas are a useful heuristic tool; but observing the ways in which such heuristics fall short is a useful tool from the anthropological theoretical toolbox to deploy in the postsoviet realm. Let us examine the ways that the case studies complicate and are complicated by two particular binary axes prevalent in transition discourses. First, the axis of autonomy/dependency, and second, the axis of public/private – both of which are at play in conversations about liberal democracy and its entanglement with neoliberal economics.

### *Autonomy/Dependency*

Anthropologist Melissa Caldwell has observed that transition discourses assume “that the postsoviet state is flawed and that what is needed to fix it are reforms that shift the balance of political and economic power away from the state and to citizens who have been given autonomy to act as individuals with free choice” (2004:7). Embedded in the narrative of national transition is an imperative to transform postsoviet citizens into autonomous actors, bearers of self-governance and personal independence (which assumes that Soviet citizens fundamentally lacked personal liberty during Soviet autocracy). As Foucault has observed, at the root of contemporary assumptions about this notion of the enlightened, liberal subject is the expectation that the truly free citizen acts independently of tutelage, a reliance or dependence on the thinking of others, and independently of the direction of a sovereign power (1984). Choices, and freedom of choice, have subsequently become entangled in the vernacular of capitalism; anthropologists have observed that Westerners frequently conflate an uninhibited (or

particularly well-executed) exercise of consumer choice with personhood (Appadurai 1986; Taylor 2008; Mol 2008).

This is what I am calling the *axis of autonomy/dependency*: a binary relationship between the morally positive autonomous neo/liberal independent citizen and the morally questionable dependent person. In this understanding, implicit in transition discourses, is the idea that each citizen may be plotted on a teleological line between dependent and autonomous, in action and self-realization. The ideal new citizen must emerge from Soviet models of dependency as a newly minted, autonomous consumer-citizen.

This question of what qualities we value in the individual as a person and as a citizen has implications for both our understanding of how a new Russia unfolds, and for questions of disability justice. A disability studies perspectives adds the critique of ableism to our understanding of what is at stake in how we value the autonomy/dependency axis. Michael Berube has observed that in the course of our daily lives we are continually compelled “to determine what kind of ‘individuality’ we will value, on what terms, and why... to ask about our obligations to each other, individually and socially, and about our capacity to imagine other people (1998: xix)”. Questions of individuality, and thus what types of dependency and interdependency between persons and between citizens and the state are valued by a society, are critical to conversations about disability justice. This is true for people with disabilities lobbying for themselves, and confronting situations in which they must ask more of family members, communities, or government than their peers.

Questions of dependency are also intimately related to the ways that parents of children with disabilities negotiate between providing more demanding care to a child,

and simultaneously becoming a parent who must ask more of family members, communities, or government than their peers (Kittay 1999; Rapp and Ginsburg 2001:540-541; Kittay and Carlson 2010; Phillips 2010). Moreover, for parents, and particularly mothers, questions of dependency are intimately related to the ways that care and caretaking are devalued as non-labor or gendered moral obligation (Kittay 1999, 2002). In other words, dependency and kinship have been highlighted by critical scholars as an arena for investigation of new possibilities for disability justice. However, while Phillips calls for an investigation of these concepts in relation to postsoviet disability (2010:240-243), the proverbial dots remain, heretofore, unconnected. If *autonomy to act* and *dependency on care* are not linked in the way that (neo)liberal categories expect, what does this mean for parenting a disabled child, and for building new possibilities in Russia?

Considering this axis of dependency/autonomy, how can we further unpack the mismatch between an initial reading of Nina's story as one of survival and social dependency, and the revelation that a closer reading reveals a more agentic decision-making? Reading the narratives of these two mothers, we would be hard pressed to describe one as *autonomous*, a citizen claiming civil rights from the state, and the other as *dependent*, a subject in need of state support. These categories are not absolute, and the ethnographic examples illustrate complex relational interdependencies. Although Katya has more options, and a broader sense of possibility than Nina, she too is caught up by the question of what will happen to her family in the future as her disabled daughter ages. Both women develop thoughtful strategies to produce heretofore unseen outcomes of their own design. The horizon of possibility for a child of Marina's age begins from the

horizon of what was possible for Sveta. Where raising a *DTsPnik* at home and educating her to participate as a citizen was radical for Nina, Katya may take this as a given and mount new battles.

Plotting Katya and Nina on axes of autonomy/dependency is complicated by the relative meanings of these terms in translation. What, precisely is “autonomy”? Russian critical feminist Olga Chepurnaya has considered the ways that the expectation of autonomy as a political attribute takes on different valences in the Russian context. Principally, she calls for an understanding of personal autonomy not as a philosophical normative concept, but as a particular constellation of practices, or, a variably invoked life strategy. The question of dependency/autonomy as Chepurnaya considers it builds on an ongoing discussion in global critical feminism (69-70). She is in dialogue with North American feminist theorists including Nancy Fraser, Martha Nussbaum and Martha Fineman, who have taken up the question of dependency/autonomy. These works have documented the ways that “political rhetoric and popular ideology in the United States have become so fixated on the myth that citizens should be autonomous that they fail to recognize the inevitability and normality of dependency” (Eichner 2005). In turn, they have called for new imaginaries that recast the relationship of state to citizen so as to reconfigure moral connotations of autonomy or dependence. Chepurnaya’s deployment of autonomy-as-life-strategy (71) draws on Marilyn Friedman (2003), who posits that, in spite of the critiques leveled against autonomy, there exist in contemporary society a set of personal self-reflexive practices that are best described as emotional and rational resources deployed by particular women. So, autonomy may not be a clearly defined prescriptive, but rather a mode of decision-making. Or, one way of describing relational

and changing valences of reciprocity.

Furthermore, as I have discussed elsewhere<sup>19</sup>, the dimensions of *dependency* in the Russian language do not cleanly align into a single linguistic marker as in English. In particular, the *stigma* of being a *dependent person* that is implicit in contemporary American English does not hold in Russian. As Adele Lindemeyr has observed in a historical exploration of the subject, in Russia, “poverty is not a vice” (1996). Will it become one as the language of neoliberalism immigrates to Russia? Since Caldwell’s research, have these values changed? How does this friction as to the moral meaning of poverty play out?

This departure of the Russian notion of autonomy/dependency from the stigma of its English counterpart is made clear by anthropologist Melissa Caldwell's description of the social place of impoverished and food-insecure elderly in Moscow in the late 1990s; rather than feel that they are dependent, in a morally negative sense, these pensioners, who frequent a soup kitchen that was the site for Caldwell's fieldwork, seem to offer a counterpoint to Chepurnaya's autonomous woman. Rather than autonomy, these elders actively seek interdependent relationships as a means of building and ensuring social connectedness and well-being. She asserts that her ethnographic research indicates that postsoviet citizens of Moscow

translate their apprehensions about material scarcity into concerns about the durability and productivity of their relationships with relatives, friends, neighbors, and other members of their community. In contrast to conventional policy interpretations of poverty, and of the circumstances of Russian poverty more specifically, Muscovites conceptualize material shortages as evidence of insufficient social resources and identify social isolation, not financial limitations, as the primary cause of scarcity in Russia today. Accordingly, they actively invest time and energy in personal relationships with other people as forms of social security, a practice that anthropologists and

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sociologists have documented among other social groups facing limited material resources (Allahyari 2000; Desjarlais 1996; Dordick 1997; Glasser 1988; Myerhoff 1978; Newman 1999; Stevens 1997). [Caldwell 2004:6]

By locating scarcity as a failure of a personal network of reciprocity, Caldwell's pensioners deploy strategies of interdependency to survive in, rather than escape, poverty. Prosperity, inversely, then is not linked to monetized markets, or presumed a morally good endpoint. That is to say, market-based logics do not apply to these pensioners. This extends to other postsoviets, more recently, Nancy Ries (2009) describes an ethic of saving and sharing in spite of rational cost-benefit analyses that demonstrate that certain practices – saving apple peels, farming potatoes on a small family plot rather than buying them – simply don't add up. Both indicate that postsoviets embrace an ethic of community preservation, a strategy of survival in case the state should fail. At the same time, these same citizens are not afraid to demand of the state anything to which they are entitled – from pensions, to bus passes, to food subsidies.

This ethic, described by Caldwell and Ries, resonates with that deployed by the mothers of children with disabilities whose stories are related here. I hesitate, as do Caldwell and Ries, to attribute these strategies to some imagined blanket “Soviet mentality” of dependency on provisioning by the arm of a patrimonial state. These parent-activists not only turn to the state as a resource to help to fund efforts, or to provide official channels of complaint or entitlement, but also in turn create spaces of autonomy and grassroots association outside of the jurisdiction of the state.

Chepurnaya's insight, that autonomy as a practice or strategy is invoked variably, where convenient, coalesces with Sarah Phillip's concept of “hybrid claims” (2010) and Matza's notion of liberal assemblage (2009:493). Given the case studies of Nina and Katya, we can see that both women were prepared to make hybrid claims for the benefit

of themselves and their families. Nina, for example, because she is concerned with not asking for anything from anyone outside of her family, declines to participate in collective action toward claiming “rights”, though she and her daughter continue to accept the benefits that social services allot to them, as she considers these deserved. Katya, meanwhile, outwardly more ambitious and active, relies on the tutelage of foreign activists and the support of their charity to help her pursue policy change.

Caldwell makes similar observations about the strategies and self-perception of her interlocutors who frequented a soup kitchen, and were therefore “dependent” on subsidized food. She writes,

approaches that locate poverty and welfare solely within economic and political discourses, and especially those that privilege the sovereign individual, neglect the long and rich relationship between economy and society in the history of poverty and welfare in Russian social life. More important, these perspectives overlook the ways in which welfare programs are in fact beneficial to society because they foster social cohesion (Pine and Bridger 1998:12). In many ways, poverty occupies a place of honor in Russian discourse as a form of expression about one’s experience with state and society. As Nancy Ries (1997) and Dale Pesmen (2000) have described, themes of poverty, scarcity, and assistance are the tropes around which Russians’ sense of self and social solidarity are formed. [2004: 8]

That is, in the Russian context, unlike the muddling of neo/liberalism in the late American context, strategies of poverty may not be equated with political impotence. Rather, relying on communal or public forms of support can be a viable path to effective personhood and citizenship. Or, simply, autonomy/dependency do not equal absolutes, but relational attributes.

This helps get to a central point: while, as popularized by transition discourses, the Soviet state deployed a model of citizenship that normalized what Americans call *dependency* or the practice of relying on state subsidy and pensions for survival (Fraser 1997; Kymlicka and Opalski 2001), this picture is further complicated by the case of mothers of children with disabilities. While depending on the state carries less stigma in

postsoviet cosmologies, parenting disabled children was still a burden and a stigmatizing experience for soviet and postsoviet women. The (post) Soviet welfare state, oriented toward institutionalization, was unprepared to support this new trend of raising children with disabilities at home. Considered in relation to our case studies, this means that the women who kept their children with disabilities at home in the 1990s were not “dependent” on the state in the way that other segments of the postsoviet population are lambasted in transition discourses that value liberal autonomy as a moral good. With insufficient public resources to depend on, their “private” resources of will and strength and networks of distribution were the central manner of survival. As such, women like Nina simply could not be dependent in the way that Westerners imagined: not only did the link between moral/political and economic dependency not exist in the Russian language or the Soviet cultural framework, the very institutional structures available offered no option for dependency in such a circumstance. Perhaps, then, we might wonder what change has occurred that has for Katya opened the possibility of the state as a resource to be deployed to private ends.

### ***Public/Private***

This leads us, therefore to the second axis of investigation, that of *public/private*. The question of divided public and private spheres is one that is central to theories of the political, and in particular to the notion of civil society, a key dimension of transition discourses, and therefore of interest to critical scholars of the postsoviet. The binary arrangement of public/private is most cogently categorized as the opposing political arrangements of family (private) and state (public), wherein civil society is imagined as a



realm of interaction between the two. These questions dovetail with the ways that relationality, kinship, and interdependence are perceived and deployed: the private, or domestic, sphere is the assumed site of relationality and caretaking, while the public, or political, sphere is cast as a rational arena of political claims-making independent from private. At the same time, questions about the heuristic division of public and private spheres have been interrogated by critical feminist and queer theorists, as an intersection around which deeply rooted notions of personhood, citizenship, and rights constellate.

Disability theory fundamentally troubles the dyad of public/private. On the one hand, disability, understood as bodily alterity that attenuates embodied experience, is profoundly “private”. As Matthew Kohrman has observed, disability is “a sphere of difference that is deeply grounded in... the most quotidian and most intimate aspects of existence” (2005:30). A common conundrum presented by writings in disability studies is the lack of privacy that people with certain disabilities are afforded in situations in which privacy would be a minimum requirement of respect for others: a blind woman in the voting booth, a quadriplegic man arranging and engaging in sexual encounters, the question of toileting for people with a range of physical limitations (e.g. Shuttleworth 2002; Siebers 2008; McRuer 2010). These profoundly *personal* experiences make up what some might call the indignities of disability (Murphy 2001).

On the other hand, the very category of disability is profoundly “public.” Only by considering an aggregate public norm can a concept of bodily alterity arise – disability is, in essence, comparative (Davis 2006). Moreover, the structural apparatus that we use to measure or determine these degrees of bodily alterity, the so-called bureaucracy of disability, involve complex calculations that relate economy and work capacity, medical

diagnosis, prognosis and treatment, and state structures of redistribution. The “universal” concept of disability (Murphy 2001), which has allowed for the very emergence of the field of disability studies is a Western concept that emerged with industrialization and the corresponding methods of governance of the nation state (Helander 1995; Baynton 1996; Linton 1998; Ingstad and Whyte 2007). This concept travels in friction, with multiple heterogeneous definitions and incarnations (Kohrman 2005). It is the *citizen* that is *disabled*, whereas *subjects* were merely *needy*, wretched, or lame (Lindenmeyr 1996). Therefore, disability is fundamentally a question of the public, or *political*, sphere. In everyday terms, we can observe that the manner in which disability benefits are determined, appropriated, and disbursed, is of public concern, as public funds are at stake.

The narratives of Nina and Katya further complicate the normal types of public/private and family/state. As parents of children with disabilities, their so-called private lives are intimately linked to the realities of state policies. And, as Michael Warner (2002) has observed, when interest groups form, new publics emerge to consume the materials they have produced with the intention of reaching a public audience. As Katya and her cohort organize around parenting children “who can't care for themselves” (although, of course, this is a euphemism, as children by definition cannot care for themselves, and it is through a mismatch between needs and available services that these children become marked as different), they also produce new publics. By speaking for an audience about their experiences, audiences are created: news reporters eager to engage with questions of westernization, younger parents, local teachers and young adults considering careers in rehabilitative services, even national and foreign policy makers

interested in “rule of law” and “building civil society” begin to listen. Katya’s lobbying, in turn, evolves to respond to these audiences, by taking up vocabularies that indicate that she is speaking to these interest groups. At the same time, when the parent organization holds a press conference, it is by speaking personally of their hardships as mothers, by showing their children as loved family members, that they make claims as citizens.

This demonstrates a complexity that seems to explode the categories of public/private from within. In these examples, they don’t seem to explain anything about the political. If civil society is taken to be any negotiation between the ostensibly separate spheres of family/state, private/public, then it seems that everything concerning parenting a disabled child is civil society! Public/private, like disability, is a relational distinction, and anthropologist Susan Gal and Gail Kligman (2000) observed that the distinction therefore has a fractal nature, so that every public might be divided into a further distinction of internal public/private, in a dizzying and ever-extending manner.

Therefore, if the public/private divide is misleading in conceptualizing family/state relations in Petrozavodsk, in order to complicate it, we must consider the same dimensions of local meanings that troubled the axis of autonomy/dependency. Are there more relevant categories? Susan Gal has done much to localize the concepts of public/private to the East European case. She writes that in the socialist context,

'Private' became the designation for that aspect of life that the state tacitly ignored. It was the realm in which families, along with informal networks of friends and kin, worked extraordinarily hard so as to be able to consume more. The informal economy produced by this partial withdrawal of the state occupied a disproportionately large part of the country's economy and of the workers' energy and productivity. Men and women invested the bulk of their time, energy, pride, and self-respect in this officially ignored private sphere. Minutely imbricated with the official, socialized economy, the informal sector may have been experienced by some workers as a form of resistance, but it also became part of the logic of the centralized, planned, command economy, enabling the latter to survive. [Gal 1997:36]

So, where Nina's life during her daughter's youth was devoted primarily to this "private" sphere of associations, the cultural logic that led her to focus most of her energies and attentions in this realm were significant. Transition discourses would hold that those of Nina's peers who chose to participate in a more formal group oriented by ties of interest (parenting a disabled child) rather than kinship (participating in an informal, unarticulated, cooperative network of parents, "*nashi*"), may be judged to be superior citizens according to transition discourses. However, when Nina says that she relied only on herself and her kinfolk, this is not the whole picture.

Gal observes that throughout the Soviet period spaces of association emerged that did not cleanly fit coding of family versus state. These "interstitial" modes of relations and networks - the 'gray' economy or sphere - were critical to social function. Even so some outsiders saw the gray sphere as a form of corruption, in a sense undermining a state monopoly on planning, distribution, etc. "Nevertheless, whatever they were called, we may as well recognize in these social structures a well-developed, though stigmatized, form of organization situated between state and family" (34).

Imagining Nina's experience not as evidence of the lack of relational substance between state and family, but as embedded in these gray interstitial networks shifts our understanding of her narrative. In this perspective, Nina does not avoid the public sphere activism because of some failure to act in the so-called civil realm. After all, she participated in an international exchange, and works hard to support her daughter's collegiate education so that Sveta herself might participate as a citizen. In this light, Nina's lack of participation in even informal associational interest groups made up of other layperson parents designates a preference for private kinship networks of

interdependency that represents a viable and widespread strategy for obtaining and insuring sufficient goods for survival through the gray economy. Nina was participating in organizing – it was simply a different kind of organizing, and a different mode of negotiating between citizen and state.

Gal writes,

Since interstitial structures are not new, I argue that we should understand civil society in the region not primarily as a determinate set of institutions and organizations, which it also is, but as an ideological formation that produces the quite real social effect of newly perceptible boundaries between 'politics,' 'economics,' and 'family,' or, more simply, between a 'public' that refers to market and political organizations and a 'private' that refers to household domesticity. Such redefinition makes newly visible a range of what can now be called nonstate organizations. [1997:34]

That is, Gal argues that, by highlighting a particular neoliberal interpretation of civil society, transition discourses impose a foreign ideological formation that incurs a "separation" of market, state, and family where such distinctions did not previously exist as normative categories.

In a separate essay, Gal suggests that in the Russian context, this division of the world into public/private is most analogous to a Russian concept of us/them or *nashi/oni*. These distinctions too can theoretically be “recursively applied, so that any imagined assembly of 'us' can be divided further into an 'us' and a 'them.' The same is true for any group of 'them'” (2005: 33). Placing this observation in conversation with anthropologist Michele Rivkin-Fish's discussion (2005a) of *misrecognition* à la Pierre Bourdieu (1984), which observes the failure of members of postsoviet society to place themselves accurately in systems of power, can help to further situate us/them in relation to the case of Nina and Katya. Rivkin-Fish, seeking to explain the seeming indifference with which doctors treated patients in maternity wards in a Saint Petersburg hospital in the 1990s,

was referred by one interlocutor to an anecdotal truism called *the streetcar law*.

According to this law, service providers remind one another: “if you stick your neck out, it'll get cut off. Don't interfere, stay in your place and everything will go smoothly”

(Rivkin-Fish 2005: 147).

For Nina, the state and its legal arena is patently an arena of “them”. Therefore it is a realm into which she prefers not to venture, so as to avoid the proverbial streetcar. Subsequently, Katya encounters an ontologically shifted public sphere, in which the apparatus of the state is cast not as “them”, but as a medium by which to obtain certain ends. Both women would assert that the system has failed them; but they engage contrasting strategies to obtain sustainable ends.

## CONCLUSION

A comparison of the contrasting strategies that Nina and Katya deploy gets at questions of who is authorized to speak, when, and how. At the crux of the matter is what, precisely, it might take to move people take action, or, engage in political participation. This question of impetus to action is at the heart of both emancipatory social movements in an international context, including movements for disability justice, and of transition discourses of Russia.

Where Nina chooses not to engage with parent organizations, and accepts state care as something that may be used when offered, Katya perceives herself as capable of speaking back to the state. In some ways, this is not a formulation that is particularly Russian, or postsoviet. As Tom Shakespeare has emphasized, not all people with disabilities [or family members/allies] must be politically engaged, that is, lobbying in the so-called public sphere. At the same time, considering the particularly postsoviet perceptions of state and public, the self-perceptions, impetus to action, and perceived rewards of engaging the state may have different stakes for Russian activists.

This conjectural specificity leads to complex assemblages. At first glance we might be tempted to arrange Nina and Katya into preconceived categories, so that Nina copes with her child's special needs in a manner that is dependent and private, while Katya makes claims in public with autonomy. But, upon sustained reflection, we discover that these categories don't fit: both Nina and Katya deploy what seem to be unexpected combinations of strategies that do not align neatly with neoliberal axes of

dependency/autonomy and private/public. As the discussion above has helped us to see, these strategies appear *hybrid* to the outsider, but may be explained by attending to the ways that postsoviet concepts of dependency/autonomy and private/public do not align neatly with those of neoliberalism. Nina considers herself more autonomous for not engaging in parent activism, while Katya has license to speak out and make claims because as a mother her concerns are considered to be private and apolitical. These practical strategies reveal that the assumptions implicit in transition discourses about what moves contemporary postsoviet citizens to participate in the political fail to align with the actual complexity of on-the-ground decision-making.

The question of disability justice in the Russian context highlights certain assumptions about what emancipatory political agendas might look like. If accessibility or inclusion is raised as a measure the effective distribution of justice in a given political system, transition discourses are revealed as increasingly absurd. A teleological path from Soviet governance toward neoliberal democracy, ostensibly delivering greater liberty to citizens, fails to offer a vision that is viable in terms of access and inclusion. As disability scholars in the US and Britain continually point out, a system of delivering justice via rights-based claims and capitalist principles of economic distribution routinely fail to produce accessible and inclusive social realities (Shakespeare 2006). That is, transition discourses are revealed to be ineffective not only in a failure to align with categories of the social that are meaningful to postsoviet citizens, but additionally, they are strikingly inept strategies for delivering the ends of justice for disabled citizens and their families. Certainly, Katya and her peers have manipulated the new possibilities to claim rights to improve the situation for themselves and their children. However, these



successes rely on hybrid strategies, as much as on the promise of liberal democracy: were it not for a particular constellation of gender and public/private that casts the voice of a mother as fundamentally less political than other types of rights-based or needs-based claims, she may have had less success. Or, as Nina sees it, these successes have less to do with new potentialities of civil society than it does with a postsoviet state that continues to displace the burden of labor onto citizens, while those in power appropriate their achievements as fodder in international power plays.

What, then, does this critique of transition discourses call for? Critical scholars of disability studies (Mitchell and Snyder 2010) and of development discourses (Cleverly 1996:236; Esteva; Fraser 1997) have observed that while liberatory movements have traditionally been tied to socialism, increasingly, there is a necessity to look not to one political economic form or another (Escobar 1992: 133), but to diverse economies (Gibson-Graham 2006), complex global assemblages (Collier and Ong 2005), and deterritorialized descriptions of local-global spaces (Deleuze and Guattari 1972; Yurchak 2006). In this sense, it is by paying attention to so-called hybrid strategies that we may find new openings to attend to pockets of alterity that are not fully explained by the categories of socialism/capitalism, autocracy/democracy, dependency/autonomy, and so on. At the same time that Nina and Katya deployed terminology and ideas that seemed to align with one side of a binary or another, attention to hybridity reveals that their local and personal concepts of personhood and citizenship, embodied in unfolding strategies, may constitute not a negotiation between polarities of the transition teleology, but of something else entirely.

In conclusion, we have seen here that a critical anthropological framework on the postsoviet condition can be enriched by considering disability. Likewise, by deploying this new synthesis, we might arrive at novel insights regarding the complexities of political participation as parsed along axes of autonomy/dependency and public/private. By displacing the primacy of neoliberalism and democracy as the yardsticks by which we ought to measure the activities of citizens, or the progress of disability activism, we find more nuanced and rich possibilities that indicate a diversity of potentials that need not align with expected categories, whether ideal types or hegemonies of the center. This furthers a critical scholarship of the postsoviet and approaches the frontiers of how we might imagine a liberatory politics of disability justice.

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